Unmet needs in self-directed HCBS programs

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ABSTRACT

Unmet need for long-term services and supports has been linked to a variety of harmful health outcomes. One suggested strategy for ameliorating unmet need is to give participants control of a budget and let them construct individualized plans. The evaluation of the Cash and Counseling controlled experiment (CCDE) documented a marked reduction in unmet need when compared to traditional agency-based solutions, but it also showed significant unmet needs remained. This paper reanalyzes 76 case studies from the CCDE to, for the first time gain an understanding of what those unmet needs are, who sees them, and what participants, caregivers and support brokers think might reduce this problem. Using a collective or multiple case study approach to understand this phenomenon, unmet needs were sorted into five categories using real life experiences of respondents. Unmet needs for assistance in managing the employer and budget tasks of self-direction were also captured. This paper discusses situations where the clinician researchers documented needs that were not expressed by the care recipients and provides a picture of where and why unmet needs remain. The paper concludes with strategies for reducing unmet needs and training future social workers.

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Background

One of the major goals of aging and disability policy on long-term services and supports is to minimize “unmet need.” There has been important research on the extent and consequences of unmet need in the United States. One-third to one-fifth of older adults with personal assistance service (PAS) needs report that some of those needs are not met. This even includes people who are receiving some supplementary public supports (Desai, Lentzner, & Weeks, 2001; He et al., 2015; La Plante, Kaye, Kang, & Harrington, 2004).

The consequences of unmet need are dramatic and include “discomfort, distress, mobility restriction, requiring assistance with activities that were previously accomplished independently, and more serious concerns such as..."
going hungry, running out of food, getting burned, unintentional weight loss, and dehydration” (La Plante et al., 2004, p. S104). People with unmet needs also experience higher rates of falls, emergency department utilization, and risk of hospitalization (Hass, DePalma, Craig, Xu, & Sands, 2017; Xu, Covinsky, Stallard, Thomas, & Sands, 2012). Research has identified those living alone, with a high number of activities of daily living (ADL) dependencies, and other attributes such as low income, as most likely to experience unmet need (Allen, Piette, & Mor, 2014; La Plante et al., 2004). These are the individuals who meet the criteria for publically supported long-term care services and supports.

One of the strategies suggested for reducing unmet need is consumer control (Mullan et al., 2009). Whereas there have been numerous evaluations of participant direction models, (Keitzman & Benjamin, 2016), the Cash and Counseling (C&C) Demonstration and Evaluation is the only one that focused on reducing unmet need as a major outcome measure. C&C included 6,700 people from three states; was a true randomized control experiment; and tested a particular advanced model of self-direction where the participant (with the assistance of a representative if desired) got to manage a budget similar in size to what an agency would have received to serve that person and develop an individualized spending plan where (s)he could chose to hire the worker of his or her choice and/or make renovations to their home or purchase assistive devices and goods and services that helped him or her remain independent in the community. In all three states, C&C served the elderly and adults with physical disabilities and, in Florida, adults and children with developmental disabilities were also included.

Mathematica Policy Research’s evaluation of C&C reported dramatically reduced unmet need in four areas (Carlson, Foster, Dale, & Brown, 2007). Still many participants reported unmet needs. To be more precise:

Despite the services and sizable amounts of unpaid care received, one-quarter to one half or more of the treatment and control group members reported unmet needs for help with personal care, help around the house, help with routine health care, and help with transportation. For most measures, however, Cash and Counseling (C & C) enabled the treatment group to reduce those unmet needs by 10-40% below the incidence for the control group (Carlson et al., 2007, p. 476).

Whereas the C&C large controlled experiment was unique in documenting the remaining problem of unmet need in participant-directed programs, it left open the research questions for this study: What are those needs? Who sees and expresses them? and, What do participants and their families think might be done to further ameliorate these needs? These are questions that can best be addressed through qualitative research. The 76 case studies (San Antonio, Simon-Rusinowiitz, Loughlin, Eckert, & Mahoney, 2007) each
involving a C&C participant, their primary caregiver, and their support broker, sometimes called their counselor, provide a window for observing the meaning of unmet need in a participant-directed program and can offer some insights into why some unmet need remains and what might be done about it.

Before going further, it is important to define “unmet need” and to specify the different vantage points. Here, we turn to the seminal work of La Plante et al. (2004) who defined unmet need as the gap between felt need and expressed need where “felt need” means the level of help the individual feels he or she needs and “expressed need” means the amount of help received or demanded. These authors also describe “normative need” which is expressed by experts. They give numerous examples of the conflict between these definitions and point to studies suggesting self-ratings of unmet need may be conservative compared with professional ratings of unmet need (e.g., Morrow-Howell, Proctor, & Rosario, 2001 as cited in La Plante et al., 2004). As the aim of this study was to learn more about unmet needs in participant-directed programs, these definitions provided a blueprint.

