

FAMILY AND CONSUMER RESPONSES REGARDING CASE MANAGEMENT

A consumer on the Case Management Steering Committee sent out a request to various groups requesting feedback on case management and the desired outcomes. The request included groups such as the Family Council, Family Support Network, ECAC, FV, etc. The comments below are the responses received.

These are excellent suggestions.

Thank you for compiling the voices of families and care providers who are not at the discussion table. I am overwhelmed by everyone's eloquence and encouraged by the commitment to service and the desire that families as well as the individual be strengthened by the partnerships that are critical for success. I know several of the identified individuals and know how representative they are in terms of geography and socioeconomics (I think because of distribution and time constraints there is less representation across ethnicity and race). Considering there was less than a week to solicit comments, it is great to hear from such a rich cross-section of NC families and providers.

Thank you again, for your efforts to support consumer voices. There is no partnership without participation. You were instrumental in trying to bring partnership to the discussion.

the only thing i'd consider is if adding a piece of 'watching for service holes' would be worthwhile. i mean, being the watchdog for how the legislation plays out in real life. for instance, when my son went home with an ostomy, medicaid is written so that supplies are covered when you get medicaid home health nursing.

which doesn't exist in eastern nc.

which means no official way to get supplies for ostomies for children under ssi medicaid in eastern nc.

which everyone knows about but nobody seems to be able to fix.

(the patch was switching to cap-c medicaid, though that took a month or so, during which we had no supply coverage.)

so i wonder if adding a piece about reporting problems with how the various pieces fit together would be beneficial.

thank you for your time,

Care planning is mentioned in the definition but it needs to be clear this means writing the person centered plan is a billable activity. The State has hinted that in the final definition of case mgt. writing care plans will no longer be an activity case managers will be paid for. If case mangers don't write the PCP, who will?

I received XXXXXXXX email regarding the input for Case Management objectives that you and team are working on due this upcoming Wednesday for DMA.

I would like to share my voice on this issue. I am a parent of an adult daughter with autism/seizure disorder/intellectual disability, and our experience with case management has been very positive. She and I and the rest of our family are most grateful for the service of case management as it helped us to connect to the community services available, understand the overall system of care, and to better advocate for the pieces needed by recognizing the gaps and targeting those areas to focus on meeting for my daughter, etc.

I believe a good measure of the outcome of case management service would be to have two components:

1. to quantify how many community service ties have been made over time for an individual with disabilities
2. and then to measure quality of those ties in the lives of the individuals with disabilities as measured by a satisfaction scale or similar targeted rating scale &/or to see how many areas of the life of the individual with disabilities that particular tie relates to... (i.e. community tie to Borders bookstore could relate to person's employment/vocational, social, and educational areas of life if the links were encouraged through quality work by the case manager to make sure the schools, friends, and VR circles were aware of this potential area of growth for the individual in these areas and assisting with tools needed to make these connections, etc).

Basically, if we can show the outcome of various linked community/service areas into various linked personal areas for the person with disabilities being served in a way that covers all the important aspects of healthy, happy living and then add a component showing this result over a solid period of time... then that would be a truly successful model in my mind.

It is important to also allow an open feedback area for individuals with disabilities and their families to answer so other targets could be identified potentially as well to improve this instrument over time as well.

Without case management services, I am very concerned about individuals with disabilities and their families being able to effectively know how to navigate and advocate for needed services in our existing systems (& evolving systems are even more difficult to learn to navigate, etc.) resulting in increased community frustrations from within and without... providers and those in need matching up well for success. Also, the individual with disabilities and without strong family (or other) advocacy will be the one to suffer the most and those in most need could very potentially be neglected or worse, even abused, without some intervention in a timely fashion. Response to need is always a vital measure for quality as well.

I greatly appreciate this opportunity, and hope these comments were helpful. Certainly, let me know if there is anything I can do to further assist this important work as well.

p.s. In full disclosure, I am also the recently elected co-chair of the xxxxxx and am involved with various

non-profit organizations that assist people with intellectual and developmental disabilities.

The current definition for case management is:

"Case management is an activity that assists recipients in gaining access to necessary care and medical, behavioral, social and other services appropriate to their needs. Case management should be individualized, person-centered, empowering, comprehensive, strengths-based, and outcomes-focused. The functions of case management include assessment, care planning, referral/linkage, and monitoring/follow-up."

