

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

July 13, 2007

This survey was produced by
PAD-CO (Parents of Adults with Disabilities – Colorado)
Denver C. Fox, Ed.D., Moderator
Contact PADCOWEB@aol.com
for a copy of the Executive Summary

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
INTRODUCTION.....	6
BACKGROUND: COLORADO’S DEVELOPMENTAL DISABILITY DELIVERY SYSTEM	7
METHODS.....	11
0 TO 2 YEARS OF AGE: RESULTS AND ANALYSIS.....	13
KEY FINDINGS	13
DEMOGRAPHIC INFORMATION.....	14
HOPE-DESPAIR CONTINUUM.....	15
ADEQUACY OF SERVICES.....	16
CASE MANAGEMENT.....	16
PLANNING.....	18
ABILITY TO ACCESS INFORMATION & UNDERSTAND THE SYSTEM.....	18
3 TO 14 YEARS OF AGE: RESULTS AND ANALYSIS.....	19
KEY FINDINGS	19
DEMOGRAPHIC INFORMATION.....	20
HOPE-DESPAIR CONTINUUM.....	21
ADEQUACY OF SERVICES.....	22
CASE MANAGEMENT.....	24
PLANNING.....	25
ABILITY TO ACCESS INFORMATION AND UNDERSTAND THE SYSTEM.....	27
15 TO 21 YEARS OF AGE: RESULTS AND ANALYSIS.....	29
KEY FINDINGS	29
DEMOGRAPHIC INFORMATION.....	30
HOPE-DESPAIR CONTINUUM.....	30
ADEQUACY OF SERVICES.....	31
CASE MANAGEMENT.....	33
PLANNING.....	35
ABILITY TO ACCESS INFORMATION AND UNDERSTAND THE SYSTEM.....	37
21+ YEARS OF AGE: RESULTS AND ANALYSIS.....	38
KEY FINDINGS	38
DEMOGRAPHIC INFORMATION.....	39
HOPE-DESPAIR CONTINUUM.....	40
ADEQUACY OF SERVICES.....	41
CASE MANAGEMENT.....	44
PLANNING.....	46
ABILITY TO ACCESS INFORMATION & UNDERSTAND THE SYSTEM.....	49
COMMON THEMES.....	50
DISCUSSION/CONCLUSION.....	55
APPENDIX 1	59

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). Reference Appendix 1 to view a sample survey.

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
0-2 (n=11)	83.3%	4.50	**N/A	N/A	N/A	3.67	2.00
3-14 (n=98)	42.0%	2.67	2.60	2.41	N/A	3.15	1.80
15-21 (n=47)	29.7%	2.58	2.75	2.50	N/A	2.96	1.60
21+ (n=83)	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!!”*¹

*“Th[e] lack of knowledge, insight, accommodation, planning, values, community [and] caring exemplifies the stupidity in the system for our young adults today.”*²

*“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!”*³

*“Working outside the system has been more positive than work inside.”*⁴

*“‘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!”*⁵

Introduction

Thousands of individuals with developmental disabilities reside in Colorado.⁶ 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 unique problems, concerns, joys and successes of parents, guardians or anyone in a parental role of adults and older children with disabilities.”⁷ 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.

Background: Colorado's Developmental Disability Delivery System

History: In the 1960s Colorado began a transformation, moving from an institutional care setting towards community-based care. To facilitate this process, a series of not-for-profit organizations, called Community Centered Boards, emerged. Since 1977, spending in Colorado for community services has increased from just under \$50 million to approximately \$338 million in 2002. By contrast, institutional care spending steadily decreased from around \$70 million in 1977 to \$7.5 million in 2002.⁸ Since that time, the trend towards community-based services has continued.

Current Structure: As of June 2007, Colorado funds approximately 11,000 individuals with developmental disabilities, with thousands more on the waitlist for services.⁹ To serve this population, the state currently maintains three institutional facilities (regional centers), contracts with 20 Community Centered Boards (CCBs) and offers an array of Medicaid waivers both within and external to the CCB system. The school system provides special education services. Services are typically delineated as follows:

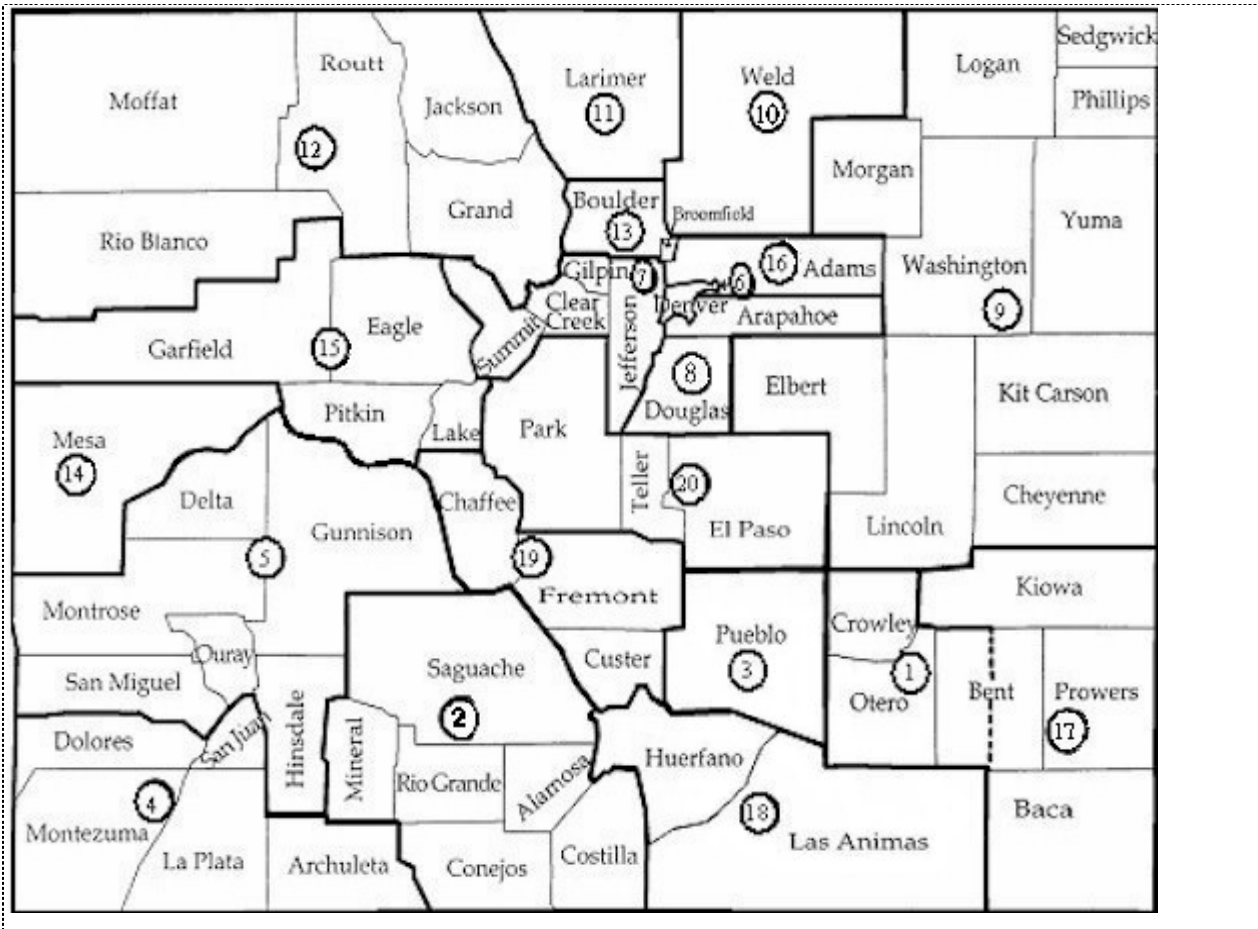
- 0-3 years of age = early intervention administered by CCB
- 3-21 years of age = special education and transition run by schools; CES and Family Support coordinated through CCB
- 21+ years of age = adult system (Comprehensive Services, Supported Living Services, Family Support) run by CCB

Community Centered Board (CCB) system: According to the *Volume of Developmental Disabilities Services*, a CCB is a private, for profit or not-for-profit, entity authorized by the state of Colorado to provide case management services to persons with developmental disabilities. The CCB acts as the single point of entry to the system and determines eligibility for services. Services and supports are provided either directly by the CCB or through sub-contracted support agencies.¹⁰

Each CCB has a non-overlapping geographic service area covering one or more counties. The CCBs vary greatly in size, population served and level of direct service care. See Index 1 and Map¹¹ below for a list of each CCB and the counties they serve.¹²

Index 1 & Map 1
20 CCBs in Colorado and the Counties they Service

- | | |
|---|--|
| 1. Arkansas Valley Community Center | 12. Horizons Specialized Services |
| 2. Blue Peaks Developmental Services | 13. Imagine! |
| 3. Colorado Bluesky Enterprises | 14. Mesa Developmental Services |
| 4. Community Connections | 15. Mountain Valley Developmental Services |
| 5. Community Options | 16. North Metro Community Services |
| 6. Denver Options | 17. Southeastern Developmental Services |
| 7. Developmental Disabilities Resource Center | 18. Southern Colorado Developmental Services |
| 8. Developmental Pathways | 19. Starpoint |
| 9. Eastern Colorado Services | 20. The Resource Exchange |
| 10. Envision | |
| 11. Foothills Gateway | |



CCBs coordinate five major programs. 1) Early Intervention; 2) Children's Extensive Support Waiver; 3) Family Support Services; 4) Comprehensive Services; and 5) Supported Living Services (SLS).

Early Intervention is provided exclusively by the CCB for children ages 0-3. Children's Extensive Support (CES) is a Medicaid waiver program. Children aged 0-18 are eligible for CES services, provided they have a developmental disability that requires direct and constant supervision for 20 out of 24 hours each day.¹³

Family Support Services are available to families living with a developmentally disabled individual older than three years of age. Unlike the other four programs, Family Support Services are funded entirely by the state of Colorado and are not income based. To name a few, the funds supplied through family support can be used to pay for respite, therapies, home modifications and community participation activities.¹⁴

Once an individual reaches 21 years of age they are classified under the adult system. Adults eligible for services typically qualify for one of two services: 1) Comprehensive Habilitation Services and Supports; or 2) Supported Living Services (SLS). Adults that do not qualify for services or do not desire services leave the special education system and enter the next phase of their life unassisted by state DDD services.

Comprehensive Services provide a full day, or 24 hours, of supports. Said services and supports exist to ensure the health, safety and welfare of the individual with the developmental disability. They further offer training and habilitation to foster skill acquisition aimed at self-sufficiency and community inclusion. As such services include integrated, or non-integrated, employment and activities services.¹⁵ According to *Colorado's Volume of Developmental Disabilities Services*, Comprehensive Services are designed to provide access to typical community activities.¹⁶ While receiving Comprehensive Services, the individual is prohibited from living in their own home or a parent/guardian home. (Note: this regulation is in process of being changed). Instead, the individual resides in a host home or group home.

Supported Living Services are designed to provide supports and services to individuals with developmental disabilities residing in their own, or a parent/guardian home.¹⁷ These services do not provide a full day (24 hours) of support. Rather, they are designed to augment available supports for those living independently or with the support of a family member.¹⁸ (Note: Individuals 18 years and older are eligible for SLS).¹⁹

Inequality between CCBs. Inequity between Colorado's Community Centered Boards (CCB) is a concern. The crux of the problem is high growth coupled with low funding. A report generated by two CCBs, The Resource Exchange and Developmental Pathways, notes two facts. 1) The disparity in funding among CCBs ranges from a high of \$126 per capita to a low of \$31 per capita. The difference between the two is 300 percent. (Calculations based on the population of each CCB service area). And, 2) Some CCBs have the funding to serve 90 percent of their local need, while others' funding is sufficient to serve less than 30 percent of their local need.²⁰

Support external to CCB system: It should be noted that some Medicaid Waivers provide support to the DD community outside the CCB system. The Medicaid Elderly, Blind and Disabled (EBD) Waiver is one such example. Physically disabled persons aged 18 and older who meet the nursing facility level of care are eligible for the EBD waiver. Services provided under said waiver range from adult day care, to home modification to non-medical transportation and respite.²¹

School system: An individual with a developmental disability enters the school system at age 3 and is eligible for services until the age of 21.²² Developmentally disabled individuals were legislatively integrated (physically) into the school system in 1975 with passage of the Education for All Handicapped Children Act.²³ In 1997, the Individuals with Disabilities Education Act (IDEA) amendments established a new title for the provision and required school districts to provide access to general education curriculum, with the intent of more than just physical integration. IDEA was most recently reauthorized in 2004 and continues to regulate special education in schools.²⁴ To establish learning objectives and implement action strategies, an Individualized Education Plan (IEP) is developed for each child.

Funding mechanism: According to a Joint Budget Committee report by staff budget analyst Amanda Bickel, the vast majority of services are funded through Federal Medicaid waivers for home and community based services (HCBS). The state General Fund contributes matching funds at a rate of 50 percent. Comprehensive Services, SLS and CES are funded

primarily or entirely through this mechanism (Medicaid plus state matching funds). However, unlike other parts of the Medicaid program, the state has the ability to limit the total number of program participants. Early Intervention is funded primarily by the state General Fund, while Family Support Services are funded entirely by the state General Fund.²⁵

Funding for developmental disabilities in Colorado is quite low. According to a study conducted by the Coleman Institute, Colorado ranks 48th out of 50 in funding²⁶, per \$1,000 of aggregate statewide personal income²⁷, for the developmentally disabled population.²⁸ This despite the fact that Colorado ranks 8th in the nation for per-capita wealth.²⁹

Waitlist: As a result of limited funding, Colorado boasts an extensive waitlist of individuals in need of services.³⁰ In fact, as of November 2006 approximately 3,000 adults and 130 children with developmental disabilities were on the waitlist for long-term health care services and supports. Of the 3,000 adults, over 400 were 40 years or older and living with senior-aged parents. At the same time, more than 4,000 families supporting children await family support services.³¹ Between June 2001 and June 2006, the waitlist for Comprehensive Services and SLS has grown 189 and 117 percent respectively.³²

Individuals are eligible to place their name on the list for services beginning at age 14. However, it could take many years before any services are provided. According to a report by Alliance, a non-profit, statewide association of CCBs and Service Provider Organizations, some wait lists are nearing 80 years.³³

Methods

Survey Characteristics: In February of 2007, the PAD-CO survey was administered on-line using the survey tool “Survey Monkey.” The survey consists of 59 questions, 14 of which solicit 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). Reference Appendix 1 to view a sample survey.

