

Case Managers' Perspectives on Consumer Direction

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Over the past decade, the growth of consumer direction as a model of service delivery for older people has been dramatic. Three-fourths of the 40 states responding to a survey offer consumer-directed home and community-based services; 20 states offer two or more consumer-directed options within their home-care system for older adults (Infeld, 2004). As a growing trend in long-term services for older people, consumer direction (CD) has implications for consumers, their families, workers, clinical professionals, and service agencies. One of the greatest challenges, and greatest hopes, for consumer direction as a service option is to integrate this approach into existing case-managed programs. In such programs, case managers are crucial to the success of CD. For this reason, the perspective of case managers on the realities of implementing CD is invaluable. Case managers provide the initial training and the tools to support the consumers who enroll in the program, and they see firsthand which approaches work and which do not. The role of case managers becomes more complex and multifaceted in the case of self-directed clients, continuing a trend in the evolution of case management as a profession that must be flexible, dynamic, clinically sound, and responsive to consumers.

The expansion of CD into traditional case management structures raises the possibility of either “common ground or contested terrain” between the philosophies and professional practice standards of case management and the goals of consumer self-direction (Kunkel, Duffy-Durham, & Scala, 2000). A recently completed CD demonstration project provides insights into strategies for, and challenges of, blending self-direction and case management. The Consumer-Directed Care (CDC) option was opened to participants receiving services from a tax levy-funded home-care program in southern Ohio. In CDC, consumers hire and manage their own workers and direct their own services. For consumers, case managers are the first point of contact about the new option; they provide training to consumers who choose to self-direct; and they continue to provide care planning, assessment, and ongoing support for their consumer-directed clients. This paper reviews the intersection of consumer direction and case management and presents findings from the CDC demonstration to shed light on this issue. Specifically, we present data from a survey of a cross-section of case managers about their attitudes about consumer direction. This survey was conducted a few months before the CDC option was implemented. We also present findings from case manager focus groups conducted 1 year after consumers began to enroll in self-direction.

CASE MANAGEMENT AND CONSUMER DIRECTION: THE TWAIN SHALL MEET

CD arose during the 1970s as part of the independent living movement for younger adults with disabilities (Scala & Mayberry, 1997). In the late 1980s, CD began to move into the area of long-term care services for older adults, although adoption of this concept was initially slow. This

slow implementation may have been due, in part, to a long-term care system that emphasizes safety, protection, and the provision of professional supervision of services for older consumers (Schneider, Mahoney, & Simon-Rusinowitz, 2001).

Despite a later start, CD is taking root in home care for older adults; some of the recent growth is occurring in programs that include traditional case management services. In a recent study of 40 states, 68% of the consumer-directed programs offered traditional case management services (Infeld, 2004). The basic philosophy of CD is that people with disabilities (including older people) have the capacity *and* the right to assess their own needs; determine how, when, where, and by whom those needs should be met; and continuously assess and improve the quality of the services they are receiving.

This philosophy contrasts with views of traditional case management as “an intervention using a human service professional to arrange and monitor an optimum package of long-term care services” (Applebaum & Austin, 1990). Traditional case management emerged as a method to assist individuals with the coordination of needed long-term care services. Due to a fragmented and complex system, older adults were faced with serious obstacles as they tried to access services (Applebaum & Austin). Many of the services they needed required several different providers, and often multiple funding sources (such as Medicaid waivers, Older Americans Act, and Medicare). Case managers have the clinical skills, professional training, experience with the service system, and a commitment to beneficence—doing good for others; all of these are useful skills and characteristics to provide the assistance needed by older people in navigating the complex system. However, this combination of attributes can tip the scales in favor of the primacy of professional expertise, client safety, and minimal risk; in contrast, consumer direction places greater emphasis on client independence and autonomy (Kunkel, Duffy-Durham, & Scala, 2000).