Our Case Manager is XXXXXXXX and he has been a part of our family for about 10 years as he has helped us navigate through the special needs services for our child with autism.

I believe the definition should include

Advocate

Assisting in the empowerment of seeking information, knowing your legal rights, school advocacy and the IEP

Case management is assisting in finding services or even the way to retaliate when services are not available

Laying it all out in simple terms, providing it all also in written materials

Acute and chronic care for the person with the disability and the family

Crossing into services for other family members when the difficulties originate with the person with the disability

The case manager must know the rules, regulations, and services and environment in which they live and consult on

I believe the follow up should be often, maybe even weekly in times of difficulty and the lines of communication should always be open and welcome and never degrading or deliberate avoidance. The case managers work place needs to be open and noncritical ever!

Just some thoughts.

My name is XXXXXX.I have A 29 year old son who has cp.He is on cap and his case management is very important to his needs.Our family depends greatly on his case worker for the help we need understanding the definition of everything that concerns our son.I really hope that before any drastic decisions are made that you will consider the needs of all people involved.Idon't know what our family or our son would do without the help we get through cap.

We think it would be good to emphasize coordination of client status and services between client, client's family and all providers

Thank you for being the voices for families in NC I hope you receive a lot of feedback.

Case Management;

Our family request the position remain with duty as is in place. Our special needs person is presently in a group home, Our case manager helps to remove the worries we have for our daughter. she makes sure her needs are met, as well as her over all safety. The pop in visits that she does in her day program and home, are so needed. It's a shame to say, but in all walks of life we have to have a check and balance. The people that perform these duty's go the extra mile day or night for the welfare of their client when they have concern's. Parents that are unable to keep a close eye or visit their special needs person, this is a blessing.

Without reading through the entire material on case management, which your deadline doesn't permit me, I'm not sure if I can provide significant input into the definitions and objectives. Instead, my wife and I discussed what we found useful in a case manager for our son, who is now 19 and out of the system. We had several case managers over the years. I'm sure it was rather frustrating, because while the case workers' education and training was in some variation of social work, they were most helpful to us in their role as almost a legal-aid. This role is mentioned in the goals, and even the definition since it is broadly stated. However, it is not clearly stated and I think it would be useful to state it. The role I am thinking of is to help the recipient or and/or family in navigating the requirements and paperwork need for the various services. First, they have to suggest the appropriate services, as it is currently noted. However, most families are not accustomed to filling out the paperwork required and the assistance was very helpful to us.

I was also struck by the recipient goals/outcomes. It mentions that "the recipient must be the center of our care". I would argue that the family must also be a focus of the care. The family is the child's primary source of care giving. It is difficult for the parents to focus on care giving when their stress levels have risen because they are trying to get through the system and can't determine the proper resources to help the child. I am not suggesting the case worker is responsible for analyzing the family dynamics and

identifying all the other resources that could be brought to bear, but sometimes little more is needed than helping to educate the parents.

Thank you for the opportunity to providing input.

Since, I have just received the information about case management at 647pm I hope my voice will not be left out. We do need strong case managers for the assist to gain access resources, help with communication between the LME, VO, and DMA. As a parent of a special needs person, he cannot speak for himself and needs help, not only a parents voice but an advocate voice with experience to receive adequate assistance. Cutting this position would be detrimental to all those who receive services.

I doubt you will remember me, but I'm the family advocate and mom of three special needs adopted brothers from foster care. I brought four other parents with me to the training.

I see you already have a current definition for case management. It's well-written, as I would expect it to be with you involved. The only thing that is noticeably missing to me is the inclusion of "community based" terminology, since our esteemed legislators have cut the budget and services with the intent of returning current patients in residential treatment facilities back home where they can be served in their communities...(a joke at best, a nightmare in reality)...where they will absolutely need to utilize case management services. Of course, that's like putting a band-aid on an amputated leg...but we won't go there, will we

I also wonder if the term "activity" is correct. Wouldn't it more appropriately be a "service" or an "action of services?" Maybe it would make sense to word it as:

"Case management is an action of community-based services that assists recipients in gaining access to necessary care and medical..." and so forth.

