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Emergent Disabilities and Centers for Independent Living:  
The Case of Chronic Fatigue Syndrome

Renee R. Taylor, Ph.D.  
University of Illinois at Chicago  
Heather Eisele, B.A.  
DePaul University

Abstract

Over 500 Centers for Independent Living exist internationally. Centers for Independent Living are community-based, empowerment-oriented organizations that provide advocacy and linkage to resources for individuals with a wide range of disabilities. Historically, people with invisible disabilities such as chronic fatigue syndrome (CFS) have not made extensive use of Centers for Independent Living, and have not been formally introduced to the independent living philosophy. Conversely, Centers for Independent Living have encountered difficulty outreaching to and serving individuals with CFS, and have not been adequately informed about their resource needs and entitlements. The purpose of this study was to assess attitudes and knowledge about chronic fatigue syndrome among staff members of a Center for Independent Living before and after an educational intervention designed to raise awareness about CFS and provide guidance about the resource needs and entitlements of the CFS population. Before the intervention, over half (62%) of the staff members regarded CFS as having a biological cause, most considered CFS as a severe or very severe condition (76%), and most (74%) were of the opinion that an empowerment-oriented, independent living philosophy would benefit individuals with CFS. As a result of the intervention, all (100%) respondents either gained increased factual information about CFS, increased empathy toward individuals with CFS, or increased general awareness of CFS. Most (67%) respondents reported that the intervention changed their prior level of awareness of CFS, empathy toward those with CFS, or awareness of the medical legitimacy of CFS. The implications of these findings are discussed in terms of their relevance for community-based alternatives to health care for individuals with emergent disabilities in the 21st century.

Key words: chronic fatigue syndrome, independent living, attributions

Chronic fatigue syndrome (CFS) is a highly debilitating condition characterized by six or more months of medically and psychiatrically unexplained, persistent fatigue. The fatigue is not due to ongoing exertion, not substantially alleviated by rest, is of new or definite onset, and results in substantial reduction in previous levels of occupational, educational, or personal activities (Fukuda et al., 1994). Current diagnostic criteria endorsed by the United States Centers for Disease Control and Prevention (Fukuda et al., 1994) require the fatigue to be accompanied by four or more of the following symptoms for at least six months: impaired short-term memory or concentration, sore throat, tender lymph nodes, muscle pain, multi-joint pain without swelling or redness, new type headaches, unrefreshing sleep, and post-exertional malaise for more than 24 hours.

CFS has been recognized as a disability under the Americans with Disabilities Act (ADA) (Banks, 1993) and legitimated as a medically determinable condition by the social security administration (Social Security Ruling 99-2p). Despite these developments, individuals with CFS continue to report negative experiences with service providers characterized by outright disbelief, lack of knowledge or understanding of CFS, over-emphasis upon psychological or psychosocial explanations, and a general lack of responsiveness or treatment planning (Anderson & Ferrans, 1997; Banks & Prior, 2001; Green, Romei, & Natelson, 1999). Perhaps as a result of this tension, persons with CFS report a lack of social support in their environment and tend to under-utilize rehabilitative services and community-based resources traditionally available to individuals with other disabling conditions (Jason, Ferrari, Taylor, Slavich, & Stenzel, 1996).

Because researchers have yet to identify an exact etiological agent, lab-based diagnostic marker, or medical cure, a key question for service providers involves how to respond to individuals with CFS in ways that validate the severity of their illness experience, address functional limitations, promote empowerment and self-advocacy, and adequately respond to the multifaceted economic and service needs of this population. Traditional medical and psychological treatment approaches for individuals with CFS have demonstrated contradictory outcomes and remain in an experimental phase of development (Taylor, Friedberg, & Jason, 2001). It is possible that empowerment-oriented rehabilitation efforts emphasizing the integration of public and private community-based service systems, peer counseling, advocacy, civil rights, and education may offer effective means of supplemental health care for individuals with this syndrome. For these reasons, Centers for Independent Living offer a most appropriate avenue for resource acquisition and coordination for individuals with CFS.

Centers for Independent Living are community-based, empowerment-oriented organizations that are operated by and for individuals with disabilities, providing advocacy and resource linkage. The idea behind Centers for Independent Living began in the late 1960s, when Ed Roberts, a student with post-polio respiratory quadriplegia, became one of the first severely disabled persons to be admitted to a University (Zukas, 1975). Ed

led a group of disabled students in the Cowell Residence Program at the University of California, Berkley to form their own class, "Strategies of Independent Living." In subsequent years, a unique philosophy about disability developed, which later became known as the independent living philosophy.