Given the philosophy of CD, it is clear that the case manager role is certainly affected. Even though case managers espouse a sincere respect for client voice, the balance of responsibilities and authority does change in consumer direction. In the national Cash and Counseling demonstration, the use of titles such as counselor, consultant, and support broker speaks to this shift in emphasis. These titles reflect a fundamental change in the roles of consumers and professionals. Even though some consultants/counselors in the Cash and Counseling program are trained as case managers, when they are working with self-directed clients, they fill a different function—emphasizing coaching, training, and supporting the client, rather than intervening on their behalf.

Early research on CD revealed concerns from case managers regarding their changing role. Case managers within one independent living program expressed ambivalence about whether increased risks to consumers would be offset by gains in autonomy (Micco, Hamilton, Martin, & McEwan, 1995). Many case management concerns stem from the inability to let go of a sense of responsibility for clients. As noted previously, case managers traditionally intervene on behalf of their clients; consumers give input, but the traditional assumption is that professional training and experience gives the case manager more expertise in care planning and service management than the client. The beneficence that is an underlying value of case management can manifest as maternalism toward clients. CD calls that value into question.

Although case managers want to encourage consumer autonomy, they worried about who would monitor client services to prevent fraud, misuse of funds, or substandard quality of care (Scala, Mayberry, & Kunkel, 1996).

CASE MANAGEMENT AND CONSUMER DIRECTION: THE TWAIN DO MEET

The Council on Aging of Southwestern Ohio (CoA) began the CDC pilot project in 2001, offering the option to clients in the Elderly Services Program (ESP) in two counties. ESP is a tax-levy-funded home-care program, serving approximately 3,900 clients. The target population for the ESP program is individuals with significant need for assistance who do not meet the Medicaid-waiver income and need eligibility requirements. Case managers coordinate all home-care services for the client and are required to see the client at least twice a year. The CDC option was open to all ESP clients, with an enrollment limit of 150 clients for the two counties.

Nine ESP case managers volunteered to participate in the design and early implementation of the new option. These case managers maintained their traditional client caseload as well as their new CDC clients. During the initial discussions about CDC, these care managers expressed some concerns (sometimes on behalf of their colleagues who were not participating in the design phase). Mirroring the tensions described by case managers in previous research on consumer direction, these case managers asked about the following issues:

What if the case manager did not think the client could handle their own care?

How will we stay informed about the client's health and problems with service?

Who will be monitoring their care?

What about the fear of abuse or exploitation from an employee?

What will happen to our jobs?

The first four of these questions reflect concern that self-directed consumers might not receive good care or appropriate monitoring if they (the consumers) were given too much responsibility. These case managers were worried about negative outcomes and about the fact that they might not be able to intervene appropriately to prevent or manage problems with care. These concerns illustrate well the beneficence versus maternalism struggle. The final issue regarding case manager jobs had two components: whether the new program was designed to cut case manager costs (assuming that case managers would spend less time with self-directed clients), and whether giving more responsibility and autonomy to clients would undermine the professional role of care management. As early volunteers for the program, these case managers were comfortable enough to be honest about their concerns; they were also invested in helping to get the new program off the ground. They worked through their concerns during the course of the discussion, concluding with the following comments:

“CDC is the epitome of self-determination. As case managers, we are allowing our clients to make their own decisions, handle their own home care problems, and contact case managers at appropriate times.”

“We are trusting our clients to let us know when there is a problem, if they become overwhelmed, or have a change in health status.”

“We are first a trainer, then an observer.”

“The joy and personal satisfaction felt by case management staff in monitoring a client’s health and homecare services becomes a joy in seeing her [be] the most independent person she can be.”

As the demonstration got close to implementation, a training session for all case managers was arranged. The training occurred prior to any enrollment into consumer-directed services; before the training session began, participants completed a survey of their knowledge, attitudes, and opinions about consumer direction. All case managers within the program were expected to attend the training session, whether they were going to be involved with consumer-directed care or not. This decision to train all case managers on consumer self-direction reflected a commitment by agency leaders to promote awareness of the philosophy and practice of this new program option. Fifty case managers attended the training and completed the survey. These 50 participants covered the spectrum, including those who had indicated early interest in CDC, as well as those who had expressed serious reservations and did not want to work with self-directed clients.

