

## **Final Report on the Survey of Surveys, March 28, 2014.**

During March, 2014, a “Survey on Surveys” was conducted by PAD-CO (Parents of Adults with Disabilities in Colorado) to determine the responses by parents to, and involvement with, periodic surveys used by the Community Centered Boards in Colorado and the DDD in Colorado, and responses to and potential for participation in an NCI survey wherein the Community Centered Boards and case managers will assist in providing background data on those surveyed.

To gain broad participation from across the population of parents of individuals with disabilities, emails were sent to a variety of organizations including all Colorado Arcs, the Colorado Cross Disabilities Coalition, Parent to Parent of Colorado, PAD-CO requesting their announcement of the survey and requesting participation of as many individuals as possible, and furthermore, asking that the survey participation request be sent to other organizations/listservs.

This is a “Final Report” representing 91 respondents. At this time, the NCI face-to-face surveys appear to be in process, and we believe the information is important in the methodology of the administration of the NCI survey.

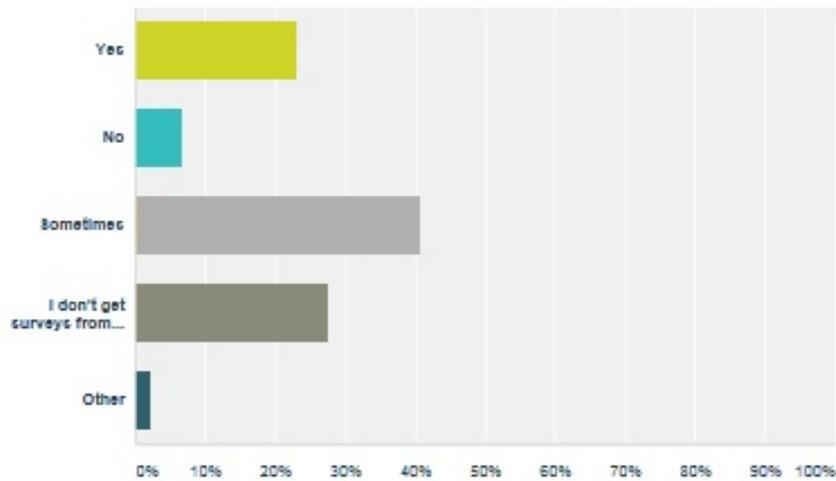
47 varied and significant comments from parents were received and are included for your review at the end of the graph and results section.

Following are the directions to participants for taking the survey, graphs and charts showing the questions and results and the 41 comments.

“This is an absolutely anonymous survey by PAD-CO - Parents of Adults with Disabilities in Colorado. Attention: Parents and Guardians in the CCB system. Do you respond to the annual and other DDD/CCB Surveys? Do you answer them honestly? A new "Face-to-Face" survey of 400 people is being implemented by the Division for Developmental Disabilities, using background information about you and your child(ren) supplied by the Community Centered Boards. Please help us by answering the following questions. The results will be shared with top administrators at DDD/HCPF and some legislators.”

Each year and at other times evaluation surveys are sent by CCBs to parents/guardians of, and individuals with, intellectual and developmental disabilities.  
Do you respond to these surveys by returning them?

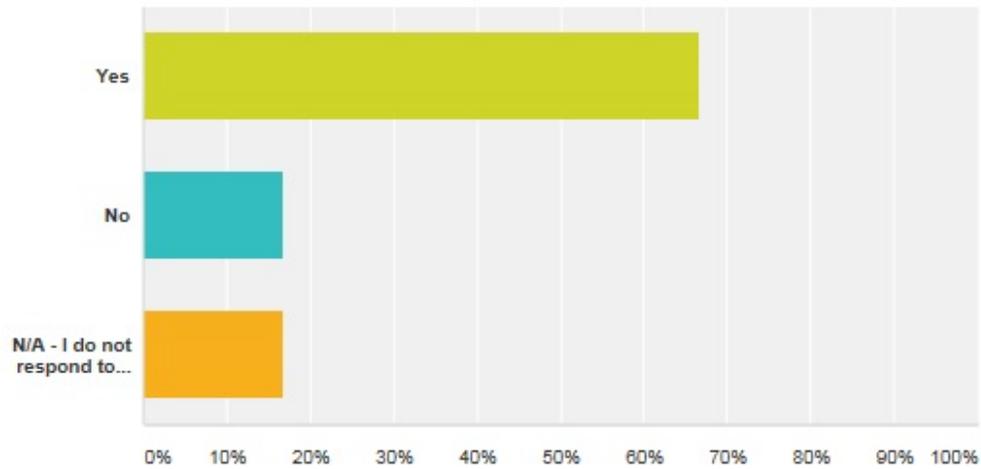
Answered: 91 Skipped: 0



Answer Choices	Responses
Yes	23.08% 21
No	6.59% 6
Sometimes	40.68% 37
I don't get surveys from my CCB	27.47% 25
Other	2.20% 2
Total	91