Methods

In that this study represents a secondary analysis of existing data, it is important to provide a description of the context and methodology used for collecting the original data prior to presenting the methodology applied by the research team for the current study. The secondary data for this paper were originally collected as part of a larger qualitative study of the Arkansas (AR), Florida (FL), and New Jersey (NJ) C&C Demonstration Programs (Eckert, San Antonio, & Siegel, n.d.; San Antonio, Eckert, Niles, & Siegel, 2003; San Antonio & Niles, 2005). The 76 case studies collected for that study derived from interviews with approximately 25 “care units” in each of the three participating states. The care unit for each case study was composed of the program participant or their representatives when appropriate, their primary caregiver, and, where feasible, their state support broker/consultant. The support brokers were the operational link between the program and participants. They helped the participant think creatively about his or her needs; find the necessary resources; develop a back-up plan; and think through where to find needed training, while providing ongoing monitoring and consultation. Support brokers are the Counseling component of C&C. Although a complete discussion of the methodology and findings of the original study is beyond the scope of this paper, this prior research aimed to provide a detailed description from the varied perspectives of the members of “care units” showing how they interacted around issues of participant-directed care.
The original data collection took place from March through June 2000 in Arkansas, in July and August of 2001 in New Jersey, and in July and August of 2002 in Florida. Face-to-face, semi-structured, and open-ended interviews lasting 1–1.5 hours were conducted. The consumers interviewed in the original study were chosen to provide a sample that included diversity in four selection criteria that were identified based on the initial results from the quantitative evaluation: age; race/ethnicity; type of worker hired (family/non-family); place of residence (rural or suburban/urban); and whether they had a representative. The tape-recorded interviews were conducted by two interviewers and took place in the participants’ homes. Each participant or representative had participated in the C&C Programs for at least 6 months. Participant or representative interviews included questions about previous care experiences, reasons why they decided to enroll in the program, type of help they needed, services their caregiver provided, the schedules and tasks of caregivers, qualities they looked for in a caregiver, the greatest benefits and/or drawbacks to their participation in the program, and comparisons between their experience in C&C and their experience with previous services. Caregiver interviews included questions about their previous caregiving experience; services they provided to cash-option participants; their schedules; and their experiences in the program. Interviews with support brokers focused on their work with consumers and caregivers and differences in their work with C&C personal assistance versus other programs (San Antonio et al., 2007).

Methodology for current study

Our study aims for a better understanding of unmet need in programs where the participant controls the budget. We set out to learn directly from participants and their “care unit” what those unmet needs were; who saw and expressed them; and whether these people have thoughts on how to address these unmet needs.

The current study was guided by a “collective” method of case study as outlined by Stake (1994), whereby the 76 case studies were considered jointly in order to understand a phenomenon, population, or general condition often referred to as an Instrumental or multiple-case study method aimed at providing insight into an issue or problem or to refine a theory. In this instance, understanding the complexities of the case is secondary to understanding something else (Stake, 1994), namely, the process and experience of implementing participant direction.

In reviewing the case studies, we utilized the four general areas of unmet need that Mathematica Policy Research defined and used in the quantitative evaluation of the C&C Demonstrations (Carlson et al., 2007). The categories are the following: ADLs; household activities like instrumental activities of
daily living [IADLs]; transportation for medical, employment/education, or recreational/social activities; and routine health care including the management of medications, blood pressure, and exercise. The use of previously established framework and categories for initial coding (Potter & Levine-Donnerstein, 1999) allowed the researchers to use a directed approach (Hickey & Kipping, 1996). Recognized as one of the three approaches to content analysis, a directed approach is a qualitative approach to a content analysis that is used to expand a conceptual or theoretical framework (Hsieh & Shannon, 2005).

As the team discussed how to operationalize these categories, we decided to add an “Other” category to capture additional unmet needs that were expressed, but did not fit into the a priori categories, as well as an “Unmet need for help in managing the program.” The latter category was further broken down into “help on employer functions” (finding workers, submitting time sheets, and getting workers paid in a timely manner) and “help on budget functions” (establishing a spending plan, locating appropriate goods and services, or knowing what one can purchase).

As previous research discussed the difference between felt need and normative needs identified by a professional (Morrow-Howell et al., 2001; as cited in La Plante et al., 2004), our research team of clinician researchers (three social workers and one nurse) felt it was important to record and note their own professional judgments where they saw needs beyond what the participant’s care unit had voiced.