The guiding principles of this philosophy, which in part derive from a number of major U.S. social movements occurring during the 1960s and 1970s (Shreve, 1994; Zukas, 1975) are: (1) peer counseling (an offshoot of self-help) - the notion that those most familiar with the needs of individuals with disabilities and how to meet those needs are the individuals with disabilities themselves; (2) consumerism - an emphasis on the rights and power of consumers to be educated about the nature and quality of the products and services they are receiving; (3) de-medicalization - a rejection of disability as pathology and a rejection of any situation that engenders dependence on professionals; (4) de-institutionalization - the notion that individuals with disabilities should be provided with resources that allow them to be fully integrated into their communities; and (5) comprehensive programming - the idea that the needs of individuals with disabilities can be most effectively met by comprehensive programs that provide a variety of services.

Later, in 1979, the first Center for Independent Living was funded and developed. Over the past thirty years, the movement has gained increased momentum throughout the world. Currently, over 500 Centers for Independent Living exist within the United States, Canada, Africa, Brazil, Australia, and in the United Kingdom and other European countries. The central purpose of Centers for Independent Living is to empower individuals with disabilities to advocate for themselves socially and politically, encouraging increased self-direction and autonomy. Examples of core services offered through these centers include information and referral, peer counseling and self-advocacy training, civil rights and legal advocacy, deinstitutionalization, housing renter assistance and homeownership counseling, technical and transportation assistance, public education, and independent living skills training.

These services are shaped by the independent living philosophy, which encourages people with disabilities to gain both physical and psychological independence by acknowledging their power as consumers, educating themselves and others about disabilities, self-advocating for political and economic rights, and decreasing dependence on others (including medical professionals). The philosophy rejects any situation or entity that places individuals with disabilities in a position of inferiority.

Since Centers for Independent Living are, in large part, well established, staff of these centers have easy access to networks of public and private resources for individuals with disabilities. Such networks could benefit others with invisible disabilities that have been unaware of such resources, have been reluctant to utilize them, or have experienced difficulty accessing them. If individuals with CFS can gain entry into Centers for Independent Living, they will not only have an easier time accessing important resources, but they will also have a larger support and advocacy system available to them.

Given that CFS is an emergent disability only recently

recognized by the United States Centers for Disease Control and Prevention in 1988 (Holmes et al., 1988), and given that the Independent Living Philosophy is a relatively new international movement, a certain amount of disjunction may accompany the introduction of individuals with CFS into Centers for Independent Living. Part of this tension may involve the need to adjust the Independent Living Philosophy to fit some of the unique aspects of less visible disabilities like CFS.

The Independent Living Philosophy locates many of the problems for people with disabilities within society and in its environmental barriers, discriminatory acts, and socially stigmatizing attitudes. According to this externalizing orientation, the main objective of people with disabilities is to break down societal barriers and integrate themselves fully into the community in an effort to be treated equally. Conversely, individuals with chronic fatigue syndrome want to be recognized as disabled individuals before community integration occurs, since part of the stigmatization involving their condition is that it is invisible and thereby minimized and disregarded by others around them, ultimately preventing them from accessing appropriate resources and services to which they are entitled.

Another important part of the Independent Living Philosophy involves rejection of the medical model and the consideration of individuals with disabilities as complete individuals not in need of treatment or a cure (Shreve, 1994). By contrast, individuals with CFS do not view their disability as something that they want to embrace, or as something that contributes positively to their identity.

The pride and acceptance that people with disabilities have in themselves has contributed to the creation of a disability culture (Johnson, 1987). Those with invisible disabilities like CFS may find it difficult to enter into this culture, particularly because it may be difficult for them to accept themselves as having a disability. Moreover, many individuals with CFS do not embrace the notion of taking pride in their disability, but instead struggle with their illness, seek a cure, and hope to return to their pre-CFS way of life. If this process is not identified and addressed, staff of Centers for Independent living may sense this denial, and although they may try to work through it with CFS clients, ultimately, they may not see individuals with CFS as an appropriate population to serve.

Given these potential sources of disjunction, the objective of this investigation was to implement an educational intervention for staff of a Center for Independent Living in Chicago and evaluate pre- and post-intervention attitudes and knowledge regarding CFS held by the staff members. One expected outcome of this project was that staff members of the Center for Independent Living unfamiliar with CFS would increase their awareness of CFS, increase their knowledge about the resource and service needs and entitlements of individuals with CFS, and increase their empathy toward individuals with CFS.