## If you do get a survey and respond, do you usually answer the questions honestly?

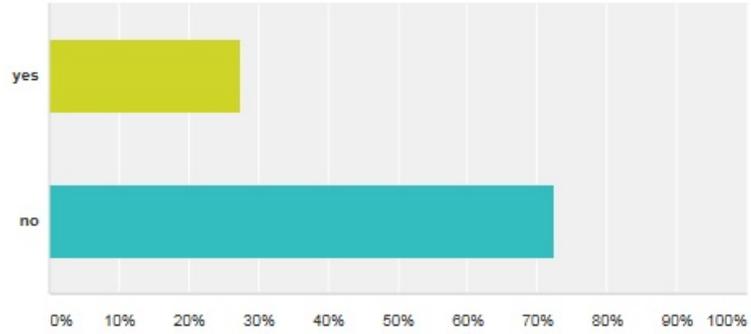
Answered: 84 Skipped: 7



Answer Choices	Responses
Yes	66.67% 56
No	16.67% 14
N/A - I do not respond to surveys	16.67% 14
Total	84

### Do you notice "hidden" markings on the return envelope identifying you as the respondent?

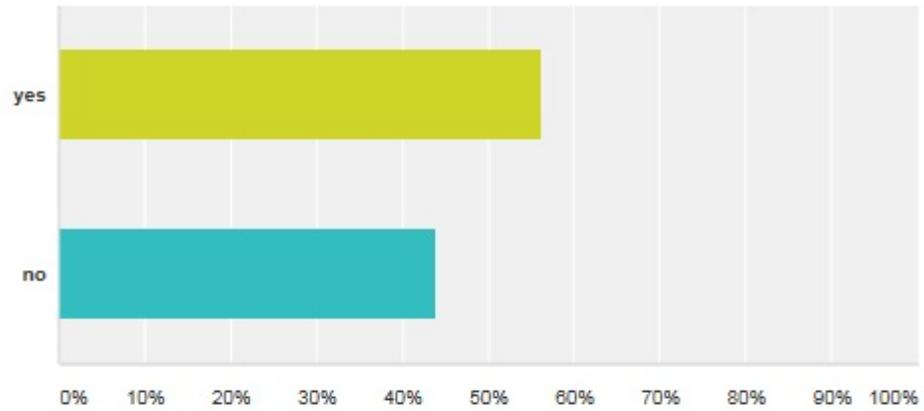
Answered: 80 Skipped: 11



Answer Choices	Responses	
▾ yes	27.50%	22
▾ no	72.50%	58
Total		80

## Are you afraid of retribution/loss of services and the like if you answer negatively?

Answered: 82 Skipped: 9



Answer Choices	Responses	
▾ yes	56.10%	46
▾ no	43.90%	36
Total		82

# Confidentiality

Click on Sign and place sig PDF File.

All information will be kept confidential

No client will be retaliated against or will lose services because he/she participated in the survey

Case managers/CCBs will assist in gathering the background data but will not have access to the information provided by clients during the interviews

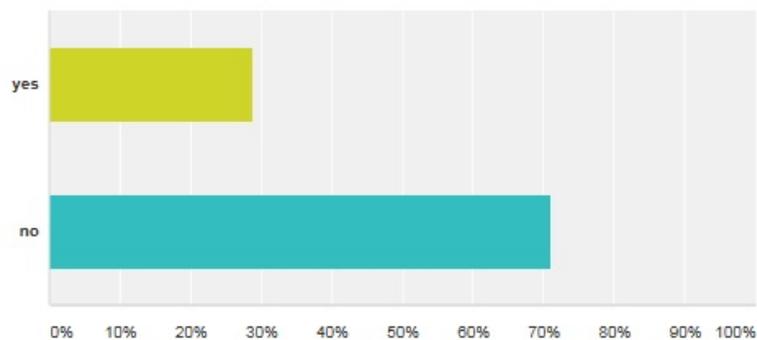
Q5

Customize

Export

Looking at the picture above, would you trust that your answers in a face-to-face survey would be confidential from the CCBs?