Survey Demographics: Two-hundred and 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. Respondents most often reside in Arapahoe, Boulder, Denver, Douglas, El Paso, Jefferson, Larimer, and Pueblo counties. (Note: henceforth, the term "parent" is used to describe a parent, guardian or representative of an individual with developmental disabilities; unless contained within one of the four 'demographic information' sections of the report. In that instance, the term 'parent' refers only to parents).

Analysis Technique: To organize and assemble the survey information into a coherent picture of Colorado's developmental disability delivery system as parents view it, two techniques were utilized. First, "Survey Monkey" automatically quantified discrete, non-open ended questions. The second technique involved coding qualitative responses along a Likert scale. Common in survey research, a Likert scale is used to characterize a response. In this case, the Likert scale was established as follows:

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

Each qualitative response received a rating from "1" to "5" by this author, with review by Denver C. Fox, Ed.D. one of the survey developers. All told, over 1,300 qualitative responses were catalogued and coded according to the Likert scale. The results were then combined to generate an aggregate numerical score in the areas of case management, case management turnover, adequacy of services, funding, ease of system and Colorado compared to other states.

The data set is organized by age bracket and includes: 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. (See Table 2 below). The groups are delineated in this manner based on the services available and a community of interest/experience. Individuals 0-2 years of age are eligible for Early Intervention but not school services. At age three, schools are federally mandated to provide services until the age of 21. The school-aged population is divided into two segments because around the age of 14,

parents typically shift focus towards transition services and the adult system. Therefore, the outlook and experiences of the 15-21 group, tends to be different than the 3-14 group. After age 21, individuals with developmental disabilities leave the school system and enter the adult system.

Table 2
Broad Overview: Division of Services by Age Bracket

Age Group	Grouped together because...
0-2	Eligible for Early Intervention services only – no school.
3-14	Eligible for school services.
15-21	Eligible for school services but looking towards transition program and adult services.
21+	Eligible for adult services only – no school.

*This table does not include all services, such as the EBD Waiver, available to individuals with DD. Rather, it is intended as a broad overview.

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.

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>

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!"³⁴

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."*³⁵

DEMOGRAPHIC INFORMATION

General: Only 11 of the 239 respondents represent children aged 0-2, making it the smallest of the four groups analyzed. The average respondent in this group can be characterized as a 22-30 year old parent, whose child has a learning (54.6%) or neurodevelopmental (45.5%) disability. Nearly 73 percent benefit from some or multiple services for their child, namely Early Intervention. Just over 27 percent collect Social Security or Supplemental Security Income (SSI).

Areas of Service: Four respondents reside in Larimer County, while two call El Paso County home. The counties with one respondent each are Adams, Arapahoe, Boulder, Broomfield and Jefferson.

Waitlist: Zero respondents in the 0-2 group supplied waitlist information.

HOPE-DESPAIR CONTINUUM

Utilizing a hope-despair continuum, respondents were invited to describe their outlook as it relates to getting supports for their children. The scale of feelings ranged from optimistic at one end to despair at the other. Half are optimistic, one-third are hopeful and only one respondent feels discouraged. (See Table 3 below). When put to the question – *I am hopeful about the services I will receive for my child in the future* – five out of six respondents were in agreement.

Table 3
Hope-Despair Continuum: 0-2 Age Bracket
(**n = 6**)

Feelings	Percent of Respondents	Percent of Respondents (categories collapsed)
Optimistic	50%	83.3%
Hopeful	33.3%	
Satisfied	0%	0%
Pessimistic	0%	16.7%
Discouraged	16.7%	
Despair	0%	

Optimism and despair sit at opposite ends of the continuum. A comparison of the two feelings, by age group, better illustrates the degree to which the 0-2 group is positive with regard to the future. (See Table 4 below). The 0-2-age bracket has the highest percentage of optimistic respondents (50%) and the lowest percentage of respondents in despair (0%).

Table 4
Hope and Despair as it relates to Getting Supports by Age Bracket

Age Group	% of Respondents that feel Optimistic	% of Respondents that feel Despair
0-2 (<u>n</u> =6)	50.0%	0.0%
3-14 (<u>n</u> =98)	2.5%	6.2%
15-21 (<u>n</u> =37)	2.7%	13.5%
21+ (<u>n</u> =70)	11.4%	8.6%

ADEQUACY OF SERVICES

Respondents in the 0-2 group indicate extreme satisfaction with the overall quality of services. On a scale of one to five, where “1” equals ‘very poor’ and “5” is synonymous with ‘excellent,’ services were rated at 4.50. This rating far exceeds the score generated by the entire sample of 239 respondents, which rated adequacy of services at 2.74. The standard deviation of the 0-2 group is 0.92, while the standard deviation of the entire sample is 1.53, indicating less variation in response by the 0-2 group. (See Table 5 below).

Table 5
Adequacy of Overall Services: 0-2 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.74	1.53
0-2 Respondents (n=11)	4.50	0.92

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

The praise for services includes therapists, hospitals and CCBs.

*“Overall, I believe all the services we have received for our child have been beneficial to her and the rest of our family.”*³⁶

*“We have had such wonderful therapists enter our home who have taught myself and my son so much.”*³⁷

*“Children's hospital and the Children's hospital North therapy clinic are all excellent.”*³⁸

*“We've had an excellent experience with them [CCB] so far -- I don't know what will happen in the future.”*³⁹

When asked which systems need improvement, the modal response was ‘I don’t know.’ One parent responds, “I can't think of anything specific as we've only been doing this for 2.5 years.”⁴⁰ (Note: There are too few respondents to break down adequacy of services by county. Similarly, there are too few CCB-specific responses to calculate a CCB service score. Instead, CCB services are rolled into the ‘overall’ category).

CASE MANAGEMENT

General: Seventy-five percent of respondents have been assigned a case manager, whom they typically interact with on a quarterly basis. Each of the respondents feels they gain

knowledge from their case manager including information about: activities to do in the community (33.3%), disability inclusive community activities (66.7%) and programs/services for which they qualify (66.7%).

Case management services generated a rating of 3.67, falling between adequate/acceptable and good. As with adequacy of overall services, this score is higher than the entire sample at 2.96. (See Table 6 below).

Table 6
Case Management: 0-2 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (<u>n</u> =239)	2.96	1.47
0-2 Respondents (<u>n</u> =11)	3.67	1.60

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

According to respondents, case management services are good when their case manager is helpful, easy to access, listens and communicates frequently. A parent describes level five case management, “I have a wonderful relationship with our case manager. She checks in with us regularly - keeps me informed and I can call her anytime I have a question or concern and she is always more than helpful. We value her greatly.”⁴¹ The few who experienced poor case management cite short and infrequent contact, as well as the inability to provide answers, as an underlying factor.

Turnover: Five out of six parents always meet with the same case manager/resource coordinator/planner. As such, the 0-2 group enjoys the lowest incidence of turnover. In fact, an analysis of turnover by age group reveals two trends. (See Table 7 below.) 1) As an individual with DD ages, the frequency of turnover increases. And, 2) Turnover appears to be correlated with the quality of case management services. Age brackets with lower turnover rate case management more favorably, while those experiencing high turnover generate lower scores. This (low turnover) likely contributes to the higher than average rating for case management services in the 0-2 group.

Table 7
Case Management Ratings compared to Case Management Turnover by Age Group

Age Group	Case Management Rating/Score	% of Respondent Group that Always Meets with the Same Case Manager
0-2 (n=11)	3.67	83.3%
3-14 (n=81)	3.15	44.6%
15-21 (n=47)	2.96	30.6%
21+ (n=83)	2.71	21.5%

PLANNING

General: Most respondents (72.7%) have a plan in place for their child. The planning experience in this group is primarily limited to the Individual Family Support Plan (IFSP) and Early Intervention, with 88.9 percent participating in the IFSP and 55.6 percent in Early Intervention.

Individual Family Support Plan (IFSP) and Early Intervention: Six of seven respondents were present during plan development, while five report contributing ‘a lot’ of input. Fifty percent of parent’s claim responsibility for actually carrying out their child’s plan. Most feel satisfied that their plan was created by a [highly] qualified individual and is fully implemented. Those with an Early Intervention plan find it easier to amend, than do respondents working with an IFSP.

In terms of effectiveness, both the IFSP and Early Intervention received high marks. On a scale of one to five, in which “1” means ‘not at all effective’ and “5” translates to ‘highly effective,’ IFSP garnered a 4.0 and Early Intervention a 4.40. (See Table 8 below).

Table 8
Plan Effectiveness: IFSP and Early Intervention: 0-2 Age Bracket

Plan	Score/Rating
Individual Family Support Plan (IFSP)	4.0
Early Intervention Plan	4.40

*Ratings based on scale of 1-5, where 1 = not at all effective and 5 = highly effective

ABILITY TO ACCESS INFORMATION & UNDERSTAND THE SYSTEM

As the newest group to the DDD system, parents of children aged 0-2 face a large hurdle when it comes to accessing information and understanding the system. A parent illustrates this

point well, “[s]ometimes when you are a parent that is NEW at this and has no idea what to expect, you don't know what questions to ask or what types of services are available or why to get onto waitlists and things like that, and you don't learn about helpful services until it is too late.”⁴²

With these challenges in mind, the survey contains the sentence - “*I really need more information about _____.*” Responses include, 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!”⁴³

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 identified 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 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. 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.”⁴⁴ 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!!!!”*⁴⁵

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.”*⁴⁶

DEMOGRAPHIC INFORMATION

General: The group with children aged 3 to 14 comprises the largest of all four-age brackets within the sample. Specifically, the 3-14 group 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. A

majority (72.5%) of their children have neurodevelopmental disabilities. Many also have cognitive and learning impairments.

Areas of Service: The counties with the greatest percentage of respondents, from most to least, are Arapahoe (19.4%), El Paso (17.4%), Denver (12.2%), Jefferson (9.2%), Douglas (8.2%), Larimer (7.1%) and Boulder (6.1%) counties. Almost 43 percent receive some services, while only 20.4 percent receive multiple services. Special Education in schools represents the system most utilized (78.4%). Of the four age categories, respondents in the 3-14 group are least likely to collect Social Security and SSI.

Waitlist: Five of the 93 respondents indicated they were on the waitlist for services. Their wait ranges from under one year to five years. Services for which there is a wait include Comprehensive Services, SLS and ‘Other’ – all administered by the CCB. Of these, the average wait for SLS is the longest.

HOPE-DESPAIR CONTINUUM

In response to the question – *which word best describes the way you feel about your situation as it relates specifically to getting supports for your child now and in the long term* - 39.5 percent (the single largest segment of the group) describe themselves as hopeful. However, large portions of the group also describe themselves as pessimistic, discouraged or in despair. The three categories combined account for 53.1 percent of all 3-14 responders, turning the overall outlook of the group negative. (See Table 9).

Table 9
Hope-Despair Continuum: 3-14 Age Bracket
(n = 81)

Feelings	Percent of Respondents	Percent of Respondents (categories collapsed)
Optimistic	2.5%	42.0%
Hopeful	39.5%	
Satisfied	4.9%	4.9%
Pessimistic	22.2%	53.1%
Discouraged	24.7%	
Despair	6.2%	

ADEQUACY OF SERVICES

Background: Slightly more than 78 percent of children with developmental disabilities in the 3-14 age bracket participate in special education programs through their school district. Additionally, some of these children are involved with CCBs, Medicaid Waiver, Social Security or SSI and City/County Mental Health.

Results – Overall: The overall adequacy of services received a rating of 2.67, which on a scale of one to five, falls below the adequate/acceptable mark. This score dips below the rating for the entire survey sample by 0.07 of a point. (See Table 10 below).

Table 10
Adequacy of Overall Services: 3-14 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.74	1.53
3-14 Respondents (n=98)	2.67	1.59

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

To further digest the survey data, an individualized look at the overall quality of services in Adams, Arapahoe, Boulder, Denver, Douglas, El Paso, Jefferson, Larimer and Pueblo counties was conducted. All other counties in the state of Colorado were combined into a single ‘Rural/Other’ category. The results produce ratings as low as 2.13 and as high as 3.44. (Note: Services in Pueblo County scored lower at 1.50. However, with a small count of only two, the results are not included in the county-by-county analysis). Douglas County scored the highest, while both Adams and Denver counties scored at least 3.0 (adequate/acceptable). The worst rated counties include Boulder, El Paso and Larimer.

According to respondents, all systems in Colorado need improving, including Early Intervention, Special Education, CCBs, Mental Health, Medicaid Waivers, Social Security and SSI, Vocational Rehabilitation, Transitions and Regional Centers. The two systems most often marked for improvement are special education (71.6% of respondents) and CCBs (53.1%). A closer examination of both follows.