This educational intervention was nested within a larger grant-funded project (The CFS Empowerment Project) designed to investigate a number of questions involving the relationship between people with CFS and the disability community. The CFS Empowerment Project attempts to integrate individuals with CFS into Centers for Independent Living by offering CFS management

training groups, ongoing goal-setting, self-advocacy training, and one-on-one coaching in resource acquisition. As a whole, the project not only aims to evaluate the effectiveness of the group and one-on-one sessions on the medical quality of life of individuals with CFS, but it also aims to evaluate the process of second-order change, or the extent to which Center for Independent Living staff members' knowledge and attitudes about CFS change as a result of housing this project within their center.

Since many of the staff surveyed have disabilities themselves and also serve as advocates for individuals with disabilities, it was expected that, even prior to the intervention, they might be more informed and empathic toward individuals with a wide range of disabilities than would otherwise be expected. However given that there has been little integration of people with invisible disabilities such as CFS into Center for Independent Living environments, we hypothesized that staff exposure to individuals with CFS was very likely to have been limited prior to the intervention, and that they would report increased knowledge and a change in attitudes regarding CFS as a result of the intervention.

## Methods

### Participants

The sample consisted of staff members from a Center for Independent Living in Chicago. The staff is comprised of 48 men and women over the age of 18, many of whom identify as ethnic minorities (predominately Latin American and African American) and 75% of whom identify as having disabilities involving physical functioning, cognitive functioning, chronic illness, or sensory impairment. All staff members were provided with an opportunity to answer anonymous pre- and post-intervention questionnaires assessing their knowledge and attitudes about CFS. Because the questionnaires were anonymous, exact sociodemographic information on the sample could not be obtained.

### Procedures

This study was nested within a larger grant-funded project designed to integrate individuals with CFS into Centers for Independent Living. Two peer counselors with CFS were hired by the Center for Independent Living through a grant subcontract. Their role in the project was to collaborate with other staff members in offering CFS management training groups, ongoing goal-setting, self-advocacy training, and one-on-one coaching in resource acquisition to clients with CFS.

One expected outcome of this overall project was that the medical quality of life of individuals with CFS would improve as a result of their involvement in the program. A second expected outcome was that staff members of the Center for Independent Living unfamiliar with CFS would, as stated before, increase their awareness of CFS, increase their knowledge about the service needs and entitlements of individuals with CFS, and increase their empathy toward individuals with CFS.

During the initial stages of this project (before the two peer counselors with CFS had contact with other center staff and before the intervention was initiated with the CFS participants),

an anonymous, pre-intervention questionnaire was distributed to all staff members in person by a research assistant available to answer questions, assist with any necessary accommodations for completion, and administer informed consent. Three weeks after survey administration, the educational intervention was then offered to all staff members in the format of an in-house two-hour in-service.

The first author, the two peer counselors with CFS, and the president of a collaborating local CFS self-help organization who also has CFS provided the educational intervention. Responses to the pre-intervention attributions questionnaire provided information regarding areas of educational need among the Center for Independent Living staff members, and this information was used to guide the planning and content of the educational intervention.

The first author provided factual information about the diagnostic criteria, cause, severity, prognosis, treatment of CFS, and reviewed and commented on findings from the pre-intervention questionnaire. The peer counselors provided information about service needs within the CFS population, and the president of the local CFS self-help group introduced herself to the center staff and discussed some useful referral sources and other resources available to people with CFS through her organization. Lastly, the peer counselors provided some personal testimony about their experiences with CFS to illustrate the impact of CFS on their lives with the objective of engendering a feeling of empathy among other staff members. Immediately following the intervention, all staff members in attendance were administered a post-intervention feedback questionnaire.

## Measures

### Pre-Intervention Measure

An adaptation of the CFS Attributions Questionnaire used in previous studies of attitudes toward individuals with CFS among health care providers and undergraduate students (Jason, Taylor, Stepanek, & Plioplys, 2001; Jason, Taylor, Plioplys, Stepanek, & Shlaes, in press; Taylor, Jason, Kennedy, & Friedberg, 2001), was administered to all participants as the pre-intervention measure. Questions contained in this measure are presented in Table 1.