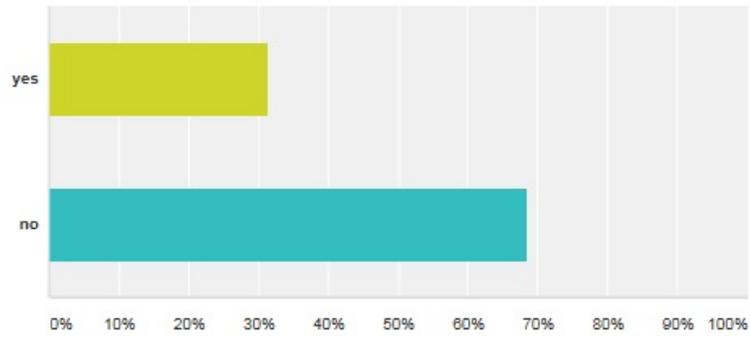
Answered: 90 Skipped: 1



Answer Choices	Responses
yes	28.89% 26
no	71.11% 64
Total	90

**Looking at the picture above, would you trust that a negative answer in a face-to-face survey would not lead to possible retaliation or possible loss of services for your child and/or yourself?**

Answered: 89 Skipped: 2



Answer Choices	Responses
yes	31.46% 28
no	68.54% 61
Total	89

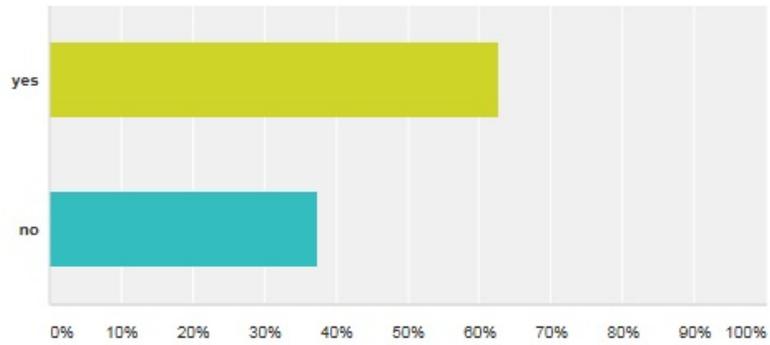
Q7

Customize

Export ▾

### Is your situation so different or unique that your response would easily identify who you are?

Answered: 91 Skipped: 0

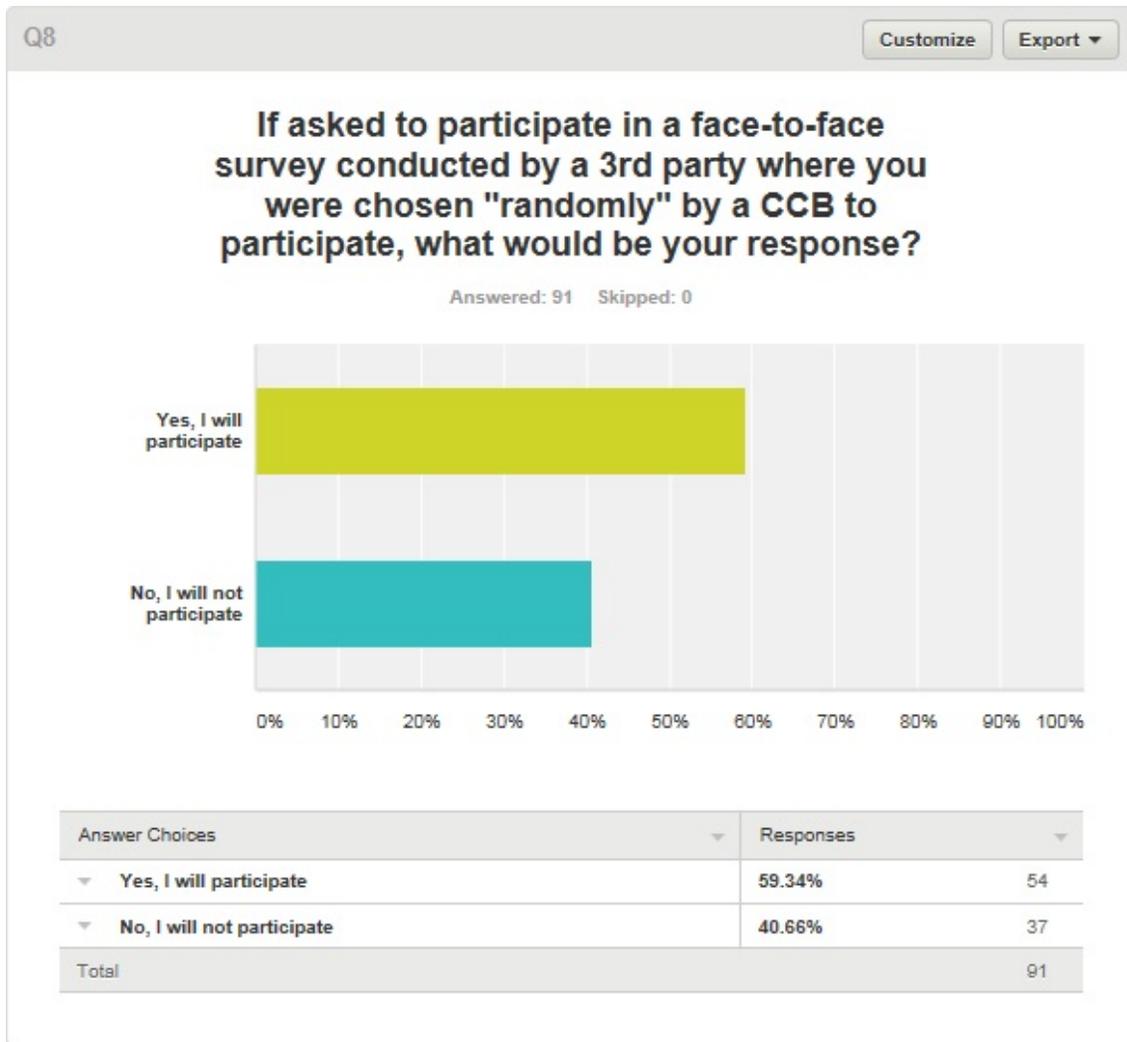


Answer Choices	Responses	
▾ yes	62.64%	57
▾ no	37.36%	34
Total		91

Q8

Customize

Export ▾



Q9 Export

**What else would you like to say?**

**Following are 47 parent written comments placed in reverse chronological order:**

#2 While I answer honestly, I frame it differently than if I trusted the confidentiality of it. While I am not a paranoid person, I have first hand knowledge of retaliation and breach of confidentiality.

3/24/2014 10:06 AM

**It never occurred to me that there might be a problem with information leakage and CCB reprisal. But now that the topic is brought to my attention, I can see how there could be, especially in the case of a given CCB in the Pikes Peak Region that I intentionally no longer work with. Know that my answers reflect how I felt on this topic prior to considering the implications of the information imparted in this survey.**

3/24/2014 10:04 AM

This questionnaire seems to ask questions in a slanted way... guiding one to the negative. also, the 'lite-bulb' graphic ..doesn't produce anything when clicked..which is confussing. We are, however, very content with our daughte's services..and are grateful for the help she gets. Thanks very much. a parent