Results – Special Education: Special education services are inadequate with a rating of 2.41. It is not uncommon to encounter a respondent reporting both high quality and low quality services within the same school category. For example, an elementary school might be excellent, while a middle school in the very same district is problematic. Or a second grade teacher proves helpful, but the third grade teacher does not, and so forth. A parent notes, “[s]ervices seemed to be dependent upon the school he attended and on funding and school staffing/resources.”⁴⁷

Those pleased with the quality of educational services report that staff help to foster inclusion/acceptability and are caring. The Child Find program, an evaluation process designed to locate children who may have a disability and be eligible for special education services,⁴⁸ also received praise.

More respondents have negative experiences to report about the school system than they do positive.

“The state educational system is pathetic when it comes to Special Ed. They only care about doing the bare minimum to be legally defensible.”⁴⁹

“[I wish someone had told me that] CO was the worst state for special education.”⁵⁰

“My son's educational experience was VERY POOR. It destroyed his self-esteem for learning and I will always wonder how he could have been different if he had been presented with an appropriate educational experience at the outset. This is tragic and heartbreaking, and astounding that it continues in this day and age and in one of the ‘best’ school districts in the state.”⁵¹

Parents cite lack of empathy, disregard for parental input and inadequate funding as factors contributing to the poor quality of service. The Extended School Year (ESY) program also received negative feedback. Respondents repeatedly identify three problems. 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. To quote a parent, “[t]oo few staff with not enough training and good para[professionals].”⁵² Another recalls, “The teachers could use more training on how to help kids with special needs.”⁵³ An inability to understand and implement IDEA and the Individualized Education Plan (IEP) represents the third and probably most substantial problem. “I would like to see more mandatory training for ALL teachers about the IEP process and the laws of IDEA, ESPECIALLY at the Elementary School

level.”⁵⁴ (See the ‘PLANNING’ section below for further detail). One respondent puts forward an idea for improvement.

”[W]e need to find ways of staffing our children adequately! Some schools in California are doing a Peer Tutor Program that sounds great and benefits not only kids with disabilities, but also those taking the elective class. Peers earn credits for this class and are TRAINED to assist kids with disabilities in the classroom. They are then assigned a child to work with in a certain class and fills out reports, etc. This could be utilized for the kids that need minimal or even moderate help and freeing up time for the Para[professionals] to work with those with more significant needs. I think if we can staff our kids with disabilities, there would be more things in the education system that would fall into place.”⁵⁵

Results – CCB: Only 46.4 percent of the 3-14 respondent group use services in the CCB system, though 53.1 percent call for its improvement. Services are rated at 2.60, lower than the total respondent average or the average of any other age bracket. (See Table 11 below).

Table 11
Adequacy of CCB Services: 3-14 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.85	1.53
3-14 Respondents (n=98)	2.60	1.59

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

CASE MANAGEMENT

General: Only 52.9 percent of respondents claim to have a case manager, by far, the lowest of the four age brackets. 28.5 percent of those with a case manager report receiving either no information, or information that doesn’t apply to them at all. 48.2 percent are supplied with information regarding community activities, and 25 percent about programs and services. The remainder of respondents marked ‘other’ but many report information regarding school services. Case management services received an adequate/acceptable rating (3.15), which is higher than the score generated by the entire group of 239 respondents. (See Table 12 below).

Table 12
Case Management: 3-14 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.96	1.47
3-14 Respondents (n=98)	3.15	1.52

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

Turnover: More than three-quarters (76.7%) of parents with children aged 3-14 ‘always’ or ‘usually’ meet with the same case manager. 14.3 percent ‘never’ encounter such consistency. (See Table 13 below).

Table 13
Turnover in Case Management Personnel: 3-14 Age Bracket
(n=56)

How often do you meet with the same case manager?	Percent of Respondents	Categories Collapsed
Always	44.6%	76.7%
Usually	32.1%	
Seldom	1.8%	23.2%
Almost Never	7.1%	
Never	14.3%	

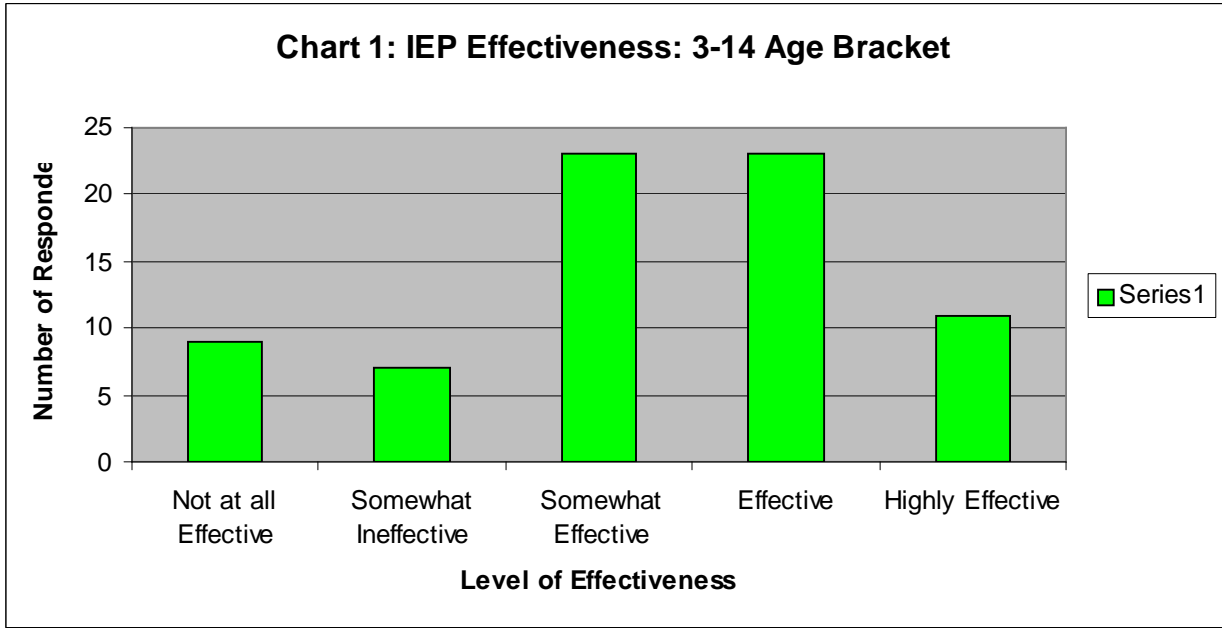
*These percentages total to 99.9 percent

PLANNING

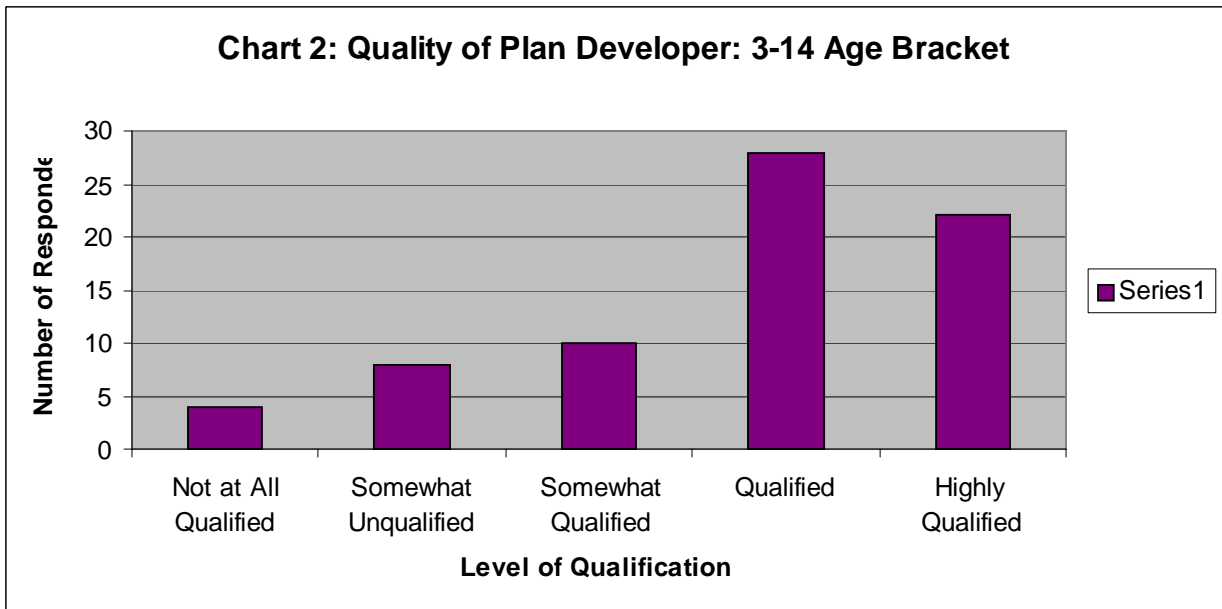
General: 90.6 percent of parents in the 3-14 group have an individualized plan in place for their child. Of the various plans possible, the vast majority (95.4%) has had an Individualized Education Plan (IEP) through their school district.

Individualized Education Plan (IEP): Most parents were present (92.8%) and had at least ‘some’ input (83.2%) in the development of their child’s IEP. The IEP team is the primary entity responsible for plan development and implementation. Teachers represent the individuals most often cited as the individual responsible for actually carrying out the plan, though 17.9 percent of parents play a role as well.

In terms of effectiveness, answers range from ‘not at all effective’ to ‘highly’ effective’ with most rated ‘somewhat effective’ and ‘effective.’ (See Chart 1 below).



Respondents were asked – *How qualified did you feel was the person responsible for creating your plan in the State of Colorado.* 65.7 percent consider the plan developer(s) to be ‘qualified’ or ‘highly qualified.’ Only 5.3 percent describe their developer(s) as ‘not at all qualified.’ (See Chart 2 below).



Though the quantitative data demonstrates that IEPs are developed by qualified personnel and implemented [somewhat] effectively, the 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. Furthermore, the planning process can be adversarial. The following quotes come directly from survey respondents.

*“[X] Middle School was a horror story. They told me one thing and then didn't implement any of it. They didn't even know how to assign hours on their IEP form. I had to teach them how to do their jobs and they supposedly had years of experience. I ended up taking them and the school district to the Office of Civil Rights and having them mediate my complaints.”*⁵⁶

*“Schools do not understand the laws and the IEP process.”*⁵⁷

*“[Y] School district has a lot to learn about IEPs and listening to the parents.”*⁵⁸

*“In [Z] school district it was very frustrating to participate in the IEP process. Not everyone present was helpful and on our daughter's side.”*⁵⁹

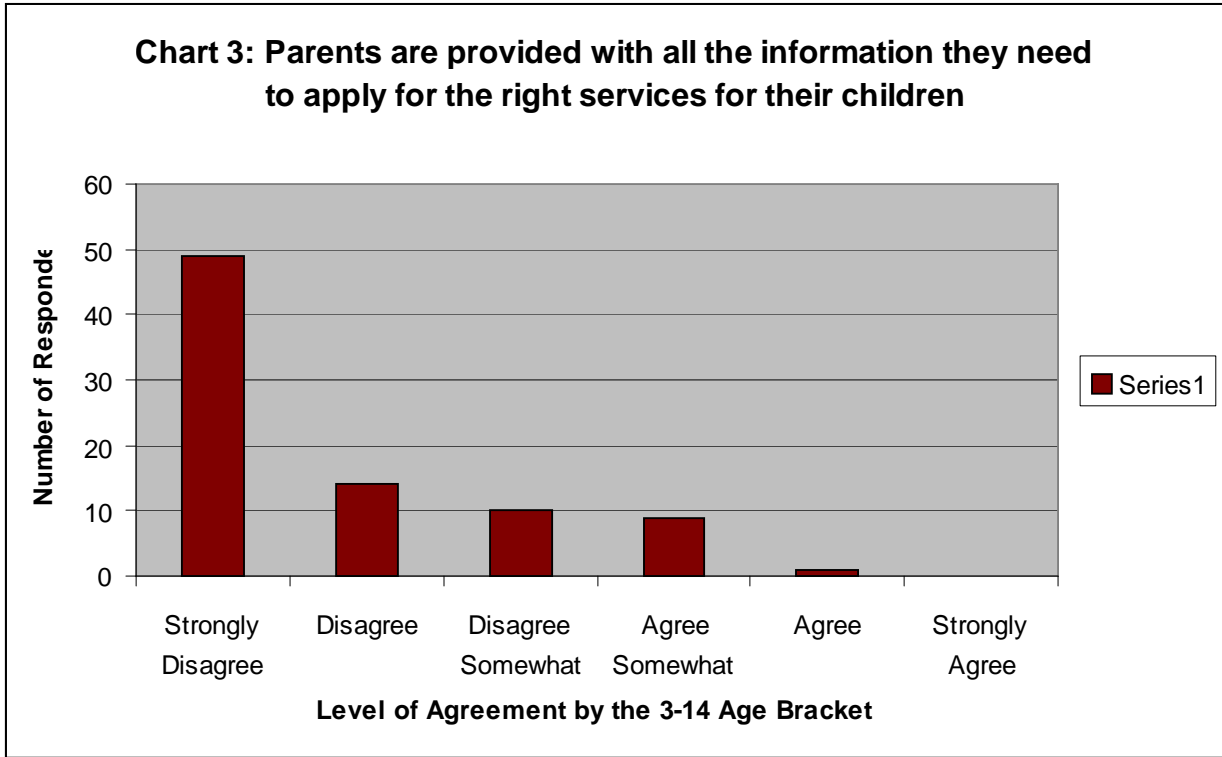
*“The IEP has been a struggle and until we did our homework we found the school was doing things they shouldn't have been.”*⁶⁰

*“At present, the district administrators are providing courses for teachers on how to prepare a legally defensible IEP. Instead they should be providing courses on how do you write an IEP that will educate a child.”*⁶¹

*“[The] IEP services' page is written in vague, double talk, confusing [language] so services can be pulled at any time or not provided at all.”*⁶²

ABILITY TO ACCESS INFORMATION AND UNDERSTAND THE SYSTEM

According to parents, the information needs of the 3-14 group are not being met. When asked to agree or disagree with the statement – *Parents are provided with all the information they need to apply for the right services for their children at each appropriate stage* – 87.9 percent disagree, with 59 percent in strong disagreement. At the same time, not a single parent ‘strongly agrees.’ (See Chart 3 below).