Table 1  
Participant responses to pre-intervention  
questionnaire (N = 41)

CIL Attributions Questionnaire Items            % likely or very likely

#### Diagnosis/Cause:

- 1) What is the likelihood that individuals with chronic fatigue syndrome are suffering from primary depression, rather than being physically ill?            26%
- 2) What is the likelihood that chronic fatigue syndrome is stress-related?            34%
- 3) What factors do you believe are most likely to be responsible for causing chronic fatigue syndrome?
  - Psychiatric/Psychosocial Explanation            19%
  - Biological/Physiological Explanation            62%

Environmental Contamination Explanation 19%

Severity of Illness:

- 4) What is the severity of chronic fatigue syndrome? 76%
- 5) How disabled are people with chronic fatigue syndrome? 61%

Contagion:

- 6) How contagious are people with chronic fatigue syndrome? 3%
- 7) To what degree should individuals with chronic fatigue syndrome take precautions to avoid passing this illness on to her spouse, children, and friends? 7%

Prognosis:

- 8) What is the likelihood that individuals with chronic fatigue syndrome will improve over time? 21%
- 9) What is the likelihood that individuals with chronic fatigue syndrome will worsen over time? 38%

Treatment:

- 10) What is the likelihood that medical treatment may improve the functioning of individuals with chronic fatigue syndrome? 37%
- 11) What is the likelihood that psychiatric treatment may improve the functioning of individuals with chronic fatigue syndrome? 29%
- 12) What is the likelihood that an empowerment-oriented, independent living philosophy will benefit individuals with chronic fatigue syndrome? 74%

Prior Familiarity with CFS: % yes

- 13) Do you know someone diagnosed with Chronic Fatigue Syndrome? 56%
- 14) Have you read any articles about Chronic Fatigue Syndrome? 51%

This 14-item measure assessed knowledge and attitudes about CFS regarding causality, diagnosis, severity, contagion, prognosis, treatment and prior level of familiarity with the illness. A six-point scale was utilized in coding 11 of the questionnaire items. The codes ranged from one, denoting "not at all severe" or "very unlikely" as a response, to six, indicating "very severe" or "very likely" as a response.

There was one qualitative question on the survey that assessed what respondents considered as the cause of the illness. For this question, all responses were independently coded into one of three major categories (Psychiatric/Psychosocial Explanation; Biological/Physiological Explanation; or Environmental Contamination Explanation), once by the first author and once by the second author. Internal reliability for the coding of responses was 100%. The final two questions on the measure utilized a yes/no format to assess direct familiarity with CFS.

Post-intervention Measure

Staff members were also administered a questionnaire that consisted of two open-ended questions, each presented at the top of Tables 2 and 3. These questions were designed to assess

changes in staff members' attitudes and knowledge as a result of the intervention.

Table 2  
Participant responses to post-intervention  
Question 1 (N = 20)

As a result of the in-service, what did you learn about CFS that you did not know before?

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Acquired Factual Information about the Illness (60%)

- "Some of its symptoms."
- "Many of the symptoms and characteristics of people with CFS. How to interact with a person suffering from CFS. More of accommodations."
- "Large range of symptoms that people with CFS can have, connection to MCS, the length of the symptoms/CFS much longer than I expected."
- "Didn't know some of the accommodations required. Learned about lights, fatigue."
- "Yes, the symptoms and how it occurs."
- "That more women are diagnosed with this than men."
- "The many symptoms."
- "Yes - acute onset at any time plus triggered by trauma."
- "I'm surprised about how much I already knew - but I learned quite a bit about the extent of the symptoms."
- "Unexplained fatigue - short term chronic memory problems - body tremors - sleep disorders - chills - sweats - new to ADA - may be associated with fibromyalgia."
- "That it is not caused by stress, and that there's no cure."
- "That it might be contagious or passed through blood - not stress related."

Increased Empathy (25%)

- "The personal devastation it brings to individuals and the family."
- "That it is an incredibly serious and life shattering condition. It is devastating!"
- "The traumatic consequences and the toll it takes on your personal life."
- "That it mimics other disabilities. I learned of the victimization of those who self-identify."
- "How progressive CFS can be - very traumatizing to the individual as well as to that person's surroundings."

Increased General Awareness of CFS (15%)

- "Definitely yes and I suspect that I may have CFS without knowing it."
- "CFS has similarities of other diagnoses such as sleep apnea, which I was diagnosed as having."
- "I learned lots about CFS - sorry I can't think of anything more specific to say."

Table 3  
Participant responses to post-intervention



Question 2 (N = 21)

As a result of the in-service, did your opinion about individuals with CFS change in any way?

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Change in General Awareness of CFS (19%)

"Yes. Now I am aware of CFS."