3/24/2014 8:08 AM

**Looking at the graphic referred to 5 and 6 doesn't change my basic trust of confidentiality. I have a general mistrust of any bureaucracy and don't mind talking about it. In the case of CCB/DDD/HCPF, I think there is much room for improvement.**

3/24/2014 8:07 AM

At least doing a survey provides data. I would hope someone would do something positive with the data. Our CCB has not been extremely useful over the years so loss of services are not a cause of concern. We have gotten used to working around them and without them.

3/6/2014 9:14 AM

**For people to be better served and to also feel more confident with CCBs full consumer direction needs to be honored and facilitated for those individuals and families that choose it. Also, effective oversight needs to actually exist so case mgrs aren't the gatekeepers to necessary additional services. Lastly, there should be more equity between salaries of the CEOs and allocation to clients. Those salaries should be commensurate with good service delivery.**

3/6/2014 7:39 AM

I would need more information on question #8 to give a definitive answer. I have been pretty happy with my CCB, however just going through the CES process for services was very stressful (unlike the process for family services and autism waiver). I felt like there was much more confusion trying to figure out what was needed due to too many case managers and not enough knowledge of providers by the case manager. I understand they can't know everything about every provider, but it was my understanding they were suppose to be a resource for me? I'm hoping things will be better now that my son will have just one case manager under CES.