Quotes illustrative of the information gap are as follows:

“I had to find out everything the hard way. I researched and asked millions of questions to millions of people and then sorted out the facts for myself.”⁶³

“I felt like I was walking in a fog, not understanding all the various acronyms and what to expect next.”⁶⁴

“There needs to be a better way to inform parents of what is available and how to access it.... For example a brochure listing all of the above [early intervention] services and who and what they are intended for, how to access them. This brochure should be available in all hospitals, pediatrician's offices, schools, and therapy centers.”⁶⁵

As such, many require help navigating the “maze of available systems.”⁶⁶ 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?

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.

DEMOGRAPHIC INFORMATION

General: Forty-seven of the 239 replies, or 19.7 percent of the total, fall into the 15 to 21 year old age bracket. The typical respondent in this group is a parent aged 41 to 60 whose child has a cognitive (68.1%) impairment. Though, several suffer from a wide range of disabilities including behavioral, physical, special medical needs, learning and neurodevelopmental.

Areas of Services: The counties with the most respondents are Arapahoe (23.4%), Jefferson (17%), Boulder (8.5%), Douglas (6.4%) and El Paso (6.4%). Half are the recipients of some or multiple services, while 21.8 percent receive no services, either because they do not need them, do not know where to apply or have been denied. The 15-21 group works with a wide variety of services. Most frequently among said services are Special Education (64.4%), CCBs (44.4%) and the Transitions Program (40.0%) described as high school to adulthood provided by schools. Just over one-third of respondents collect Social Security and Supplemental Security Income.

Waitlist: Of the 47 respondents, only seven provided waitlist information. Waiting anywhere from under a year to five years, respondents are on the list for Comprehensive Services, Supported Living Services and Other services through their CCB. Three respondents wait for services from entities other than their CCB. SLS is the service with the most (5 of 7) individuals waiting.

HOPE-DESPAIR CONTINUUM

The outlook of those with children aged 15 to 21 is negative. Moving along a hope-despair continuum, the largest portion of the group reports feeling pessimistic. Furthermore, combination of the pessimistic, discouraged and despair categories account for 67.5 percent of respondents. Only 29.7 percent report being 'optimistic' or 'hopeful.' (See Table 14 below). Based on these figures, the 15-21 group feels more discouraged than any other age bracket. (See Table 15 below).

Table 14
Hope-Despair Continuum: 15-21 Age Bracket
(n = 37)

Feelings	Percent of Respondents	Percent of Respondents (categories collapsed)
Optimistic	2.7%	29.7%
Hopeful	27.0%	
Satisfied	2.7%	2.7%
Pessimistic	32.4%	67.5%
Discouraged	21.6%	
Despair	13.5%	

*These percentages total to 99.9 percent

Table 15
Hope and Despair as it relates to Getting Supports by Age Bracket

Age Group	% of Respondents that feel Pessimistic, Discouraged and/or Despair
0-2 (n=6)	16.7%
3-14 (n=98)	53.1%
15-21 (n=37)	67.5%
21+ (n=70)	41.4%

ADEQUACY OF SERVICES

Background: Individuals aged 15 to 21 are still very much a part of the school system. However, their experiences and needs likely differ from younger children in the school system. This is because between the ages of 14 and 16 focus shifts to the appropriate academic and vocational supports necessary for graduation.⁶⁷ Often, the transitions program aids in this phase of the educational experience. (Forty percent of respondents participate in the Transitions Program).

Results – Overall: Respondents rated the adequacy of services overall at 2.58. On a scale of one to five, 2.58 falls between ‘poor/improvement needed’ and ‘adequate.’ Compared to the entire sample, which scored 2.74, services in the 15-21-age bracket are substandard. What is more, this group rated the quality of overall services lower than any other age bracket. (See Table 16 below).

Table 16
Adequacy of Overall Services by Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (<u>n</u> = 239)	2.74	1.53
0-2 Respondents (<u>n</u> = 11)	4.50	0.92
3-14 Respondents (<u>n</u> = 98)	2.67	1.59
15-21 Respondents (<u>n</u> = 47)	2.58	1.51
21+ Respondents (<u>n</u> = 83)	2.82	1.53

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

An analysis by county, excluded Adams, Douglas and El Paso counties for counts lower than three. Of the remaining counties (Arapahoe, Boulder, Denver, Jefferson, Larimer, Pueblo and Rural/Other), Larimer scored the highest at 3.25 and represents the only county to score above 3.0. All other counties scored between 2.25 and 2.82. Rural/Other and Boulder counties scored the highest, while Denver, Arapahoe and Jefferson scored the lowest.

Results – School: School services received a rating of 2.50, which is slightly higher than the rating generated by the 3-14 group at 2.41. Regardless, both age groups in the school system view their services as inadequate. In fact, seventy-one percent of 15-21 respondents report that special education needs improvement. (See Table 17 below).

Table 17
Adequacy of School Services: 3-14 vs. 15-21 Age Brackets

Group	Score/Rating
3-14 Respondents (<u>n</u> = 98)	2.41
15-21 Respondents (<u>n</u> = 47)	2.50

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

School services rated at a level four or five are typically described as positive based on parental experience with teachers. Specifically, respondents report that their child’s teacher is supportive, understanding, committed to educating, communicative with parents and able to implement the Individualized Education Plan (IEP).

Parents displeased with services cite a lack of training, understanding, caring and communication. Several respondents criticize the lack of integration/inclusion offered to their child. “Many teachers are not willing to include students with disabilities.”⁶⁸ Others are frustrated with the low expectations educators maintain for their children. Finally, the Transitions Program received negative feedback.

“Our transition plans for successfully getting our kids out of the school system and into the adult world is beyond terrible.”⁶⁹

“Transition in [X school district] is a joke. No services that my son needs are being provided. I have been told by the CCB that it is likely my son won't receive services until he is 21 because transition is supposed to be providing services.”⁷⁰

“High school to work transition programs are sometime nonexistent. Young adults are not adequately prepared for community involvement.”⁷¹

“I worry about the 18-21 transition program at our school.”⁷²

Results – CCB: Just under half (44.4%) of 15-21 respondents currently utilize CCB services. However, 68.4 percent believe the CCB system needs improvement. With a count of only 16, limited responses yielded a score of 2.75 for CCB services. Though this score is below the adequate/acceptable mark, it is higher than both overall and school services within the 15-21-age bracket. (See Table 18 below). Responses in regard to CCB services range from good staff, helpful, wide range of services offered to disorganized, too slow, too complicated and a lack of parental choice.

Table 18
Adequacy of Services: Overall, by School and by CCB

Classification/Setting	15-21 Respondents (<u>n</u> = 47)
Overall	2.58
School	2.50
CCB	2.75

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

CASE MANAGEMENT

General: Eighty-five percent of those in the 15-21 group have a case manager, from which 27.8 percent receive information that is either irrelevant, or non-existent. On a scale of one to five with “5” being excellent, case management services scored a 2.96 – an exact parallel to the entire sample score for case management services. (See Table 19 below). In terms of the

quality of case management by age, the 15-21 group falls in the bottom half with groups 0-2 and 3-14 scoring higher. Only the 21+ group rated case management services lower.

Table 19
Case Management: 15-21 Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.96	1.47
15-21 Respondents (n=47)	2.96	1.40

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

According to parents, case managers that do a good job are kind, caring, supportive, informed and available. Furthermore, they understand the needs of the individual with developmental disabilities. Overwhelmed personnel who fail to be effective, to follow-through or to provide information characterize case management services in need of improvement. Communication also seems to be a problem. (See communication below for greater detail).

Turnover: 66.7 percent of respondents always or usually meet with the same case manager, while the remaining 33.3 percent seldom, almost never or never meet with the same case manager. Those few respondents (4 out of 47 or 8.5%) rating turnover, gave it a score of 1.60, indicating they are displeased with the rate of case management turnover.

Communication with Parents: When asked to quantify the level of contact with their case manager/resource coordinator/planning, the largest segment of the group (36.1%) reports contact ‘whenever I need to.’ 19.4 percent have contact annually, 16.7 percent monthly and 5.6 percent quarterly. Despite this, multiple respondents vented frustration with a lack of or poor communication by their case managers.

“It seems that information is "parceled" out. Most times we have found out about services ourselves and not from people in the "system.”⁷³

“I've had the names of two people - one almost never responds to calls (even though her voice mail says she returns all calls within 3 days) and the other called me once late at night to tell me she's the case manager but that she's leaving on vacation.”⁷⁴

“I’ve never talked to the same person twice, and I went 3 years between contacts.”⁷⁵

“It seems like they really do not want to be there. Getting info out of them is like pulling teeth.”⁷⁶

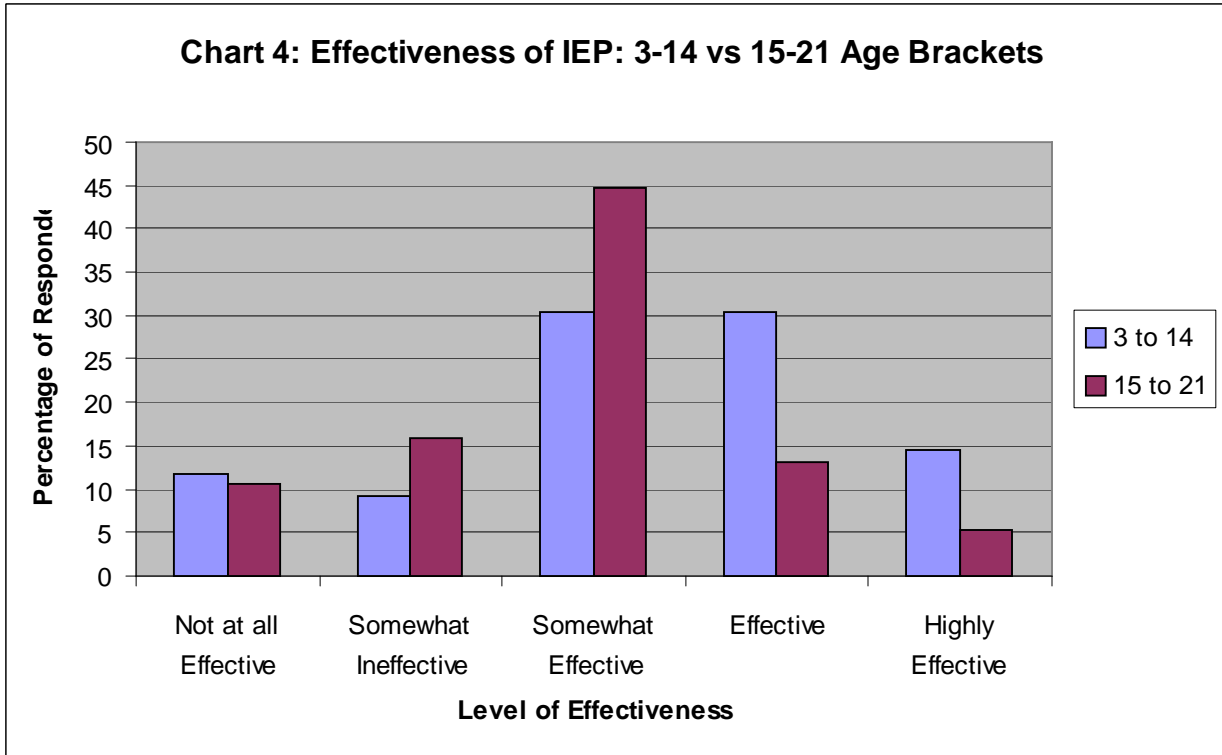
“I can’t seem to get a straight answer about when, if ever, she will be able to have comprehensive services.”⁷⁷

PLANNING

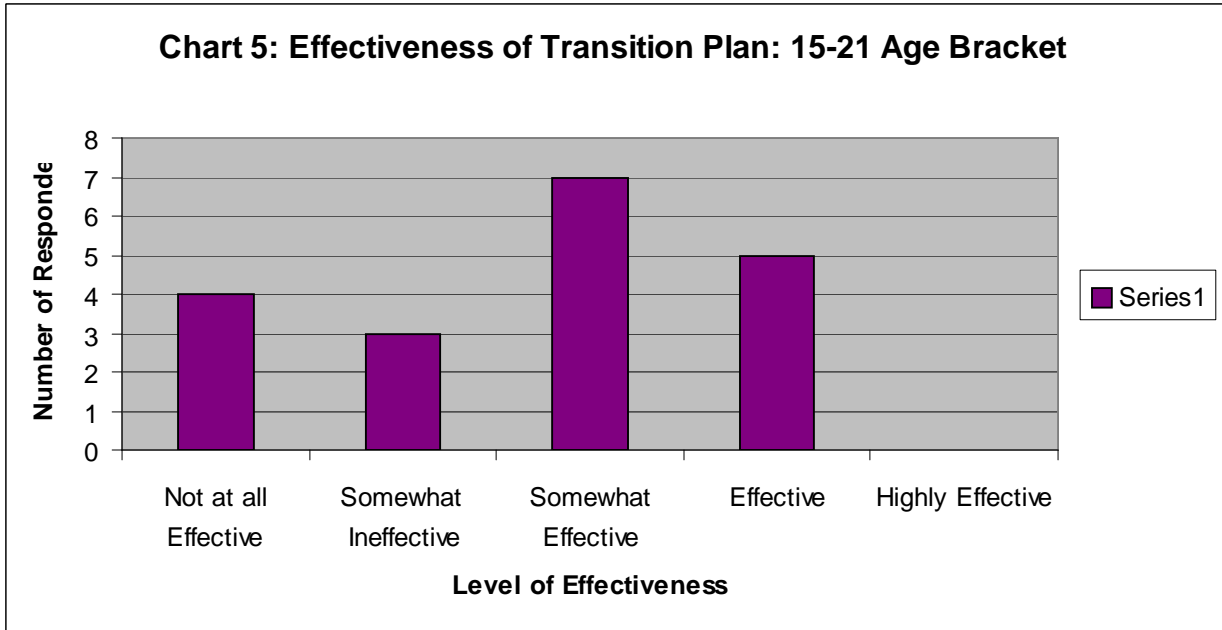
General: More than 93 percent of respondents have had or currently have an individualized plan for their child. Accordingly, the majority (88.4%) uses an Individualized Education Plan (IEP). Only 37.2 percent report experience with a plan for the transitions program. However, the fact that the 15-21 group is the age bracket in which school transition plans are most relevant necessitates a need for analysis.