Given there were 76 case studies, the research team agreed to organize the review process by focusing on approximately six to eight transcripts at a time during each of the team meetings until all the case studies were analyzed. Several steps were taken to ensure qualitative rigor (Tong, Sainsbury, & Craig, 2007). Each transcript was independently coded prior to research meetings so that we could discuss, compare, and contrast coding and categorization. We analyzed the data by type of unmet need, highlighting any differences by type of respondent. The researchers used an iterative process to review what had been coded in different categories, discuss patterns, and memo exemplary/interesting quotes. Similar codes were grouped into themes, and similar themes were grouped into categories (Creswell, 2013; Hsieh & Shannon, 2005). As suggested by Sandelowski (2001), themes were tracked, and when they appeared often, we reported the frequency. Team members coded the same transcripts prior to each meeting and cross-checked results in order to ensure inter-coder reliability. Any inconsistencies were discussed at team meetings until a consensus was achieved. Team meetings were also used to ensure reflexivity of the researchers (Cohen & Crabtree, 2006). This process resulted in the team participating in more than 30 meetings with each lasting a minimum of 90 minutes. The review/analysis process followed the “logic of repetition” as suggested by Yin (2009) to ensure that a similar approach to the data was used for each case study. When
referencing a particular case study, the state abbreviation (AR = Arkansas; FL = Florida; and NJ = New Jersey) is used to identify the origin.

**Results**

*Activities of daily living*

Although participants and caregivers explicitly expressed relatively few unmet needs for human assistance in daily living activities, several expressed needing equipment and environmental improvements. Of the 15 or so participants who mentioned some degree of unmet ADL need, half spoke of the need for help in the areas of transferring and mobility both within and outside the home. To give an example, one older woman in Arkansas spoke of how on weekends, when no one could come, she remained in her chair (AR 26). Other needs participants mentioned were for supervision in performing ADLs such as bathing/showering and incontinence. Almost a third of the participants expressed some unmet need for ADL assistive devices, particularly in the areas of inadequate bathrooms (e.g., not accessible, need for grab bars) or the need for lifts or ramps. As one representative said: “When we get the bathroom redone that will help a whole lot. I can get a bath chair and he can be in there and out. No lifting. There’s a lot of time when (caregiver) is not there and (participant) needs a bath because he might have an accident and it’s hard.” (AR 22). The representative of a 23-year-old with cerebral palsy described their challenges with toileting: “it means (we don’t have a bathroom downstairs) having to assist him, you know, going up and down the stairs because we’ve got him on a two hour bathroom schedule” (AR 21). There were many references to fear of falling.

For caregivers, the most frequent ADL concerns centered around lifting and training on proper methods for lifting and again the need for supervision and getting out of the home. “Sometimes he does not leave the house for two weeks at a time.” (FL 16), or the older woman who became wheelchair bound while living in a third floor walk-up apartment and had not found other housing (NJ 5). Another caregiver explained wanting to take her daughter out into the community, but: “she’s heavier than I am … If I put her in a wheelchair, I can handle her but I can’t put it in the back of the truck. It’s hard to do” (AR 18). In the case of FL 24, the participant required a wheelchair and weighed 100 lbs. His caregiver explained that in addition to toileting, lifting him out of the wheelchair was her biggest issue, due both to her physical strength and ability but also due to worrying about the participant’s safety.
Instrumental activities of daily living

IADLs were much more frequently mentioned, especially by participants in New Jersey and Arkansas. These included inadequate kitchen facilities or cramped conditions or inadequate cooling or ventilation for participants with respiratory conditions. Most of the items mentioned dealt with the home environment and the need for home repairs/alterations, appliances like microwaves that would help with meal preparation, or fans/air conditioners in hot weather. Two participants explicitly mentioned nutritional concerns regarding inability to find, purchase, or prepare appropriate foods for their diets, for example: “Without money you can’t get food, and without someone to prepare it properly you can’t eat decent, and that’s it” (FL 16).

Caregivers had much less to say but, when they did, they echoed the same issues as the participants they assisted. In addition, several cases emerged where the research interviewer saw problems, or normative needs, the participant and their family did not explicitly identify as unmet needs, for example, visiting an older participant on a hot day, noting that the house was uncomfortably warm and had no visible air conditioning (AR 13) or, “one small fan circulating the still air” on a 100 degree day (NJ 19).

Transportation

Except for Florida’s children and younger adults (nearly all of whom were people with developmental or intellectual disabilities), between 80% and 90% of those receiving C&C allowances used part or all of their budget to hire workers (Schore, Foster, & Phillips, 2007). Of the participants who hired workers, between 46% and 76%, depending on the state and population, hired workers who provided some transportation. This is notable because agency workers are typically unable to transport clients. It is therefore not surprising that a relatively small number (10/76) of the participants in our case studies, and only one of the caregivers, reported unmet needs for transportation. Most of those who did report unmet needs were trying to use formal providers who needed a great deal of notice or would not cross county lines, etc. Of those who expressed unmet needs for transportation, it tended to be to medical appointments versus transportation for work, education, or social purposes. Still, some cases exemplify the problems faced. Many transportation companies are reluctant to go far out of town or down dirt roads, and in one case, the caregiver reported that some transportation providers did not believe that the participant could authorize their services and kept calling the support broker for approval. A Florida participant used an electric scooter to get around, but he was grounded when it rained (FL 10). An older Hispanic woman in New Jersey lived on the third floor and, although she can’t get up or down stairs, no transportation service will help her get out.
of, or into, her house (NJ 3). Finally, a participant in Arkansas used to depend on her brother to lift her into a van, but now the van is “torn up” (AR 22). There were a few participants who complained that they had to spend so much on transportation and it prevented them from addressing other needs.