3/4/2014 12:56 PM

**What I'd like to do is demonstrate to our legislatures HOW the system wastes the money for the very clients that are trying to help AND to offer a pilot program alternative to demonstrate responsible fiscal management.**

**3/4/2014 11:34 AM**

Yes, we need forums for getting our stories and information to the correct ears to hear our complements and our complaints and our suggestions. But this is not the way to do it. No we don't trust this type of survey. Most of us have had face to face (extreme) negative experiences (especially with CCBs) and this is not effective. There are too many systems (CCBs, schools, ARC, Atlantis/Independence Center, Long Term Options, Voc Rehab, Goodwill, government agencies, 'non' profit agencies- the list goes on and on) yet even with all these agencies and systems they are not effectively serving their clients. They have, however become very good at 'serving' government officials. Their leadership seems to have much better relationships with legislators-who often don't have a need to use these programs, don't understand what these organizations do, how they actually operate or how they are suppose to serve the clients. Another fact when 'dealing' with the disabled population is there is ALWAYS a complaint about cost. We who work with these systems know how to slash costs for these programs and put the enormous amount of money that is currently being wasted back into the clients' lives where it belongs: develop ONE system (with much fewer and better informed employees; much fewer facilities-most everything can be done by mail, FAX, email, phone, or a home visit) ONE 'pot' of funding, ONE simple way of objectively determining

clients' needs and getting the funding and services directly to the clients--period. Families and clients are sent from one organization to another, often given incorrect or no information, placed on a waiting lists (some are being told the wait period is up to 25 years), and not being helped. Over the years, we have watched executive and assistant directors of these organizations (many earning six figure salaries) literally crying to state representatives telling them how they can't get clients off waiting lists and don't have money to give to them--this is infuriating when they continue to draw huge salaries and run multiple offices. Many of these individuals are employed by so called non-profits such as the CCBs and in turn have even asked the clients to donate to their organization--since it is a charity--it is outrageous. The clients only true advocates are their families, usually their parents. When these clients age so do their parents. There are many parents who are over 50 years old, college educated, employed, informed and capable--we are the intellectual and physical workforce that could effectively operate a well designed program and manage the finances effectively serving many more individuals than the current systems allow. At least look at us understanding our input is valuable...currently communities are still pouring money into more ineffective organizations. In Colorado Springs TRE has set up a Health Care Clinic yet it will not service the needs of the severely disabled saying the University "Children's Hospital" system will take care of those needs. That system will care for specialty needs (ie: neurology, cardio/pulmonary, etc) yet they do not want to accept patients over the age of 18, yet many private offices consider 18-21 still in the pediatric age range so they also do not want to accept this age group and if they do, they will not accept Medicaid. Our PCP said she has been dropping children from her practice after age 18 because they have received SSI benefits and have been given Medicare as their primary and Medicaid as a secondary insurance and she cannot accept Medicare in her pediatric practice. This move is also dropping these clients from other Medicaid driven programs. Colorado Springs is a large city yet many clients are being told to go to Denver for services. Imagine the other outlying communities and their needs. Currently, there are many parents taking care of all the needs of their young and aging disabled children. When these parents finally run out of their own resources, become ill or eventually die, then what. We do need a voice...in an arena where we are heard, safe, and where actual, rapid change happens...not just talk.

3/4/2014 11:06 AM

**We live in a rural area. People know each other, are related in some way, or**

**work with those in various agencies...What confidentiality? We do have a great CCB case manager and she does an excellent job.**

**3/4/2014 10:49 AM**

Although I was often annoyed by some of the illogical rules which our CCB (Imagine) imposed on us, I do not believe that Imagine is as prone to retaliation as certain other CCBs. Our CCB's attitude toward us may have been moderated by the fact that we did contribute on a few occasions to the Imagine Foundation.