Individual Education Plan (IEP): Parents were present 88.1 percent of the time, during IEP development. The level of parental input varied from ‘a little’ to ‘a lot’ with most (54.8%) providing a lot of input. More often than not, a teacher implemented the IEP, though parents and case managers also played a role. With regard to effectiveness, the modal (or most often selected) response is ‘somewhat effective’ at 44.7 percent. However, 26.3 percent of respondents feel their child’s IEP is not at all effective, or somewhat ineffective. To improve effectiveness, one parent suggests the need for “[e]nforcement by an outside party to prove that services written in [the] IEP are actually carried out [and] not just sitting on paper.”⁷⁸

Compared to the 3-14 age bracket, the IEP process of the 15-21 group appears less effective. (See Chart 4 below). However, unlike the 3-14 age bracket, which posted multiple negative comments regarding the IEP process, the 15-21 group barely addressed the IEP process qualitatively.

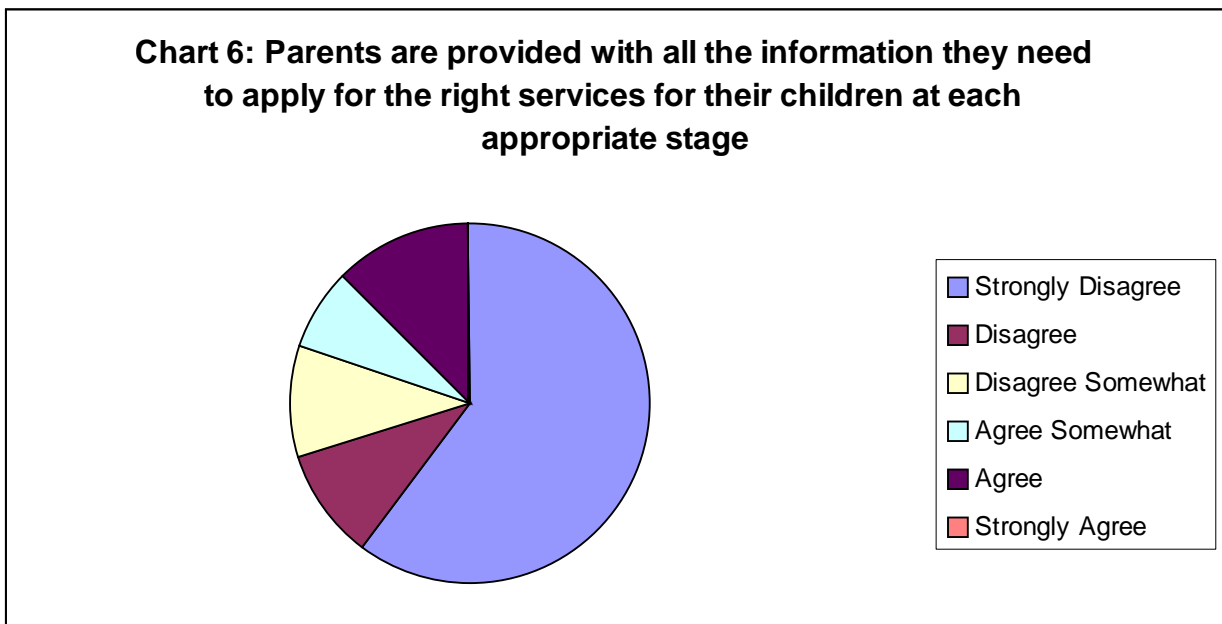


Transitions Program: The typical respondent was present during and participated in plan development. According to parents, responsibility for implementation falls on the teacher, school district personnel (31.6% each), the parent (26.3%) and the IEP team (10.5%). Mostly, respondents found their transition plan to be somewhat effective. Not a single respondent termed the plan ‘highly effective.’ (See Chart 5 below).



ABILITY TO ACCESS INFORMATION AND UNDERSTAND THE SYSTEM

Respondents could use more information. The majority (60%) believes they are not provided with the information necessary to apply for services for their children. (See Chart 6 below).



Specifically, 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. Parents responding to the statement – “*I really need more information about _____,*” have this to say:

“Supports after my child is 21 – where can she go during the day (that I can afford) so I can continue to work; where can I get respite...”⁷⁹

“Programs to prepare my child for life beyond high school.”⁸⁰

“Transitioning to adulthood. A step by step, do this. Use these words. If they say X, do Y. I read what is available but am overwhelmed with solving today’s problems.”⁸¹

“Transition from high school to adulthood.”⁸²

“What happens to my kid while waiting for Comprehensive Services? I’m a single mom, and I despair about what will happen when she turns 22. School is bad, but it’s better than nothing. I’m afraid she will be able to access nothing at that age. I’m afraid I will just have to take her to work with me because SLS will not even begin to meet her needs. I know they will push her to a nursing home, but that will happen over my dead body.”⁸³

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.”⁸⁴

“Why [do] Coloradans care so much about infants and care nothing about adults?”⁸⁵

DEMOGRAPHIC INFORMATION

General: Of the 239 replies, 83 claim children older than 21 years of age. This number represents the second largest group of respondents at 34.7 percent of the total. The typical respondent in this group is a 51-60 year old parent of a child who possesses, at the very least, a cognitive disability. Many have multiple disabilities including: behavioral, physical, special medical needs, learning and neurodevelopment.

Areas of Service: The counties with the most respondents are Arapahoe (28.9%), Denver (15.7%), Jefferson (14.5%) and El Paso (7.2%). Eighty-three percent receive some or even multiple services in the state of Colorado, most (68.3%) through their CCB. Approximately, 67.1 percent also collect Social Security or Supplemental Security Income (SSI).

Waitlist: Only four of the 83 respondents supplied information regarding the waitlist for services. Accordingly, they represent individuals who have been on the waitlist anywhere from two to ten years. Twenty-five percent of respondents have waited at least six years for SLS, Comprehensive Services and other services provided by the CCB.

HOPE-DESPAIR CONTINUUM

Utilizing a hope-despair continuum, respondents were invited to describe their outlook as it relates to getting supports for their children. The continuum moves from optimistic to hopeful to satisfied through pessimistic to discouraged and ends at despair. (See Table 20 below). The largest group of respondents is hopeful at 35.7 percent. Add the optimistic group, and the percentage jumps to 47.1 percent. However, collapsing the pessimistic, discouraged and despair categories describes 41.4 percent of respondents. In other words, though the single largest group is hopeful, the overall feeling of the entire group is split relatively evenly between positive and negative.

Table 20
Hope-Despair Continuum: 21+ Age Bracket
(n = 70)

Feelings	Percent of Respondents	Percent of Respondents (categories collapsed)
Optimistic	11.4%	47.1%
Hopeful	35.7%	
Satisfied	11.4%	11.4%
Pessimistic	17.1%	41.4%
Discouraged	15.7%	
Despair	8.6%	

*These percentages total to 99.9 percent

A second, but similar survey question adds depth to the previous findings. Respondents were asked to provide their opinion of the following statement - *I am hopeful about the services I will receive for my child in the future.* Forty three percent fell into the disagree categories, while fifty-seven percent marked a variation of agree. (See Table 21 below). Thus, in terms of hope for future services, the findings presented in Table 20 are reinforced. However, the group that ‘strongly disagree’ (20.8 percent) greatly outweigh the group that ‘strongly agree’ (2.8 percent). This indicates that while those who agree are not ardent in that belief, those who disagree do so quite vehemently.

Table 21
Hope for Services in the Future: 21+ Age Bracket
(n=72)

Feelings	Percent of Respondents	Percent of Respondents (categories collapsed)
Strongly Agree	2.8%	57%
Agree	13.9%	
Agree Somewhat	40.3%	
Disagree Somewhat	6.9%	43%
Disagree	15.3%	
Strongly Disagree	20.8%	

ADEQUACY OF SERVICES

Background: 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 typically serviced through the Community Centered Board (CCB) system. However, some individuals eligible for special education are ineligible for adult services. As such, they do not receive CCB services after leaving school, nor are they placed on the waitlist for services.

Results – Overall: The overall adequacy of services received a below average rating by the 21+ group of 2.82, on a scale of one to five, with “1” being ‘very poor/much improvement needed’ and “5” equaling ‘excellent.’ This rating is slightly above the score for the entire sample of 239 respondents, which rated adequacy of services at 2.74. (See Table 22 below).

Table 22
Adequacy of Overall Services: 21+ Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (n=239)	2.74	1.53
21+ Respondents (n=83)	2.82	1.53

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

A breakdown of overall services by county reveals that Jefferson and Rural/Other counties are ranked the highest. (Note: Adams, Arapahoe, Boulder, Denver, Douglas, El Paso Jefferson, Larimer and Pueblo are the only counties analyzed separately. All others are grouped into a single ‘Rural/Other’ category). Jefferson and Rural/Other are the only two sub-groups to receive scores higher than 3.0. Adams County scored 3.0 exactly. Excluding Larimer County with zero respondents, all other counties scored between 2.0 and 2.85 with Douglas, Pueblo and Denver ranked the lowest.

Respondents were asked which of several systems in Colorado needed improvement. They choose from a wide variety of systems/programs including early intervention, special education, CCBs, mental health, Medicaid waiver, SSI, vocational rehabilitation, transitions and regional centers. They were also given the option of ‘I don’t know’ and ‘none of the systems need to be improved.’ Not a single respondent from the 21+ group selected the ‘none of the systems need to be improved’ option. The two systems most often selected for improvement were Community Centered Boards (CCB) and vocational rehabilitation. In fact, 62.9 percent of respondents cited the CCB system, while 55.7 percent cited vocational rehabilitation. As such, a closer examination of both systems is prudent.

Results – CCB: A majority of the respondents in this group receive services through their CCB. Unfortunately, responses geared specifically towards the CCB system are limited. In fact, of all the ‘adequacy of services’ responses, only 28 percent were specifically categorized under the CCB setting. This is partly attributed to the vague quality of some responses.

The results yield a score of 2.92 for CCBs, falling below the adequate/acceptable mark. As with adequacy of services overall, the CCB rating is slightly higher than the CCB rating for the entire sample. (See Table 23 below).

Table 23
Adequacy of Services: Overall, by CCB and by Vocational Rehab: 21+ Age Bracket

Classification/Setting	All Respondents (n=239)	21+ Respondents (n=83)
Overall	2.74	2.82
CCB	2.85	2.92
Vocational Rehabilitation	1.88	1.84

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

According to survey responses, CCBs are unresponsive to parental input. Furthermore, multiple respondents noted problems with service providers. Either the quality of the programs offered is low, or oversight of said programs is poor. Problems typical of the entire system, including effectiveness, rigidity, bureaucracy and the inability to problem solve, were also cited.

Results – Vocational Rehabilitation: The vocational rehabilitation adequacy of services’ score was 1.84, indicating that respondents are extremely dissatisfied with these services. In fact, of the three service areas examined (overall, CCB, vocational rehabilitation), this score is the lowest. Additionally, it is the only score of the three in which the rating for the 21+ group is lower than the rating for the entire sample. (See Table 22 above). A parent recalls, “Voc[ational] rehab[ilitation] was a ridiculous waste of time. My son needed help learning to work with other people and to develop some other job skills. Vocational rehabilitation put him in a program that wasn't appropriate for him and then told us we needed to pay for private psychotherapy or they wouldn't work with us.”⁸⁶ A second parent adds, “It was a shock to suddenly have no future after high school.”⁸⁷ Of note, vocational rehabilitation has the smallest count of the three service areas.

Respondents claim vocational rehabilitation services are unreliable, ineffective, too rigid, difficult to work with and fails to problem-solve. One respondent observed that vocational rehabilitation places people in any job, rather than a good job.

From the qualitative responses, two suggestions for improvement emerged. The first suggests that employers need to be given incentives to hire individuals with developmental disabilities. Additionally, opportunities could be provided through partnerships with unions, chambers of commerce and city/state government. For example, an individual with a

developmental disability could work in a local government office or parks and recreation department.⁸⁸ A second suggestion relates to the support of an employed individual. To quote,

“In the unlikely event that vocational rehabilitation is successful in placing an individual in employment, support of the individual would be more effective if [a] small amount of money was available to a co-worker to be his mentor/support while on the job. The mentor would appreciate the opportunity to earn higher pay and the client would be better accepted because he is friends with a co-worker. The current on the job support strategy causes the client to stand out and [be] seen as different because he has an outsider come in and monitor his performance.”⁸⁹

CASE MANAGEMENT

General: A majority (76.3) of respondents are serviced by a case manager. Approximately 29 percent of those respondents receive either no information, or information that doesn’t apply to them at all from their case manager. Others receive information about community activities and programs/services for which they qualify. The case management rating is 2.71, below the acceptable/adequate level of service. The rating for the entire sample is 2.96. Thus, case management services in the 21+ group are below the ratings for all 239-survey respondents. (See Table 24 below).