Routine health care

Health care was an area where a majority of the case studies contained one or more unmet needs of varied kinds. Some of the unmet needs were in the areas of routine health care which Mathematica had used in operationalizing this category, namely medications, blood pressure, diabetes management, and exercise. But even within this topic area, needs varied greatly. In the area of medication management alone, problems ranged from the inability to afford needed medications, to forgetting to take medicines, to experiencing side effects. For example, in the case of FL 4, the participant reported that she suffered side effects such as drug-induced osteoporosis from the medication prednisone, and she reported difficulty finding the right medication to manage her depression stating, “Once I no longer was able to see a good psychiatrist, I had to go to a GP.” In the case of FL 5, epidermal patches to alleviate pain caused the participant to feel drowsy and groggy, stating, “I feel so drugged,” and in NJ 15, the participant reported unwanted side effects endured as a result from taking medication to treat hepatitis C.

In addition to the aforementioned unmet needs within the Mathematica category, another major grouping of unmet health-care needs dealt with medical needs and the integration of health, behavioral health, and long-term care services and supports. Examples in these categories ranged from how to deal with skin breakdown to obesity (“I’m 200 pounds overweight” NJ 4) to nutritional concerns regarding inability to find or purchase appropriate foods for managing their diabetes. Significant numbers of participants spoke of pain, even with medications, and how it impeded ADL from showering to continence. Moreover, a number of participants and/or their representatives also spoke of unmet needs for speech or language therapies. For example, in FL 18, the participant had severe learning and behavioral health disabilities, often kicking her caregivers and scratching herself. The family, who were the caregivers, stated a need for constant communication and behavioral therapy in addition to ceaseless supervision so that the participant did not hurt anyone.

A large number of participants spoke of depression or other mental health needs. Others spoke of problems with ill-fitting prostheses or teeth, feeding tubes, or catheters. To illustrate these needs, in NJ 8, the participant’s representative stated that the participant’s “feeding tube really bothers her,” and she would often pull her catheter out, causing pain which subsequently required a trained nurse to come to the participant’s
home in order to put the catheter properly back into place. Furthermore, after the participant’s first stroke, she described becoming very depressed and had to take medication to treat her depression. In NJ 17, the participant complained of having uncomfortable leg prosthesis so he did not use it. In NJ 18, the representative did not feel that the participant was receiving all of the therapy that he needed when she states, “He could use more therapy, however, they haven’t been very cooperative.” Lastly, in AR 12, the participant complained of unrelieved pain in her arms and legs that was unaffected by medication used to treat the pain and additionally complained that medication was causing additional pain. The participant’s caregiver further notes that there were many things that the participant could not eat because her new teeth hurt her mouth. In some cases, it was not clear what the unmet need was for. All the participant or caregiver could express was the problem; for example: “I can’t sleep”; or “I am dizzy much of the time.”

The most frequent unmet health-care need identified by caregivers was for training, ranging from basic training like first aid to specialized training in areas from behavior management (particularly for children) to training for their personal care workers on the specific conditions they were dealing with. Others, particularly parents who felt they had developed expertise in the care of their child, wanted professionals to understand the competing demands they were negotiating.

In a number of cases, respondents spoke of a need for more information on specialized health-related topics such as caring for participants with autism, dementia, contractures, or seizure disorders, an area the members of the research team agreed to call care literacy. Others, however, voiced general concerns that ranged from worry about leaving a participant alone to concern about the future that implied unmet needs ranging from medic alert systems to help with anticipating coming changes including preparing advance directives. For example, in the case of NJ 7, the caregiver was concerned about his mother while he was at work due to the participant’s age and her inability to speak English. Lastly, many caregivers were dealing with unmet needs surrounding their own health and mental health. In FL 7, the caregiver is upset about her sister’s health and was clearly distressed during the interview process. One caregiver’s words captured the stress spoken or implied by many when she said: “Wear and tear. It just all falls on me” (FL 17). In FL 2, the caregiver states that “you can’t be the caregiver and the love giver”; “Sometimes I go to bed and I just cry.”

Other unmet needs
Not all of the unmet needs expressed by members of the care team easily fit into the preset categories, so we established a miscellaneous, or other unmet needs, category.
Loneliness and social isolation. What stood out here was the number of participants who described feelings of loneliness and social isolation, expressing their need for companionship and meaningful relations and activities. In FL 2, the participant described feeling left out of what was happening in the household and started crying because people were not paying attention to her. In AR 20, the participant described struggling with self-respect and pride due to his illness as he was unable to earn a living. In one case, NJ 1, the participant had panic about being alone and expressed a need for companionship. In another case, NJ 14, the participant wished for company and intellectual stimulation. Lastly, in NJ 20, the participant wanted to meet more young people and share an apartment with another person with a disability.