3/4/2014 9:31 AM

**Face-to-face interviews are time consuming -- we don't have time! And they're socially awkward. Why would anyone use them?**

**3/4/2014 9:04 AM**

The current system is not person centered. High and moderate functioning adults need to have more person-centered support and not be required to move about in larger groups. The provider network is cherry picking easier clients and complex children and adults must move to CDASS or families to provide care themselves. This is a disservice to all. Young adults have been raised to live a life through IDEA but obviously still need supports - yet providers are still working off old models, except for a very few. Further, parents have 20, 30, 40 years of care giving and are very very tired. Waivers and services are underfunded, after investing years in education and public/private resources, adults are waiting so long that their skills regress. Yes, there need to be budgets. But there needs to be person-centered planning and care for all support levels. Fix the rules and regs so nurses can safely delegate to non-licensed caregivers. A whole generation of medically fragile NICU babies is growing up and providers are not prepared to deliver services. Brain Injury, Vets, Aging of America. We need to simplify the services and be prepared to provide meaningful lives for people with disabilities.

3/3/2014 10:41 PM

**Surveys and interviews are the way that we can give feedback. I do not live in fear of retaliation. I have given my opinion numerous times in my 12 year journey with my child. I feel that because of my honesty and non adversarial way it has given way for me to be at the table instead of doors closing. I have learned that "you catch a lot more flies with honey than with vinegar."**

**3/3/2014 8:42 PM**

I do not trust my CCB to work to assure adequate services for my loved one, to seek out information from parents as to what the needs are and then to work for change and development of those services. I feel that I can do a better job myself of assuring that the services my loved one needs are available.

3/3/2014 7:42 PM

**I would participate because I think that feedback is important and I have many concerns about conflict of interest matters with the CCB's. Despite being afraid of retaliation, I would speak out.**

**3/3/2014 2:13 PM**

The CCB's should not have the power to NOT tell you exactly where your young adult stands in regards to the wait lists. We have had friends with similar disabilities that were transitioned on to the adult HCBS waivers, while our daughter was not transitioned. We moved over to the CDASS program for this reason.

3/3/2014 6:15 AM

**We need to get services that follow the client, not "here are your choices". Also, fund our adults instead of wait listing them.**

**3/1/2014 10:31 AM**

That I know that my answers would not be accepted as valid and then my son could lose his services or things could be made less available to him. This is retribution and I don't want to put him at risk.

2/28/2014 4:23 PM

**I would rather do a survey like this then face to face.**

**2/28/2014 11:22 AM**

Use electronic surveys with plenty of open response areas. Include a section on Other thoughts or "What haven't we captured?" Ask if respondent wants to provide his/her name and contact info, and follow-up calls can be made to those who say it's OK. Face to Face interviews are costly, difficult to manage and arrange, and costly.

2/28/2014 10:06 AM

**The process is fine but I doubt that the answers are used to make changes**  
**2/28/2014 9:23 AM**

I think CCBs are so desperately in need of input, I would give it in any way they asked.

2/28/2014 8:20 AM

**I feel my CCB works in my favor, even if they do have their flaws.**  
**2/27/2014 4:00 PM**

First of all to be honest I can't remember if anyone sent me a survey or not. If they did I would probably return it and definitely be honest. Secondly, regarding #7 I do not believe that a situation has to be extra different or unique to contain identifying information. If you said your case manager missed two meetings with you, the case manager could very well only have one client that meets that criteria. The only way NCI can really protect confidentiality is by collecting non-identifying statistics and yes/no or rating scale answers.

2/27/2014 2:07 PM

**Our CCB always seems to have its goals and agenda decided by key staff and then just rubber stamped by the board of directors. I wouldn't trust any survey results when the CCB is allowed to randomly select certain families to participate. I would participate if a survey was done by a 3rd party, with families being chosen at random by the 3rd party, and I had a signed documentation that no one with a connection to the CCB would be involved in selecting the participants or compiling the results.**

**2/27/2014 1:17 PM**

This isn't always a clear yes/no. While I try to stay anonymous for real fear of retribution, it isn't possible and so sometimes I hedge my answers. I also question that they only send them to "happy" or "quiet" clients/parents and we don't get included if we are vocal, so there is no opportunity for feedback, even when they do a survey.

2/27/2014 12:21 PM

**Thanks for collecting and reporting on this info!**  
**2/27/2014 11:47 AM**

Face to face seems confrontational. Whether they're really from an outside third party seems as though it would be questionable.....