Table 24
Case Management: 21+ Age Bracket

Group	Score/Rating	Standard Deviation
All Respondents (<u>n</u> =239)	2.96	1.47
21+ Respondents (<u>n</u> =83)	2.71	1.39

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

Case management services are rated poor for a number of reasons. Turnover is a major problem, creating an environment in which case management personnel are ill informed and poorly trained. According to one parent, “[w]e have no continuity of resource coordinator. They are poorly informed. They never stick around a full year. Generally we are educating them, not the other way around.”⁹⁰ Others cite frustration with the lack of communication, the rude treatment and the loss of paperwork.

Parents satisfied with their case management services relate a few common themes. Their case managers are communicative, available and responsive. Furthermore, they demonstrate an ability to be kind, flexible and a willingness to advocate on behalf of their clients. For example, one respondent noted, “I recently worked with a case manager that definitely had my ward's best interests at heart and went over and above to help my ward and me find the best situation for him.”⁹¹ Those granting case management a five, the highest ranking for services, found their case manager to be knowledgeable and able to “get things done.”⁹²

Turnover: Quantitative analysis of case management turnover showed that, more than half (53.9%) of respondents seldom, almost never, or never meet with the same case manager. A parent laments, “[we have a] different one every year. Depressing. I've completely lost faith in their system!”⁹³ Another parent remarks, “[w]e have had so many different case managers in the 5 years we have been receiving services that I've lost count. It's the system's worst problem, I believe.”⁹⁴ The remaining 46.1 percent usually or always meet with the same case manager. (See Table 25 below).

Table 25
Case Management Turnover: 21+ Age Bracket
(n=65)

How often do you meet with the same case manager?	Number of Respondents	Percent of Respondents
Always/Usually	30	46.1%
Seldom/Almost Never/Never	35	53.9%

Of the four different age brackets discussed in this report (0-2; 3-14; 15-21; 21+), the 21+ group scored the lowest in terms of case management turnover. Though the sample size within each group is small, the turnover scores are 2.0, 1.8, 1.6 and 1.29 respectively. (See Table 26 below). The lower the score, the more the respondent views turnover as a problem. These results indicate that as the individual with a developmental disability increases in age, the incidence of case management turnover also increases.

Table 26
Case Management Turnover by Age Group

Age Group	Score/Rating	Count
0-2	2.0	2
3-14	1.8	10
15-21	1.6	5
21+	1.29	21

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

** These results should be interpreted with care, as the count for each age group is relatively small

Communication with Parents: Thirty-eight and a half percent of respondents are in contact with their case manager/resource coordinator/planner whenever they need to. Almost forty-five percent have contact at least annually, while 3.1 percent are in contact less than annually. Those that have no contact represent 6.2 percent of the group. (See Table 27 below).

Table 27
Frequency of Contact with Case Manager/Resource Coordinator/Planner
(n=65)

Frequency of Contact	Number of Respondents	Percent of Respondents
Whenever I need to	25	38.5%
At least annually (monthly, quarterly, semi-annually, annually)	29	44.6%
Less than annually	2	3.1%
Never	4	6.2%
Other	5	7.7%

*These percentages total to 100.1 percent

PLANNING

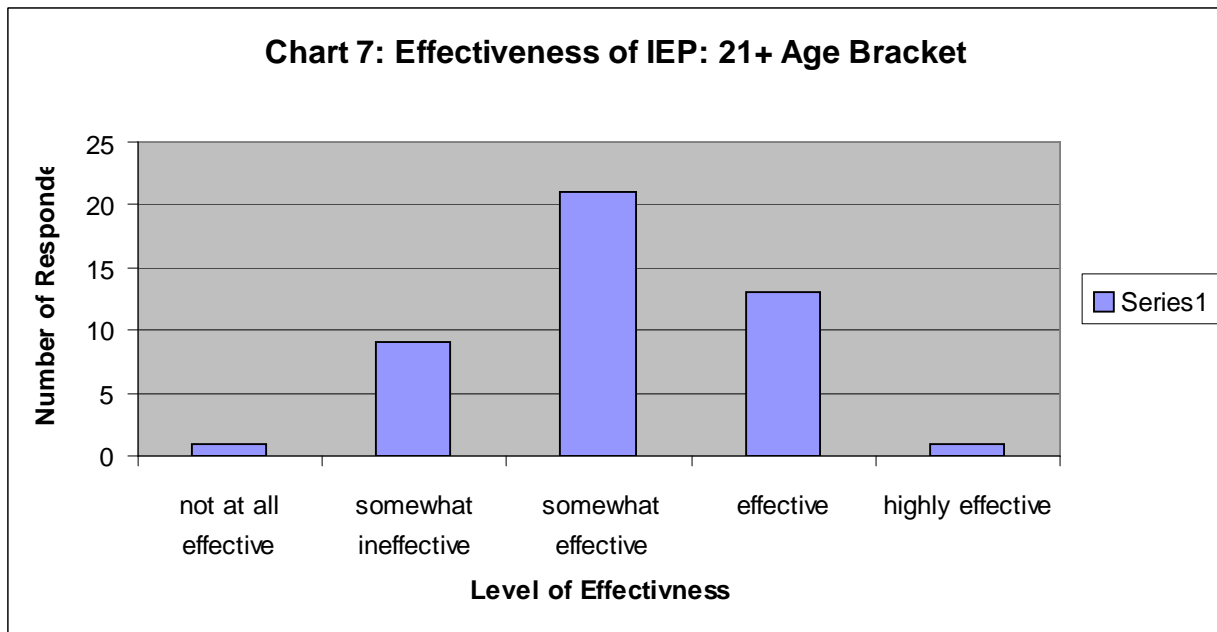
General: Just over 75 percent of respondents have had, or currently have an individualized plan in place for their child. The two most frequently utilized plans are the Individualized Education Plan (IEP) and the Individualized Plan (IP). In fact, 74.6 percent of respondents have participated in both. As such, focus will be given to the planning of the IEP and IP process.

Individualized Education Plan (IEP): Of those respondents whose child had an IEP (used in the public school setting), the vast majority (96%) were present when the plan was developed. Each of those present report having some input, varying from ‘little’ to ‘a lot,’ though a slight majority (50.8%) describe their level of input in developing the plan as ‘a lot.’ (See Table 28 below).

Table 28
Level of Parental Input in Developing IEP and IP Plans: 21+ Age Bracket

Level of Parental Input	IEP (n=50)	IP (n=52)
Little Input	3.3%	8.3%
Some Input	27.9%	13.3%
A Lot of Input	50.8%	65.0%

In terms of effectiveness, respondents choose from one of five responses ranging from not at all effective to highly effective. The modal, or most often selected, response falls under the category ‘somewhat effective.’ (See Chart 7 below).



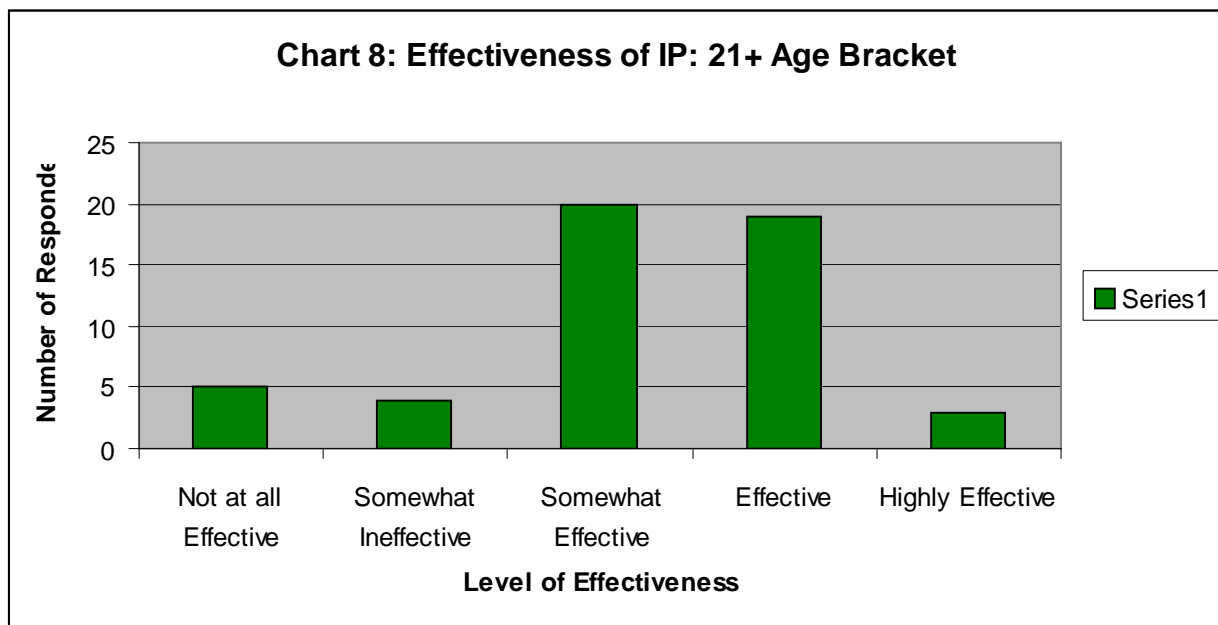
Individualized Plan (IP): The vast majority (98%) of parents were present when their child’s IP was developed. Sixty-five percent contributed ‘a lot of input’ to its development. (See Table 28 above).

According to 56.1 percent of respondents, the CCB case manager is responsible for ensuring IP implementation, while only 22.8 percent actually performed said duties. Concurrently, 45.6 percent of parents assumed responsibility for actual plan implementation. (See Table 29 below).

Table 29
IP Responsibility and Implementation: 21+ Age Bracket
(n=50)

Who is the primary person...	Case Manager	Parent/Guardian
RESPONSIBLE for plan implementation	56.1%	17.5%
Actually CARRYING OUT plan implementation	22.8%	45.6%

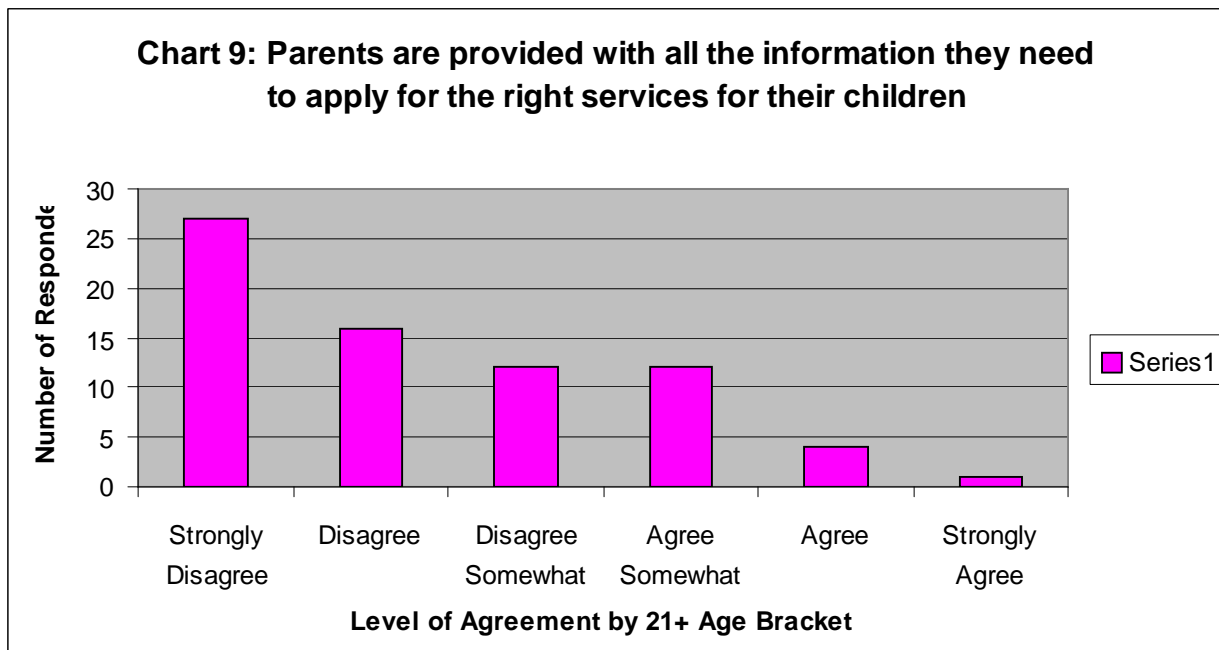
As with the IEP, respondents describing the IP process rated the plan using an effectiveness scale. The category most often selected is nearly a tie between ‘somewhat effective’ and ‘effective.’ (See Chart 8 below).



Overall: Despite the fact that the IEP and IP were both rated as being somewhat effective and/or effective, the planning system as a whole is not considered effective. Respondents were posed the following statement – *Systems work well together to develop and implement comprehensive plans* – and were then asked to agree or disagree. The most commonly occurring response to this statement is ‘strongly disagree,’ with 30.6 percent of respondents. Conversely, only 1.4 percent of respondents ‘strongly agreed.’

ABILITY TO ACCESS INFORMATION & UNDERSTAND THE SYSTEM

The ability to access information and understand the system is often cited as a concern of parents. In fact, 37.5 percent of respondents in the 21+ group ‘strongly disagree’ with the statement – “*parents are provided with all the information they need to apply for the right services for their children at each appropriate stage.*” Only 1.4 percent of respondents ‘strongly agree.’ (See Chart 9 below).



Several parents voiced frustration with the lack of information and complication of the system.