Caregiver worries about the future. On the caregiver side, “worry about the future” was expressed by a majority of the caregivers. For example, in FL 6, the caregiver was concerned about what will happen if his parents are unable to help him in the future. In FL 24, the caregiver was worried about the participant’s transition to adult services. In AR 24, there is an unstated or normative need, from the caregiver’s point of view for long-term planning, as both the participant and his wife are in their 80s and both are post-stroke.

Family treatment interventions. Another topic that came up as an unmet need was family treatment interventions, such as anger management, taking care of children, voice-directed software, quality day care, and understanding. AR 17 highlights some of the challenges of being a caregiver in relation to understanding. The caregiver states “people that don’t do this, don’t understand it.”

Respite or relief. A common theme voiced and unvoiced in the case stories was an unmet need for relief from the constancy of caregiving responsibilities. “It’s a big responsibility to have to take care of, just be available, 24 hours a day, seven days a week without any outlet of your own. I think everybody needs some time, everybody needs a time out.” (FL 17). This sentiment reverberated through the majority of caregiver and in some participant interviews.

Reference to formal respite programs was the exception and then mostly in the cases of parents in Florida who sent their child to camp with dual benefit. Other references to respite highlighted problems with agency-based models. For example:

I don’t really think that even that much more respite care would help me because I have to do the things (to care for my mother). It’s just that there are problems … If I go on vacation and I have a girl come in one day, my sister usually works from 7:30 to 4:30. I can’t get anybody here at 6:30 for her to be at work. I can’t get agency workers to work past 4:30 (FL2); or
If we wanted respite care we would have to ask for it a couple of days in advance to see if someone (from the agency) was going to be available to come in. And then the agency would have different people coming in and out of your house – I didn’t particularly like that. It was not just one person, it would be different people. [participant] would get used to one person and then they change and you’d have somebody else (FL 11).

While many participants used part of their budget to pay family or friends to provide some relief, which they described as invaluable, others desired but did not find this possible. For example, a son who had quit his job to care for his father felt that although one of the benefits of the program was that he could use the budget to hire a respite worker if they had to, he didn’t think that they receive enough every month to make this practical. His wife said: “You do give up your life …. My husband and I cannot go out together and go to family functions or just go for a walk on the beach” (FL 3). In several cases, the researchers inferred an unmet need for relief, either based on what the caregiver described as stressful or difficult, often related to not being able to leave the participant alone, or as they simply described their day. An older participant said,

She goes to work every day. She gets up and fix my breakfast and give me my bath real quick then she fix me enough for lunch and when she come in she picks me some supper. Like when I have to take a bath, she give me my bath at night and just a sponge one in the morning. (AR 13).

Similar stories were common which led us to infer a widespread normative unmet need for relief.

**Generic pleas for a higher budget.** Over half of the case studies in each of the states included some discussion of the need for more hours or a higher budget. But, upon further analysis, their reasons were somewhat different. The largest group wanted additional funds or a higher budget so they could purchase some good or service ranging from a medic alert system to an air conditioner to more days of adult day health care or home reformations. A few explained how certain necessities, like paying for one pill that was not covered by any insurance, crowded out the ability to purchase devices that could help to reduce the need for, and the strain of, providing human assistance, such as transferring devices or appliances like microwave ovens, etc.

The next highest level of expressed need came in the form of a plea for additional hours of care, i.e., not just paying for or replacing informal caregiving hours, but care during times, even days at a time, where they were left alone and homebound. The next grouping focused on the needs of the caregivers. In some cases, the participant wanted to pay a higher wage and even complained of losing workers due to inadequate wages, while in
other cases the participant or the caregiver him or herself spoke of providing many hours of care, sometimes even 24/7, and only being paid for a small number of these hours.

Certainly many people just wanted more. But not everyone; there were a few caregivers who felt guilty taking any money and one participant who wanted to have his budget reduced. We also know from program experience that many people did not spend their full budgets. The difficulty of determining need and setting budgets has received much attention (Doty, Mahoney, & Simon-Rusinowitz, 2007, p. 391) and that will continue.

**Unmet needs for assistance in managing program tasks**

While looking at unmet needs, we decided to also look at unmet needs for help in self-directing. In looking at what unmet needs people had in handling “self-direction,” comments fell into two areas: handling employer tasks and managing the budget.

**Employer tasks**

**Early transition.** The uncertainty of roles during introduction and/or transitioning of responsibility for employer authority to the participant and/or their representative was a common theme that emerged from the narratives of the participants and caregivers. Given that interviews took place six or more months after the person started on a budget, the narratives suggest that many of the earlier issues had been resolved. Understanding responsibilities such as keeping track of hours, signing pay sheets, and getting paid on time were among the issues mentioned. One participant [NJ 21] said she had been under the impression that her sister should be signing the pay sheets and not her.