Table 5.1 shows the results from this survey. Many case managers (45%) did not think they had a good understanding of consumer direction, although they appeared to know that CDC would be a shift away from traditional service provision. Just over 70% of case managers understood that case management in a CDC model would emphasize teaching and coaching. The overwhelming majority of case managers felt that it was good to give consumers more choice and control over how services are provided. Although the case managers agreed with the philosophy of more consumer choice and control, many (46%) questioned whether clients would want to manage their own services.

Would consumers’ services be better? A high proportion (67%) of case managers were concerned about the quality of care, and about one-third said that they would worry more about their clients if they chose self-direction. The choice and control that case managers believed consumers should have did *not* outweigh their concern about possible risks. About one in three case managers thought that the benefits offset the risks. Importantly, less than half felt comfortable working with self-directed clients or recommending the option based on what they knew.

Table 5.1 Case Manager Mean Responses and Percentage Agreeing to Survey Items (N = 50)

	Mean	% Agree*
I have a good understanding of what consumer direction is.	2.49	55.1
Consumer direction gives clients more control over how they receive their services.	2.19	72.9
Case management with consumer direction clients emphasizes teaching and coaching.	2.18	71.1
There is a need for consumer direction in the ESP.	2.10	70.8
It is a good idea to give clients more say in how their services are delivered.	1.82	93.9
I am concerned that my clients' needs will not be adequately met under consumer direction.	2.63	50.0
I think consumer direction is the best way for some clients to receive services.	2.36	59.6
I feel comfortable recommending consumer direction to a client	2.69	41.7
I am concerned about the quality of care for consumer-directed clients.	2.31	66.7
The benefits of consumer direction outweigh possible increased risks.	2.80	36.6
I think most ESP clients will not want to manage their own services.	2.67	45.8
I would worry more about my clients' well-being if they became consumer-directed.	2.91	32.6
I feel comfortable working with consumer-directed clients.	2.71	43.8

The findings from this survey suggest that, prior to the start of a consumer-directed program, case managers were unequivocal about the importance of client autonomy and choice and understood that the case manager role would be different with self-directed clients. But they did not feel confident about their understanding of consumer direction, and they were concerned about risks and quality of care.

After the CDC program had been in place for about 10 months, we conducted focus groups with case managers to learn about their experiences working with clients who had chosen to self-direct their services. Participants in the two focus groups were 24 case managers who were currently overseeing clients enrolled in the program. The focus groups took place at the end of August 2002. The 90-minute discussions were guided by questions regarding the impact of the CDC option on the consumer, on the current long-term care delivery system, and on the case management profession. Other issues emerged out of the conversations to illuminate case manager opinions, assessments, and feelings regarding the process and structure of the CDC initiative.

1. *What does consumer direction mean for the long-term care system, and for your clients?*

The case managers highlighted several positive aspects of CDC for the consumer, including greater flexibility, more options, fewer complaints about workers, more hours of service for the same money, more trust in the workers, a greater comfort level with workers, better workers, more independence for consumers, more satisfaction, and a greater sense of role responsibility for both consumers and family members. Some case managers also mentioned an increase in well-being and self-esteem in the consumers. One discussion group participant mentioned that because the client finally had means to give something back to the person who was helping her and this reciprocity made her feel better. Another participant mentioned how a once difficult client has appeared to “have found his niche” and is currently very happy with services. Furthermore, some case managers felt that CDC could potentially serve clients better as a more culturally appropriate choice for diverse populations since clients choose their own workers and often hire family or friends—workers who know and understand them. Participants also mentioned that consumer direction appears to be a partial solution to labor shortages within home care agencies. Some case managers thought that the increased coverage (more services for the same cost) would reduce burnout for unpaid family caregivers.

The question also elicited some negative opinions and attitudes about CDC in relationship to the family and the consumer. Several case managers wondered whether services were truly being delivered by family workers at a level of quality that would be considered acceptable under the traditional system. One case manager asked, “What if the client is happy and the worker is not doing a thing?” Other concerns included consumer difficulty in understanding the materials related to hiring workers and establishing payroll accounts, consumer unwillingness or inability to take on the responsibility of directing their own services, ideological issues about paying family members to do what might be considered their obligation, and concerns over motivations of family members. An extreme example of this latter concern was a client who admitted that she would like to hire a family member because the family member needed the money. Many of the concerns can be summarized with quotes from two of the case managers: “What is the right system of checks and balances, especially to find out if there are any changes with workers, with the client’s health situation, with the client’s needs?”, and “How do you decide that the situation is so problematic that you need to do something about it?”