“I am confused on all the services and who does what. Maybe someday I will have the energy to figure it all out. I feel very stupid in trying to figure it out and am just too overwhelmed and tired to do so now.”⁹⁵

“Getting information is sometimes difficult. Keeping who does what straight is impossible. Knowing who to call for what program is difficult. We all rely on the OM (other mothers) system.”⁹⁶

“I am a person with a law degree and I feel totally overwhelmed and frustrated by the lack of good information and clear procedures to follow.”⁹⁷

Based on the knowledge that information can be difficult to obtain, the survey included the question - *I really need more information about _____*. Thirty-two of the 83 respondents replied with answers focusing on jobs and housing options. 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. Others desire access to funding information. They want to know, “where the buck stops.”⁹⁸

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.”⁹⁹

“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.”¹⁰⁰

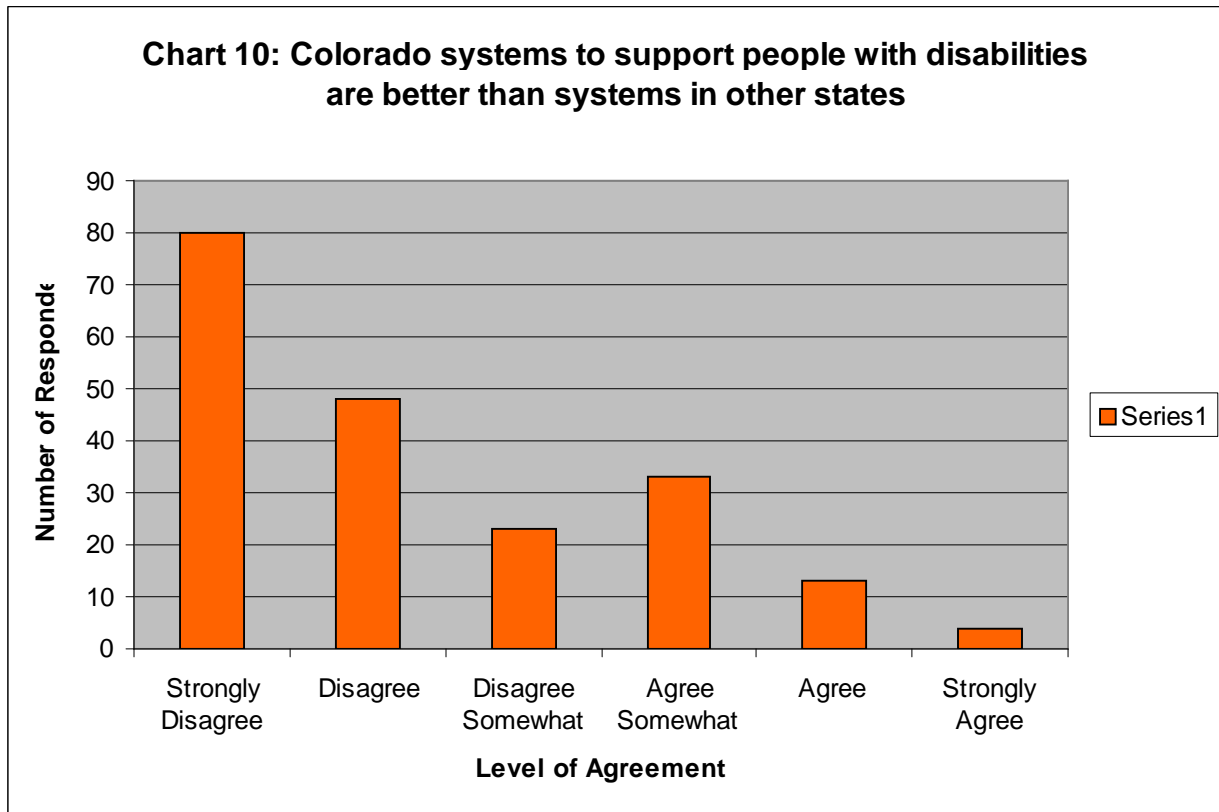
“It seems interesting to me that we can continue to build huge prisons and fund all kinds of needs for people in the justice system but we can't come up with the money to fund the needs of people with DD. Why can't some of the money that comes in from the lottery be used for DD? While parks are important, people are more so!”¹⁰¹

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.”¹⁰² 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.”¹⁰³ 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???”¹⁰⁴

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.”*¹⁰⁵

*“I have lost many of my friends because they have moved for better services.”*¹⁰⁶

*“I was very disappointed when I arrived to find such a splintered service system.”*¹⁰⁷

*“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.”*¹⁰⁸

*“... [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!”*¹⁰⁹

*“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.”*¹¹⁰

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.”¹¹¹ 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.”¹¹² 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’.”¹¹³ 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 time. I started asking if anyone had heard of a fax machine?!”¹¹⁴ 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.”¹¹⁵ 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!!!!!!!!!!”¹¹⁶

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.”¹¹⁷

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.”¹¹⁸

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.”*¹¹⁹

*“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.”*¹²⁰

*“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.”*¹²¹

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.”¹²²

The ARC, an advocacy organization devoted to improving supports and services for the developmentally disabled,¹²³ 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.”¹²⁴ Another adds, “[t]he ARC of Aurora has been a tremendous resource for advocacy for my son.”¹²⁵ And a third, “ARC of Arapahoe & Douglas is wonderful... the advocates are wonderful and understanding.”¹²⁶

The Special Olympics Program enjoys similar praise. Tasked to provide year-round athletic training and competition to individuals with intellectual disabilities,¹²⁷ Special Olympics “is the best program around for people with disabilities and most of the workers are unpaid totally exhausted parents.”¹²⁸ 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.”¹²⁹

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!”*¹³⁰

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.

Appendix 1

PAD-CO Sample Survey

ABOUT YOU

1. What is your relationship to the child (including adult children) with a disability?
 - Parent (including adoptive parents)
 - Foster Parent
 - Legal Guardian
 - Representative

2. In what Colorado County is your child served?

3. In what age range is your child?
 - Newborn up to 3 years
 - 3 up to 6 years
 - 6-10 years
 - 11-14 years
 - 15-18 years
 - 19-21 years
 - 22-35 years
 - 36-50 years
 - 51 and older

4. In what age range are you?
 - Under 21
 - 22-30
 - 31-40
 - 41-50
 - 51-60
 - 61-70
 - 71 and older

5. Please tell us which of the following disabilities your child has. (Choose all that apply)
 - Cognitive
 - Behavioral (including mental health)
 - Physical
 - Special medical needs
 - Learning
 - Neurodevelopmental (including autism, PDD, brain injury, cerebral palsy, etc.)

SERVICES YOUR CHILD CURRENTLY RECEIVES

6. Which of the following circumstances BEST describes your status in receiving services from systems that should/would serve your child?
 - Do not currently need services
 - Not currently receiving services in Colorado and have not in the past
 - Not receiving any services because I don't know where to apply

- Not receiving services because I have not applied yet
- Not receiving services because we have been denied
- Have a case manager/resource manager/planner but we are not receiving any services
- On the wait list for services
- Receiving some services
- Receiving multiple services
- None of the above

WAITLIST

7. How long have you been on the waitlist for the following services?

- Supported Living Services (SLS through CCB)
- Comprehensive Services (COMP through CCB)
- Other services through CCB
- Other services through other entity

PROGRAMS/SYSTEMS

8. Which of the following programs/systems are you CURRENTLY working with in the state of Colorado? (Choose all that apply)

- Early Intervention
- Special Education (in schools)
- Community Centered Board (Developmental Disability System such as Denver Options, Developmental Pathways, Imagine!, etc.)
- City/County Mental Health
- State Mental Health Facility
- Medicaid Waiver
- Social Security or Supplemental Security Income
- Vocational Rehabilitation
- Transitions Program (high school to adulthood, provided by school district)
- Regional Center (Wheat Ridge, Pueblo or Grand Junction)
- Not working with any system
- Other (please specify)

CURRENT MEDICAID WAIVER

9. Which Medicaid waiver program(s) are you CURRENTLY involved with?

- HCBS – Children (aka Katie Beckett waiver)
- HCBS – Children’s Extensive Support (CES)
- HCBS – Children’s Habitation Residential (CHRP)
- HCBS – Mentally Ill Waiver (MI)
- HCBS – Elderly Blind and Disabled (EBD)
- HCBS – Traumatic Brain Injury (TBI)
- HCBS – Supported Living (SLS)
- HCBS – Comprehensive Support (DD)
- Don’t know which waiver

10. Where do you CURRENTLY receive your Medicaid Waiver case management services?

- Medicaid Single Entry Point (SEP – ie, Adult Care Management Inc.)

- Community Centered Board (CCB – ie, Developmental Pathways, Denver Options)
- Other (please specify)

PAST SERVICES

11. Which of the following systems have you EVER worked with in the state of Colorado? (Choose all that apply)
- Early Intervention
 - Special Education (in schools)
 - Community Centered Board (Developmental Disability System such as Denver Options, Developmental Pathways, Imagine!, etc.)
 - City/County Mental Health
 - State Mental Health Facility
 - Medicaid Waiver
 - Social Security or Supplemental Security Income
 - Vocational Rehabilitation
 - Transitions Program (high school to adulthood, provided by school district)
 - Regional Center (Wheat Ridge, Pueblo or Grand Junction)
 - Have not worked with any system
 - Have ONLY worked with out-of-state systems
 - Other (please specify)

PAST MEDICAID WAIVER

12. Which Medicaid Waiver program(s) have you EVER been involved with (in Colorado)?
- HCBS – Children (aka Katie Beckett waiver)
 - HCBS – Children’s Extensive Support (CES)
 - HCBS – Children’s Habitation Residential (CHRP)
 - HCBS – Mentally Ill Waiver (MI)
 - HCBS – Elderly Blind and Disabled (EBD)
 - HCBS – Traumatic Brain Injury (TBI)
 - HCBS – Supported Living (SLS)
 - HCBS – Comprehensive Support (DD)
 - Don’t know which waiver
13. Where did you receive your Medicaid Waiver case management services in the past?
- Medicaid Single Entry Point (SEP – ie, Adult Care Management Inc.)
 - Community Centered Board (CCB – ie, Developmental Pathways, Denver Options)
 - Other (please specify)

WRITTEN PLANS IN PLACE

14. Do you or have you had any individualized plans in place for your child such as an Individualized Education Plan, Family Support, Individual Plan, PATH or any other written plan for your child in Colorado?
- Yes
 - No
 - Not sure

PLANS AND SERVICES

15. Mark all of the following plans your child has been under.

- Early Intervention
- IEP (Individualized Education Plan in schools)
- 504 Plan (Modified education in schools)
- IFSP (Individual Family Support Plan)
- IP (Individual Plan)
- Transition Program (high school to adulthood in public schools)
- Mental Health Treatment Plan
- Mental Health WRAP Plan
- PASS (Plan of Achievement of Self Support)
- PATH, MAPS, Circle of Friends, Circle of Support and similar
- Medicaid Waiver (Such as Elderly Blind & Disabled, Children's Extensive Support, etc.)
- Vocational Plan (IWRP)
- No plans
- Other (please name a plan)

16. Do you receive services from any other entities?

- Independent Living Center
- Mental Health Drop in Center
- No services
- Other (please specify)

17. If you are unsure about whether or not your child has any of the written plans we have mentioned, please choose Not Sure below and you will be taken to another part of the survey.

INPUT YOU HAD IN YOUR CHILD'S PLAN

18. Were you present when the plan was developed?

- Yes
- No
- N/A

19. Please rate the level of input you had in developing the plan.

- None – Couldn't attend
- None – Wasn't even invited
- None – Never asked for input
- Little input
- Some input
- A lot of input
- N/A

DEVELOPMENT AND IMPLEMENTATION OF THE PLAN

20. Who is (or was) responsible for DEVELOPING your plan(s)?

- DD/CCB Case Manager
- SEP Case Manager
- Teacher
- IEP Team

- School District Personnel
- Vocational Rehab Counselor
- Social Security Case Manager
- Mental Health Provider
- I Am/Was
- Other
- N/A

21. Who is (or was) responsible for making sure your plan is implemented?

- DD/CCB Case Manager
- SEP Case Manager
- Teacher
- IEP Team
- School District Personnel
- Vocational Rehab Counselor
- Social Security Case Manager
- Mental Health Provider
- I Am/Was
- Other
- N/A

22. Who is (or was) the primary person CARRYING OUT your written plan? (Note, we are not asking who is supposed to carry out the plan. We want to know who is ACTUALLY carrying out the plan).

- I am
- Teacher
- Case Manager
- Social Worker
- Other
- Nobody
- N/A

STATUS OF YOUR PLAN

23. What is the status of the plans you have had in Colorado for your child?

- Sitting on the shelf
- Just starting
- Partially implemented
- Fully implemented
- Was never fully implemented & past its time
- N/A

24. If you plan has not been fully implemented, how long have you been waiting for the plan to be in effect? (such as getting employment or a particularly important service for your child)

- N/A
- Less than six months
- Six months to one year
- 1-2 years

- 3-4 years
- 5-6 years
- More than six years

EFFECTIVENESS OF YOUR PLAN & QUALIFICATIONS OF PLANNER

25. How effective do you believe the plans you have had in the state of Colorado have been?

- Not at all effective
- Somewhat ineffective
- Somewhat effective
- Effective
- Highly effective
- N/A

26. How qualified did you feel was the person responsible for creating your plan in the state of Colorado?

- Not at all qualified
- Somewhat unqualified
- Somewhat qualified
- Qualified
- Highly qualified
- N/A

REVIEWING AND AMENDING YOUR PLAN

27. How often is your child's plan reviewed?

- Never
- Annually
- Semi-Annually
- Quarterly
- Monthly
- As needed
- N/A

28. Rate the ease at which you are able to amend or update your child's plan between formal reviews.

- Very difficult
- Difficult
- Somewhat difficult
- Somewhat easy
- Easy
- Very easy
- N/A

CURRENT CASE MANAGER

29. Do you have a current case manager/resource coordinator/planner?

- Yes
- No
- Maybe, not sure

EFFECIVENESS OF CASE MANAGEMENT

30. How often are you in contact with your case manager/resource coordinator/planner?
- Monthly
 - Quarterly
 - Semi-annually
 - Annually
 - Less than annually
 - Whenever I need to
 - They never contact me
 - What's a case manager/resource coordinator/planner
 - I'm in contact with someone but I'm not sure if he/she is a case manager/resource coordinator/planner
31. How often do you meet with the SAME case manager/resource coordinator/planner?
- I always meet with the same case manager/resource coordinator/planner
 - I usually meet with the same case manager/resource coordinator/planner
 - I seldom meet with the same case manager/resource coordinator/planner
 - My case manager/resource coordinator/planner changes almost every time we meet
 - I never meet with the same case manager/resource coordinator/planner
32. What kinds of information do you receive from your case manager/resource coordinator/planner?
(Choose all that apply)
- None
 - Information that doesn't apply to us at all
 - Information about activities we can do in the community (such as the zoo, etc.)
 - Information about all of the programs and services we qualify for and how to qualify
 - Information about disability-inclusive community activities, etc. that my child can benefit from
 - Other (please specify)
33. Please comment on your interaction with your case manager/resource coordinator/planner.