Also, in the last sentence, I feel it would be appropriate to add to the list of functions the words "oversight for the implementation of services," to read, "The functions of case management include (but are not limited to) assessment, care planning, oversight for the implementation of services, including referral and linkage to services, monitoring and follow-up.

SO...with my suggestions (take them or leave them), the definition might read:

"Case management is an action of community-based services that assists recipients in gaining access to necessary care and medical, behavioral, social and other services appropriate to their needs. Case management should be individualized, person-centered, empowering, comprehensive, strengths-based, and outcomes focused. The functions of case management

include (but are not limited to) assessment, care planning, oversight for the implementation of services, including referral and linkage to services, monitoring and follow-up."

I'm not sure if the state will allow us to use the "(but are not limited to)" phrase in this definition, but my position is that this service will have to grow as more information is gathered and more data is accumulated. If we limit our services to the confines of this definition then we are basically restricting options for consumers. Including a phrase "but are not limited to..." allows for someone to make a determination of needs based on the individual's needs vs. limiting service to what is outlined above. I envision that as all these definitions morph we will see an emergence of needs that we simply cannot imagine at this moment in time...if that makes sense to you.

Anyway, I don't know if any of this helps you, but hope it at least provides you with more food for thought. Keep up the good work!

I started a company in 2005 providing persons with DD TCM. We are small and serve around 220 individuals. I have been in the field locally for over 20 years. We at XXXXXX would love to provide input or help in anyway we can! The majority of people we serve or even the majority of people working in our field have no idea what case management entails or how important it is. **Please** allow us the opportunity to advocate or help improve this vital service!

I wanted to respond to the case management definition. I am a Parent of a child raising a youth with mental health challenges. The definition in itself sounds good. I just feel that it also needs to be family driven as well. I feel that one of the objectives should be making sure that case managers address the families concerns to ensure that the family are adequately equipped to reach successful outcomes. That being said making sure they are connected to resources to empower families, provide educational resources to trainings such as conflict resolution, communication skills, how to work with your child based on their strengths and etc. It would also mean for those families who have youth in out of home placements, working with those families ahead of time (pre-planning) for when that child returns back home and helping them connect to resources in their communities early to have things in place for that child return home. To me this is family driven because it is meeting the needs of the family.

Thanks for allowing me to comment and I would love to be included in any other open discussion you may have in the future.

I have been doing C M for over 20yrs for both Mental Health and DD services . We NEED Case Managers to continue the services for our folks. We often times are able to stop a crisis situation stopping hospitalizations. We get services start for folks who have never been helped before. We can also help the families in linking resources to help their family member.

Case Managers do a lot more than the definition. You really cannot put a definition of what we do.

Thank you for the opportunity...

My experience with case management has been less than adequate. I did not know how important case management really was. I always thought the charges were over inflated for the services I had been given. I did not know they were even supposed to do monthly home visits until we changed case managers.

I for one can't understand the concept behind the request process and appeals of the decisions. If I give all the tools and information to a case manager and he writes a plan, a revision to a plan, or an equipment request. How do we (as parents) become responsible for his lack of knowledge of the waiver or the improper wording on a document. If my request for services or equipment are not within reason or out of the definition of services, why should these people even waste your time sending it in?

I think a case manager should be held accountable for his lack of knowledge and lack of understanding of the waiver he is currently employed under. The cap mr/dd should be his employee handbook.

I underestimated the power of good case management. When the plan changed, as a parent I should have been told what we needed to do to maintain our level of care. Instead we are denied, sent to mediation, and set for trial. All because of the very reason, My main concern for my child at this time would behavior (on the plan by the way). We could not get an appointment for behavior assessment in time for the new plan to be submitted. There for being denied for enhanced personal Care.

In an attempt to get a piece of equipment. Same scenario applied because of poor wording we were denied and sent to the same process.

I think when it is obvious this is poor case management we should hold them accountable. As a parent I have been an advocate, a nurse, a doctor, a lawyer, and now a case manager. Thanks God for cap mr/dd. I have not had enough time to be a full time mother. I have spent the last five years fighting for services. I have been told by people from out of state that they have never seen a state that makes you fight for everything. I don't think that is the case. I have found very few people who are in the cap world who know even know what their job is. Our own county did not follow the waiver until I showed up. I think that case management is a key part to the solution.