Another illustration of a caregiver being unhappy with how the program processes workers’ pay is reflected in the following quote: “I want to know why they still send Myra a check to her old address and they’ve got this address. They sent it across town and it takes about a week or two for her to get it.” [AR 18]. Another participant spoke about uncertainty regarding how to track and process the workers’ time sheets. For others, there appeared to be a lack of clarity on how to get hold of their support brokers; this was especially true when a new broker was assigned to their case. Although there appeared to be some early uncertainty with how to best work with the support broker, many spoke about how accessible and helpful their broker was.

Although both participants and caregivers did report issues such as less than clear paperwork requirements, and difficulty submitting timesheets and scheduling workers during the early phases, the caregivers appeared more likely to report challenges in dealing with what they saw as the program bureaucracy. As one caregiver stated “… [T]he other day I went to bed at 1
The interviews did suggest that many of these issues were eventually resolved and that participants and caregivers were able to learn how to better manage other issues as they became more familiar with the expectations and responsibilities for maintaining employer authority. The interviews also provided numerous illustrations about the importance of having access to a support broker who was both familiar with the more subtle nuances of the program and available during periods of uncertainty.

**System-level challenges.** A common theme that emerged from the narratives was difficulty in recruiting and training workers, especially workers with the background to understand and work with that particular participant. Although a majority of the respondents reported employing family members as caregivers, the majority of the respondents reported having multiple caregivers. Consequently, recruiting caregivers, especially non-family caregivers, and then arranging their schedules were at times problematic for participants. The following comment demonstrates this challenge. “Most people want at least 40 hours a week, and then on top of that, it’s hard to find somebody to understand the situation and the medical problems, and is willing to come in and understand that there might be an accident.” Another stated that, when it came to having available caregivers, she used six non-family caregivers so that she wouldn’t be too dependent on any single caregiver. It is this type of creativity that exemplifies the strategies that some participants and caregivers used to maximize the benefit of employer authority. A few participants spoke of language difficulties, complaining that materials were only in English, or no one answered the phones in Spanish, or the participant could not hear or speak and was not able to communicate with program staff.

The responsibility for training workers also appeared to be a challenge for some of the participants. The majority of caregivers, especially those who were not themselves professional caregivers, received little or no training prior to being employed, but instead reported having a lot of ‘on-the-job’ training. This is reflected in the following quote: “The hospital staff trained us in Memphis as to how to take care of the tube and how to feed her and taught us about the medication and how to give it out of the tube” [AR 7].

**Budget management tasks**

Again, participant remarks could be sorted into early transition problems versus problems requiring system-level attention.
Early transition issues. Person-centered planning (PCP) is more difficult than it sounds. The responsibility for developing and managing one’s budget requires a complex set of skills that can be difficult to master; for many, it is an ongoing learning process. The role of the support broker in preparing and supporting participants and their representatives to assume this role can be challenging. As one broker reported, “My clients are pretty screwed up at the accounting level. It is very frustrating and the problems are ongoing.” This broker continued stating, “There have been some problems on this case with purchasing and feeling like I am put in a situation where I am being asked not to be honest, and I can’t do that” (FL 11). On the other hand, one participant opined for an “engaged consultant” or support broker.

System-level challenges. The uncertainty about managing budgets and confusion with what is, and is not, allowable was another theme that emerged from the data. A number of participants reported that budgeting was confusing; they needed more training; rules were unclear or kept changing; and budget balance statements were unclear or inaccurate. As one support broker reflected, “Her purchase plan was very elaborate and it actually got out of hand. It was way too confusing (so) we simplified her purchase plan. After that, it became a little easier for her. They (the fiscal intermediary) had some difficulties with the accounting and all that, in the earlier periods, until they got things straight” [FL4]. On the participant side, at least one representative felt that managing the budget was “too much responsibility” while one aide stated she felt the participant really made very few choices.

Discussion

Although we do know from the Mathematica Policy Research evaluation of C&C (Carlson et al., 2007) that major reductions in unmet need took place when people had control of the budget, important unmet needs persisted even when people got to decide how that limited amount of money was spent. This study, for the first time, presents a deeper understanding from multiple perspectives about how needs are being met and what needs remained unmet. This study shows that while self-direction can succeed where traditional services fall short, it is not a panacea. The findings do suggest ways this method of service delivery can be improved. The discussion is organized to address the initial aims of this study and to describe the unmet needs and to understand who among the participants, caregivers, and brokers perceive needs. Following a discussion of one of the more often areas, health-related problems, the discussion will present the environmental issues such as transportation and the need for respite from caregiving responsibilities. But it should be noted that these questions are quite inter-related and difficult to disentangle. For example, sometimes the description
of what not be mentioned much such as transportation provides vital clues for how that need might be addressed in other service networks.