Finally, some case managers said that what really made CDC appropriate for a client or how it affected them really depended on the clients’ unique characteristics and circumstances. For example, one case manager mentioned having a consumer that she was sure would succeed

with self-direction but did not, whereas another case manager highlighted a case where a client truly enjoyed the new services but had been a difficult client in the traditional program.

2. What is the impact of CDC on the case management profession?

Responses to this question were many and varied, ranging from positive changes that might be fostered by consumer direction to concerns about the role of case management in the future. One case manager was sure that CDC would have no noticeable impact on the case management profession. Others responded that it was a very positive development, allowing for creative and flexible approaches to working with consumers based on their needs and abilities.

This question also elicited responses questioning the role of the case manager in relation to quality management and ongoing monitoring of services. There was a fair amount of consensus about the tension between “letting go” and continuing to provide professionally sound case management. Less contact with their clients was problematic for several of the case managers. How would they know if there was a problem or if the consumer’s health situation changed in some way? Who would be liable? One specific example was the case of cognitive decline and its effects on care needs; case managers expressed concern about who would monitor those changes. Overall, there was a great deal of discussion about the ways in which consumer direction calls for something of a paradigm shift for case managers, and that perhaps there was not yet enough clarity or guidance to help in making that shift. All case managers stated their respect for the autonomy and preferences of every client, but several struggled with finding the right balance between professional intervention and empowerment-enhancing distance. Participants discussed the different kinds of roles and skills that come into play with self directed clients, including teaching and coaching.

Other topics included the appropriate level of assistance with employment-related paperwork. Most consumers have some difficulty with all of the forms related to hiring their workers. Case managers were concerned about whether getting too involved in helping with paperwork was a departure from the ideals of consumer direction. One case manager offered the analogy of a real estate agent who tells home buyers where to sign at the closing of a sale; she suggested that the agent was providing a service, that no home buyer wants to become an expert on that particular type of paperwork; and that the assistance provided to self-directed clients with paperwork can be seen as a similar kind of service, and not as a threat to their independence and autonomy.

Finally, there was a great deal of agreement that consumer directed participants do not necessarily require less case manager time than do traditional clients. The kinds of professional services that self-directed clients need might be different, but most case managers felt that CDC clients took as much time as traditional clients, especially at the beginning when they are going through training and paperwork for employing their workers.

3. Based on your experiences in this pilot program, what aspects would you change or improve?

Participants offered several suggestions about ways the program could be improved. Specific issues included consumer training, eligibility/appropriateness of participants for consumer direction, and changing expectations of case managers who are working with self-directed clients.

With respect to training consumers, one case manager said that the consumer manual included helpful information, but during the training sessions with consumers it became clear that the manual was not always well suited to the consumer's concerns and situation. Case managers generally agreed that the manual would need to be adapted to maximize its flexible use. Furthermore, there was a tendency for clients to not even follow it, leaving the case manager the task of walking them through the process from afar.

The topic of eligibility or appropriateness of clients for self direction was an ongoing issue. There were concerns about who could, should, and would enroll in the CDC option. Case managers agreed that clearer guidelines about who could choose the program would be useful. An instrument that assessed an individual's skills and training needs would allow case managers to help consumers get what they needed to succeed in consumer direction. The instrument could also potentially help them decide who is allowed to be in the program.

Another continuing challenge was the changing and sometimes unclear role of case managers and the impact of this new program on caseload expectations. Case managers felt that it was essential for their supervisors to realize the complexities involved with implementing CDC. More time was being spent with CDC clients than originally assumed. Some specific concerns were highlighted. It appeared that there was an incomplete understanding of how exactly case management should be provided for consumer directed clients. Case managers expressed a range of opinions about how best to provide support to the client. A specific example concerned the clients' formal level of care designation, which specifies a contact schedule (i.e., how frequently and in what form contact should be initiated by the case manager). This example speaks to concerns about not only giving the client autonomy and responsibility in self-directed care but also wanting to maintain some control over, and initiative in, contact with consumers. Other examples dealt with client's assessment (how often a self-directed client should be reassessed), the amount of time that should be spent with the client, and how much time should elapse between visits.