2/27/2014 11:16 AM

**The potential for retaliation is real. There is not a "need to know" standard of confidentiality. The conflict of interest issue is also real. I have seen CCB case managers promoting their own internal services to us and other families for several years now.**

**2/27/2014 6:40 AM**

I don't trust our CCB. Have been able to use CDASS and by-pass our CCB thankfully

2/26/2014 7:52 PM

**When surveys are done by the same people who are providing services (whether it is the local CCB or provider agency, or the State DDD who designates and authorizes funds to those who provide services), I have NO trust that my son/daughter will not be identified and possibly singled out for bad consequences. That is a SAD situation here in Colorado.**

**2/26/2014 3:48 PM**

There will need to be a tremendous effort to build trust on the part of anyone giving a survey which in any way involves the CCBs. And, then, so what? Surveys and more surveys - but no policy changes. Surveys are mostly worded and designed to make the surveying agency look good. For \$60,000, a child could be helped. Which is better, surveying or helping? We already know the answers - I could write the survey results out now, and the DDD and CCBs will look great. Wait and see. Think about the USM survey, which got edited for months by the dd department, and purposely delayed so the Interim Committee never saw it, as they were supposed to. Also, this appears to be a HIPAA violation, with potential fines, etc.

2/26/2014 2:49 PM

**The CCb eastern colorado service does what it can to keep the children with disabilities out of the community. Benefits are based on who you know.**

**2/26/2014 12:02 PM**

Our CCB appears to have a hidden agenda, that is not about serving clients. I always have the feeling that they are trying hard to deny services. I feel that they are not serving their clientele.

2/26/2014 10:56 AM

**I'd like to get a survey. I did not know these existed.**

**2/26/2014 10:33 AM**

I wouldn't trust the process, and I would fear that, if I participated, I would be further kept in the dark by the CCB or that my son would face negative consequences.

2/26/2014 9:45 AM

**I would like them to keep the counselor we work with whom I was on the waiting list I had three to four case counselor and now I am off the waiting list and I am waiting for another case manager thanks**

**2/26/2014 7:10 AM**

I am already known as a very outspoken advocate. Being a parent of several adopted children with IDD/DD and a spouse of someone with physical disabilities automatically identifies me. However, I get a sinking feeling in my stomach when I make negative comments - I know how vulnerable my children are to retaliation.

2/25/2014 10:30 PM

**Why are so many surveys needed, at such a high cost, when policies do not change?**

**2/25/2014 9:30 PM**

Depending on the questions or scope of the face-to-face, it's possible that the answers might not single us out for potential retribution. However, if answers are more than yes/no and are recorded verbatim, then yes we could be identified. There must be a better, more secure/confidential way to obtain input from this community that is honest, open and with guarantees of zero retribution by anyone in the system.

2/25/2014 7:08 PM

**If asked, I would participate in a face to face survey but I would be guarded**

**with my answers**

**2/25/2014 6:47 PM**

Yes I will participate, but if I feel the questions might harm the services my family member will receive, then I will refuse to answer the question(s). In the past I have only answered surveys when I can say something positive. If I am unhappy with the services then I throw the survey away because I am afraid of retaliation

2/25/2014 5:46 PM

**There are far better ways of getting the information they are seeking but it should never be by doing their own survey. It must be done by a reliable 3rd party who is not then edited to fit their desired result!!!**

**2/25/2014 4:28 PM**

There are many forms of retaliation that are not always evident. Who would do anything about it anyway. I never fill out the surveys because it compares to the police policing themselves. Are the agencies required to come up with measurable action plans in response to any consistent issues. Would they inform parents about the action plan ? Probably not. Unless there is oversight over the CCB's nothing will ever get done.

2/25/2014 4:17 PM

**It is very interesting that the survey participants will be "chosen" by the CCB. Talk about bias!**

**2/25/2014 3:09 PM**

All government contractors who utilize survey approaches 'load' the survey with questions to reflect positively on themselves. Not a good way to get to the truth, but that is how it is done. IMHO it does not help or hurt them because most people see it for what it is. The government will continue to contract with them regardless of their checkered past so the surveys are just an exercise. Not all CCBs, will utilize survey information in a negative way;.i.e, for retaliation, but sadly some do. Companies like Developmental Pathways have a long history with lots of clients in that regard. THESE kind of CCBs CANNOT be trusted with survey information, much less the case mgmt, or provision of services of our loved ones AT ANY LEVEL!

2/25/2014 1:53 PM