**What are the unmet needs?**

Certain areas of unmet need identified in this study stand out. These included health-related problems, environmental issues, and the caregivers’ need for relief. More than half of the case studies presented health-related problems that needed attention. This was true even though due to provisions in state Nurse Practice acts, family members, and workers, the participant hires often do not face the same restrictions that agency home care workers face helping clients with health care (including injections or wound care) or medication administration (Reinhard, 2010). Sometimes these were issues that the budget might address, but in other cases what seemed to be lacking was coordination with health-care professionals and health-care funding sources and/or knowledge of community resources. Given current interest in the integration of health, behavioral health, and long-term services and supports, these findings make one pay attention to what is on people’s minds. This is the real definition of person-centered care (PCP). Health issues also included the “care literacy” of both the participant and his/her caregivers, i.e., their knowledge of specialized information they are craving in areas from dementia to autism, and many more specialized areas regarding their particular situations. In the health arena, training/matching care provider training with needs of that particular person also came to the fore. Where do I find out more about seizure disorders or how to handle a Hoyer lift?

Environmental effects including lack of transportation and challenging physical environments ranging from very rural locations with no paved roads, to inadequate housing, had an important bearing on unmet need. As seen in earlier studies (San Antonio et al., 2007), characteristics of the environment, as well as of the participant and their caregivers, shape the needs people must cope with. In some cases, budgets seemed to be overwhelmed with needs that could not possibly be met by the self-directed program resources alone. Some of these might be addressed by tapping other community resources including Medicaid funding for durable medical equipment, etc. Self-directed programs generally allow people to save up for larger purchases, but that means participants go without in the short run.

A substantial number of caregivers voiced a need for relief. We hesitate to call this “respite” as “respite” has come to be seen as a specific programmatic response to the problem these people are presenting. This study sheds some light on how the caregivers are feeling and what it means in their lives. Some need help at night or some during the day to go shopping or enjoy some preferred form of rest and relaxation. Others may want companions, or just positive feedback, or peers who share coping ideas. In a few cases, we gain
new insights into the types of supports that would be supportive. Respite is clearly not a “one-size-fits-all” and it is sometimes a lot of trouble to arrange.

A good number of these case studies also showed participants and their families expressing major fears about the future – fears regarding situations they could already see clearly in front of them. These fears ranged from the deteriorating health of the participant and/or those providing care, to transitions such as losing benefits as one turned 22, to planning for death. These “anticipated needs” weigh heavily on some and deserve attention from support coordinators.

There were also certain areas where the self-direction model clearly reduced unmet need, such was the case in the area of transportation where so few reported unmet needs. Participants and caregivers were unanimous in stating that their experiences, care, and overall satisfaction with participant direction were superior to their experiences with traditional agency-based services. The flexibility, creativity, and commitment of the participants and caregivers in finding ways to get their needs met were notable. Both participants and caregivers were especially happy with the ability to hire their own workers. As one Florida participant said; “Oh, and the choice of employees! I (used to get) some bum employees. In the nine years with the agency, (there were) maybe only 3 exceptional people that I would say they were doing their job.” Similar comments were made by a participant from New Jersey; “We were using an agency … [the health aide] was good in certain respects because she was medically oriented, so she could take care of the medical end and sanitary issues [related to Crohn’s disease], but then in personality, we had trouble” [NJ 25]. Still, there were a number of areas, both in the initial implementation stage and at the systems level, where unmet needs for assistance in managing the self-direction program were evident.

Before leaving this discussion on unmet needs, it is important to look at these results holistically. When a person develops his or her own spending plan within a limited budget, s(he) is required to make choices; giving priority to one need may mean neglecting another. That is the nature of managing a limited budget. However, sometimes efficiencies can be found such as when the person used his or her budget to purchase a labor-saving device. We know from the quantitative evaluation of C&C (Carlson et al., 2007) that in some states the hours of personal assistance that people received went down, but so did reports of unmet need. C&C did not alter the amount of money available to meet a person’s needs for personal assistance; it merely let the participant decide how to spend limited dollars. The participant was able to individualize the spending plan.

That is not to say that the budgets were always adequate in the first place. In Arkansas during the C&C Demonstration and Evaluation, the median budget was $314 a month, which, according to the formula that state used, would purchase approximately 40 hours of attendant care @ $8 an hour. If
we harken back to the research done out of the University of California, San Francisco (La Plante et al., 2004), people with substantial unmet need for PASs typically need 18.7 to 16 hours of additional care per week, depending on whether they live alone or with others.

**Who sees these unmet needs?**

Different people bring different perspectives. These case studies were rich in showing the different worries of participants and those who helped care for them. Throughout this article, we tried to list participant responses followed by caregiver responses, but we noted an important degree of synergy and mutual reinforcement in their responses. One important message is that needs are not always expressed in terms of programmatic responses. This points to the need for improved mechanisms for PCP where support brokers help individuals think comprehensively and out loud about their needs and the resources available to them. In the early days of C&C, PCP methodologies were just coming to the fore. Their usefulness in the future is clear.