Time management for case managers was a real challenge as well. Case managers had been maintaining a traditional caseload of about 105 to 120 clients, in addition to taking on new CDC clients and providing their training. The CDC case managers were completing over 30 visits per month. With documentation requirements, administrative commitments, and the crises that invariably arise, case managers were extremely challenged in their efforts to remain on top of their workloads. In addition, the clients' two, 1-hour training sessions were not sufficient. Training has evolved into two, 2-hour sessions, along with phone calls, and additional visits to help with paperwork.

SUMMARY AND CONCLUSIONS

Some of the issues raised in the early discussions about the challenges of consumer direction for case managers were echoed throughout this demonstration project. The tension between commitment to greater client autonomy and worry about the client's well-being were heightened by the new CDC program. Results from the survey about case manager attitudes and knowledge of CD also reflected this tension. Focus groups with case managers that occurred after they had some experience with self-directed clients showed some alleviation of this worry. Before the

program began, two-thirds of the case managers said that the benefits of consumer direction would not outweigh the risks to clients. After the option had been in place for several months, case managers were much more convinced about the benefits of consumer self-direction.

The focus groups also provided invaluable information about what it takes to implement a service approach as innovative as consumer direction. Case managers helped us to understand the distance that can exist between the “ideal,” imagined, or philosophical version of a program and its actual implementation. Their discussion of the advantages and challenges of the program will provide guidance for the improvement of CDC at CoA and for other agencies that hope to put consumer direction into practice.

Case managers are an integral part of this program, and their evolving roles are perhaps the most challenging and central key to the success of the option. Even if only 10% of clients select this option, the new demands on case managers (i.e., helping with paperwork, taking on new roles such as educator and coach, and balancing consumer independence with professional standards) will continue to be a challenge. The overall goal for implementing CDC in this agency was to provide a continuum of service delivery options so that consumers can choose what is most appropriate for them. It is a significant paradigm shift for case managers to move among different roles and to use different priorities for consumers along this continuum of service delivery models. Certainly the same principles of professional practice underpin both approaches, but CDC pushes against existing boundaries regarding flexibility and client centeredness. The case managers in this research provided valuable insight about the challenges and benefits of making this shift.

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REFERENCES

- Applebaum, R. A., & Austin, C. (1990). *Long-term case management: Design and evaluation*. New York: Springer.
- Geron, S. M. (2000). The quality of consumer-directed long-term care. *Generations*, 24(3), 66–73.
- Infeld, D. L. (2004). *States' Experiences Implementing Consumer-Directed Home and Community Services: Results of the 2004 Survey of State Administrators, Opinion Survey and Telephone Interviews*. Washington, DC: National Association of State Units on Aging and The National Council on the Aging.
- Kunkel, S. R., Duffy-Durham, L., & Scala, M. A. (2000). Consumer direction and traditional case management: Common ground or contested terrain? In R. Applebaum & M. White (Eds.), *Key issues in case management around the globe* (pp. 104–112). San Francisco, CA: American Society on Aging.
- Micco, A., Hamilton, A. C. S., Martin, M. J., & McEwan, K. L. (1995). Case manager attitudes toward client-directed care. *Generations*, 16, 17–22.

- Scala, M. A., & Mayberry, P. S. (1997). *Consumer-directed home services: Issues and models*. Oxford, OH: Scripps Gerontology Center.
- Scala, M. A., Mayberry, P. S., & Kunkel, S. R. (1996). Consumer-directed home care: Client profiles and service challenges. *Journal of Case Management*, 5 (3), 91–98.
- Schneider, B. W., Mahoney, K. J., & Simon-Rusinowitz, L. (2001). *Encyclopedia of care of the elderly: Consumer directed care for the elderly*. Unpublished manuscript.