DENIED SERVICES

34. Have you ever been denied or turned down for services for your child with a disability for which you have applied in the state of Colorado?
- Yes
 - No

WHICH SERVICES/PROGRAMS TURNED DOWN

35. Which system turned your child down?

- Early Intervention part B
- CCB (Developmental Disability System)
- Mental Health System
- Special Education System
- Social Security or Supplemental Security Income
- Medicaid Waiver
- Other (please specify)

36. What is the primary reason your child was turned down?

- Child's IQ is too high
- Family income too high
- Testing revealed child did not need services
- Other (please specify)

37. Please tell us your story about being turned down for services.

YOUR OPINION OF COLORADO SERVICES

38. Please provide your opinion of the following statements.

- Systems to help people with disabilities in Colorado are effective
- My child will be provided with appropriate services through adulthood
- I am hopeful about the services I will receive for my child in the future
- Systems work well together to develop and implement comprehensive plans
- Colorado systems to support people with disabilities are better than systems in other states
- Parents are provided with all the information they need to apply for the right services for their children at each appropriate stage

RECEIVED SERVICES IN OTHER STATES

39. Have you received services for you child in other states?

- Yes
- No

TYPE OF OUT OF STATE SERVICES

40. What types of services/programs did you receive in other states?

- Early Intervention
- Developmental Disability Services
- Special Education
- Mental Health
- Other (please specify)

41. Please elaborate if needed

42. How would you rate the effectiveness of services you received in other states in general?

- Not effective

- Somewhat ineffective
- Somewhat effective
- Effective
- Highly Effective

43. Use this to tell us about your experiences in other states.

FAMILIAR WITH OTHER STATES SYSTEMS

44. Are you familiar with systems in other states either through other families or organizations to which you belong?

- Yes
- No

45. Tell us about other systems and what you think of them.

WHAT NEEDS IMPROVEMENT

46. From your experience in Colorado, which of the following systems do you believe need improvement, if any? (Choose all that apply)

- Early Intervention
- Special Education (in schools)
- Community Centered Board (Developmental Disability System such as Denver Options, Developmental Pathways, Imagine!, etc.)
- City/County Mental Health
- State Mental Health Facility
- Medicaid Waiver
- Social Security or Supplemental Security Income
- Vocational Rehabilitation
- Transitions Program (high school to adulthood, provided by school district)
- Regional Center (Wheat Ridge, Pueblo or Grand Junction)
- None of these systems need to be improved
- I don't know
- Other (please specify)

47. Please use this section to tell us about improvements you think need to be made and why. Please include any specific ideas you may have about how to end the waiting list, how to offer services differently, or any other ideas.

YOUR OUTLOOK

48. Please tell us which word best describes the way you feel about your situation as it relates specifically to getting supports for your child now and in the long term.

- Optimistic
- Hopeful
- Satisfied
- Pessimistic
- Discouraged
- Despair

49. I really need more information about _____ (fill in the blank).

50. I wish someone had told me _____ (fill in the blank).

PERSONAL EXPERIENCES

51. Please tell us about the most positive experiences you have had working with any system in Colorado.

52. Please tell us about the most negative experiences you have had working with any system in Colorado.

53. Please tell us about service providers and others in Colorado who you feel have done an outstanding job for your child and why.

54. Please tell us about any service providers you feel failed to help you or did a substandard job for you and why.

55. Please take this opportunity to tell us anything else you want us to know. Feel free to tell us your story, your hopes, your concerns.

56. Is there anything else we should have asked on this survey?

ARE YOU WILLING TO BE CONTACTED

57. If you are willing to be interviewed by the media about your story, please enter your name, phone number and email address here.

58. Can we contact you for clarification on your answers, if necessary? If so, please provide your name, email address and phone number. These will not be published

MORE CHILDREN

59. Do you have another child with a disability for which you need to enter another survey?

- Yes
- No

-
- ¹ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.
- ² *Ibid.*
- ³ *Ibid.*
- ⁴ *Ibid.*
- ⁵ *Ibid.*
- ⁶ Figure based on calculation of ‘# of resources funded’ (June 2007) plus ‘waiting list’ figures (June 2006) as contained within the “FY2007-8 Staff Budget Briefing Department of Human Services: Office of Operations Services for People with Disabilities Child Care” by Amanda Bickel: at 7.
- ⁷ “About PAD-CO,” PAD-CO website at <http://members.aol.com/PADCOWEB/about.htm>. Accessed June 11, 2007.
- ⁸ Mary C. Rizzolo, Richard Hemp, David Braddock and Amy Pomeranz-Essley, “The State of the State in Developmental Disabilities.” Coleman Institute for the *American Association on Mental Retardation* (2004): 16.
- ⁹ Amanda Bickel, “FY2007-8 Staff Budget Briefing Department of Human Services: Office of Operations Services for People with Disabilities Child Care.” *Joint Budge Committee* (2006) at 7. http://www.state.co.us/gov_dir/leg_dir/jbc/humbrf3.pdf. Accessed June 27, 2007.
- ¹⁰ Volume of Developmental Disabilities Services. *Code of Colorado Regulations (2CCR 503-1)*, (2007): 1-85. [http://stateboard.cdhs.state.co.us:8008/CDHS/rule_display\\$.DisplayVolume?p_vol_num=16](http://stateboard.cdhs.state.co.us:8008/CDHS/rule_display$.DisplayVolume?p_vol_num=16) Accessed May 10, 2007.
- ¹¹ Map borrowed from the Colorado Department of Human Services, Division for Developmental Disabilities website at http://www.cdhs.state.co.us/ddd/CCB_Main.htm. Accessed June 30, 2007.
- ¹² “Community Centered Boards,” Colorado Department of Human Services, Division for Developmental Disabilities website at http://www.cdhs.state.co.us/ddd/CCB_Main.htm. Accessed June 30, 2007.
- ¹³ “Supported Living Services,” Developmental Pathways website at http://www.developmentalpathways.org/supported_living.htm. Accessed June 30, 2007.
- ¹⁴ DDRC website at <http://www.ddrcco.com/cfs.htm> Accessed June 30, 200. And, the Resource Exchange website at <http://www.tre.org/services/default.asp>. Accessed June 30, 2007.
- ¹⁵ Volume of Developmental Disabilities Services. *Supra* N10 at 2.
- ¹⁶ Volume of Developmental Disabilities Services, *supra* N10 at 67.
- ¹⁷ Volume of Developmental Disabilities Services, *supra* N10 at 64.
- ¹⁸ Volume of Developmental Disabilities Services, *supra* N10 at 63.
- ¹⁹ “Supported Living Services,” Developmental Pathways website at http://www.developmentalpathways.org/supported_living.htm. Accessed June 30, 2007.
- ²⁰ “Equity in Resource Allocation: The need for change in resource distribution in the Colorado Developmental Disabilities System.” *The Resource Exchange and Developmental Pathways*. April 12, 2006.
- ²¹ Colorado Department of Health Care Policy and Financing website at <http://www.chcpf.state.co.us/HCPF/MedicaidEligibility/mefcc.asp>. Accessed July 2, 2007.
- ²² Denver Options website at http://www.denveroptions.org/services_faq_children.php.
- ²³ PL 94-142, as reported in Sandra K. Bowen and Harvey A. Rude, “Assessment and Students with Disabilities: Issues and Challenges with Educational Reform.” *Rural Special Education Quarterly*. Vol.25, N3 (2006): 24-30.
- ²⁴ Bowen, *supra* N23 at 26.
- ²⁵ Bickel, *supra* N9 at 6.
- ²⁶ Adam Schrager, “Legislators to focus on developmentally disabled ‘crisis.’” *9NEWS*, May 28, 2007 at http://www.9news.com/news/politics_govt/article.aspx?storyid=70936. Accessed June 11, 2007.
- ²⁷ This description “per \$1,000 of aggregate....” Taken from the State of the States in Developmental Disabilities: 2004 report by Mary C. Rizzolo, Richard Hemp, David Braddock, and Amy Pomeranz-Essley of the Coleman Institute for Cognitive Disabilities at 52.
- ²⁸ Schrager, *supra* N26.
- ²⁹ Equality in Resource Allocation, *supra* N20.
- ³⁰ Bickel, *supra* N9 at 6.
- ³¹ “HJR07-1043,” 66th General Assembly, State of Colorado, 2007 at http://www.leg.state.co.us/Clics/Clics2007A/csl.nsf/fsbillcont3/6C07B3A8B5ACA8A28725728E005A776C?Open&file=HJR1043_enr.pdf. Accessed June 11, 2007.
- ³² “Waiting! A Colorado Crisis for 3,746 Individuals with Developmental Disabilities.” An Alliance presentation to the JBC, (2006): 1-9 at <http://members.aol.com/padcoweb/alliancereportimages.htm>.
- ³³ “Waiting! A Colorado Crisis for 3,746 Individuals with Developmental Disabilities,” *supra* N32 at 1.

³⁴ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.
³⁵ *Ibid.*
³⁶ *Ibid.*
³⁷ *Ibid.*
³⁸ *Ibid.*
³⁹ *Ibid.*
⁴⁰ *Ibid.*
⁴¹ *Ibid.*
⁴² *Ibid.*
⁴³ *Ibid.*
⁴⁴ *Ibid.*
⁴⁵ *Ibid.*
⁴⁶ *Ibid.*
⁴⁷ *Ibid.*
⁴⁸ “Peak Parent Fact sheet” at http://www.peakparent.org/pdf/fact_sheets/child_find.pdf. Accessed July 3, 2007.
⁴⁹ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.
⁵⁰ *Ibid.*
⁵¹ *Ibid.*
⁵² *Ibid.*
⁵³ *Ibid.*
⁵⁴ *Ibid.*
⁵⁵ *Ibid.*
⁵⁶ *Ibid.*
⁵⁷ *Ibid.*
⁵⁸ *Ibid.*
⁵⁹ *Ibid.*
⁶⁰ *Ibid.*
⁶¹ *Ibid.*
⁶² *Ibid.*
⁶³ *Ibid.*
⁶⁴ *Ibid.*
⁶⁵ *Ibid.*
⁶⁶ *Ibid.*
⁶⁷ “FAQs,” Denver Options website at http://www.denveroptions.org/services_faq_children.php. Accessed July 1, 2007.
⁶⁸ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.
⁶⁹ *Ibid.*
⁷⁰ *Ibid.*
⁷¹ *Ibid.*
⁷² *Ibid.*
⁷³ *Ibid.*
⁷⁴ *Ibid.*
⁷⁵ *Ibid.*
⁷⁶ *Ibid.*
⁷⁷ *Ibid.*
⁷⁸ *Ibid.*
⁷⁹ *Ibid.*
⁸⁰ *Ibid.*
⁸¹ *Ibid.*
⁸² *Ibid.*
⁸³ *Ibid.*
⁸⁴ *Ibid.*
⁸⁵ *Ibid.*
⁸⁶ *Ibid.*
⁸⁷ *Ibid.*

⁸⁸ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*

⁹¹ *Ibid.*

⁹² *Ibid.*

⁹³ *Ibid.*

⁹⁴ *Ibid.*

⁹⁵ *Ibid.*

⁹⁶ *Ibid.*

⁹⁷ *Ibid.*

⁹⁸ *Ibid.*

⁹⁹ *Ibid.*

¹⁰⁰ *Ibid.*

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*

¹⁰³ *Ibid.*

¹⁰⁴ *Ibid.*

¹⁰⁵ *Ibid.*

¹⁰⁶ *Ibid.*

¹⁰⁷ *Ibid.*

¹⁰⁸ *Ibid.*

¹⁰⁹ *Ibid.*

¹¹⁰ *Ibid.*

¹¹¹ *Ibid.*

¹¹² *Ibid.*

¹¹³ *Ibid.*

¹¹⁴ *Ibid.*

¹¹⁵ *Ibid.*

¹¹⁶ *Ibid.*

¹¹⁷ *Ibid.*

¹¹⁸ *Ibid.*

¹¹⁹ *Ibid.*

¹²⁰ *Ibid.*

¹²¹ *Ibid.*

¹²² *Ibid.*

¹²³ The ARC of the United States website at

<http://www.thearc.org/NetCommunity/Page.aspx?&pid=1386&srcid=183>. Accessed July 8, 2007.

¹²⁴ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.

¹²⁵ *Ibid.*

¹²⁶ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.

¹²⁷ Special Olympics Colorado website at http://www.specialolympicsco.org/about/about_us.html. Accessed July 8, 2007.

¹²⁸ Anonymous, PAD-CO Survey (all quotes from the survey will remain anonymous). February 2007.

¹²⁹ *Ibid.*

¹³⁰ *Ibid.*