It is also important to note where needs were only seen by professionals. In our study, just as Morrow-Howell and others predicted, our researchers who were also clinicians sometimes saw needs that the participants and their families did not voice or did not express clearly. These situations were most prevalent when speaking of health care, training, or the participant’s environment. Was this because professionals saw options and resources that participants could not have known or because professionals had different values, like cleanliness or safety? This is another area for future exploration, but, to the extent the issue deals with knowledge of important risks and unseen resources, there are clear implications for support broker training.

**Ideas for improvement**

The value proposition of what needs the public sector will assume responsibility for will remain in the forefront for years to come. The philosophical question of what is “need” and what is “want” will not go away. We must also deal with the question of what proportion of unmet need public programs intend to cover. Clearly, public programs will never pay for all the care that informal caregivers deliver. But this debate can mask the reality of what public programs are doing. The National Long Term Care Study (Liu, Manton, & Aragon, 2000) shows that for all Americans who have needs for ADLs, over 60% receive help only from family and friends; few can survive on public supports alone. A growing percentage of those with ADL needs are getting supplemental support from public programs. But how much public support makes sense, and is there a level of public support that is clearly
inadequate. As mentioned earlier, the median C&C budget in Arkansas during the C&C demonstration would buy less than 40 hours a month at the $8 an hour rate used to compute the budget, far less than the number of hours La Plante et al. (2004) suggest is needed.

Training is complex. Current state policy is often focused on mandatory, uniform training, while these participants seemed much more interested in training on their individual conditions. Questions about who pays for this training and for the loss of time for those attending or replacement workers while the caregiver is away are coming to the fore in policy debates. What is clear is that what is good for the worker and what is good for participants are intertwined. A few of the case studies, such as those involving skin breakdown or being 200 pounds overweight, raise the issue of risk. What happens when the participant’s wishes and the support broker’s professional judgment disagree? Whereas some have argued that people with certain conditions should be excluded from the self-direction option, states have begun to use “risk agreements” where the participant clearly acknowledges the risk and the advice of the professionals but chooses to remain in the community with assistance. This whole area is again one where future case managers and support brokers will want training.

Many aspects of unmet need for assistance in program management came at the onset of program and were met over time. It is important to remember that these case studies took place early in the history of C&C. Hopefully, as support brokers and financial management services gain experience, they become more efficient and learn better ways to explain and share key aspects of the program, the supports available, and the participant’s roles. Nevertheless, some of the unmet needs for assistance presented in these case studies provide clear guidance that new supports, such as provider registries for people who lack family and friends ready to take on the additional caregiving tasks or better training for support brokers in areas like accessing other community resources, deserve attention. Here, we are reminded of the work Herman and Mandiberg (2010) have undertaken on “critical time” interventions demonstrating the importance of the timing when transitioning responsibility from professional to client/participant.

**Implications for social work**

We have already seen many findings laid out in the discussion above that have particular implications for social workers. Let us now highlight a few:

The job of support broker goes well beyond just helping with a budget. Social workers need training in PCP and how to empower participants to have a more comprehensive image of their own needs and the strengths and resources they bring to the table. It is important
to recall the work of Leutz and Capitman (2005) who found that participant satisfaction was strongly related to just knowing their service coordinator’s name! Support brokers also need to help participants access other resources and integrate their work with acute care providers and chronic disease management and health promotion programs as suggested by Meng et al. (2009). Clearly, support brokers also need to pay attention to the needs and views of family caregivers (Mullan et al., 2009). Much more attention needs to be focused on the training needs of support brokers and their supervisors. Whereas training needs to be available for participants and caregivers, this training ought to focus more on the needs of individuals (as opposed to one-size-fits-all mandatory training), and policy needs to recognize the costs of training and the needs of workers.

This is no time to cut budgets when programs are already not meeting need. Policy initiatives before Congress are considering capping Medicaid funding – leaving decisions on what to cut and what to save to the states. Research such as what we are presenting can help show that long-term care needs are already not being met. Social workers have important advocacy tasks, skills discussed in Council on Social Work Education (CSWE) guidelines for schools of social work presented in the last article in this dedicated issue. Some advocates feared the budget authority option, questioning whether it would be easier to cut budgets than to eliminate services. This research shows that cutting budgets is not the solution.

**Limitations**

We approached this project recognizing that the findings reflect data that were not collected with an intent to answer the questions posed in this study. While the sample was selected to be representative of the population enrolled in the three Participant Direction (PD) programs, the one-time interviews limit the findings to the participants’ responses at a single point-in-time. Consequently, it is not known how expressed or unexpressed unmet needs would change over time. Many of the case studies did not include the interviews with the support broker or counselor. Despite these limitations, this study is the first of its kind trying to understand participant and caregiver views on unmet need in participant-directed programs.

**Further research**

Finally, this research suggests the need for additional research looking at whether and how support broker activities and training are related to reductions in unmet need. A following article in this special issue presents
participants’ views on the characteristics of the ideal support broker, and the concluding article discusses training modules now available for future social workers. The social work profession has played an important part in the development of the self-direction option, and together with our professional colleagues in other fields, social workers and social work researchers can help make improvements.

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