"Just a new overall awareness."

"It helped me link characteristics of people's actions to CFS, which helped me understand the overall situation better."

"I have always felt the same about CFS but possess a better grasp on CFS. I need to learn more of this."

Change in Empathy (29%)

"I think it's probably the worst possible disability to have if you had no other prior or congenital disability (i.e., If you were non-disabled then suddenly got CFS)."

"Yes I know what it is to live with CFS. However, I didn't know that the symptoms I have as a diabetic were the same as victims of CFS."

"I have more of an understanding - a very overwhelming situation."

"Yes, because with my illness I'm often told 'you don't look sick'."

"Yes - more aware of their needs and sensitive to their needs."

"Be more aware and tolerant of situations and life. Symptoms vary from person to person."

Change in Awareness of Medical Legitimacy of CFS (19%)

"I often wondered about the validity of CFS. I accept it as a valid disability now."

"Coming to the realization that CFS is real and many suffer."

"Yes, I didn't know that PWC feel a lot of pain." (PWC = people with CFS)

"I understand better how severe CFS is."

No Change in Opinion (33%)

"Not really - I was already aware of many of the issues."

"No."

"Not really."

"No."

"No."

"No."

"Not really, I understood CFS before this session."

Data Analysis

Percentage data were used to summarize participants' responses to the pre-intervention questionnaire. Answers to questions that employed the 6-point scale were re-coded to a scale of 0 or 1 in order to capture extreme affirmative answers. According to this coding scheme, 1 represented the two strongest affirmative responses (i.e., likely or very likely) and 0 represented the remaining responses. The percentage data were tabulated from the affirmative responses and reflect the

proportion of individuals responding affirmatively to a given question. For the qualitative question assessing attributions about cause, percentages were calculated directly according to the three response categories. The final two questions were in yes/no format, so their frequencies were tabulated with out any additional changes to the data.

Qualitative analysis was used to analyze responses to the two open-ended questions on the post-intervention questionnaire. Each participant's response to Question #1 regarding changes in staff member's knowledge about CFS was categorized under one of three conceptual themes generated by inductive analysis of all responses. The three categories were: (1) acquired factual information about the illness; (2) increased empathy; or (3) increased general awareness of CFS.

Similarly, each participant's response to Question #2 regarding change in opinion was also categorized by inductive analysis according to one of four conceptual themes: (1) change in general awareness of CFS; (2) change in empathy toward individuals with CFS; (3) change in awareness of the medical legitimacy of CFS; and (4) no change in opinion. Internal reliability for the coding of responses to both Questions 1 and 2 was 100%. Percentage data for each of these four themes reflect the proportion of individuals classified under each response category. Results

Forty-one (85%) of the 48 staff members completed the pre-intervention questionnaire, and 21 (44%) voluntarily attended the intervention and completed the post-intervention questionnaire. One potential explanation why fewer staff members completed the post-intervention questionnaire may involve the fact that fewer staff members attended the educational intervention, which was optional for all staff members.

Table 1 presents percentage data for the 41 participants' responses to each of the 14 questions on the pre-intervention questionnaire. Table 2 presents qualitative data illustrating responses to Question #1 of the post-intervention questionnaire according to the three response themes for the 20 of the 21 participants attending the intervention (one of the 21 participants completing the post-intervention questionnaire failed to answer Question #1). Table 3 presents qualitative data illustrating responses to Question #2 of the post-intervention questionnaire according to the four response themes for 21 participants attending the intervention.

## Discussion

This study evaluated potentialities for building future service and referral relationships between Centers for Independent Living and individuals with CFS, an invisible disability new to the independent living movement. Staff members of a Center for Independent Living were surveyed before and after an educational intervention designed to raise their awareness of CFS, increase knowledge about the service needs and entitlements of individuals with CFS, and increase empathy toward individuals with CFS. Findings from this study were largely positive in that they indicated willingness on the part of most Center for Independent Living staff to consider individuals with CFS as a disabled population entitled to services and benefits accessed by

other more visible disability groups.

Perhaps of highest importance to future community-based health initiatives was that, prior to the educational intervention, most staff considered individuals with CFS as likely or very likely to benefit from the resources and philosophy offered through Centers for Independent Living. Of the three 'treatments' presented on the questionnaire, most staff members (74%) were of the opinion that an empowerment-oriented, independent living philosophy would substantially benefit individuals with CFS, while fewer thought that either medical (37%) or psychiatric (29%) forms of treatment would be of considerable benefit.

While some individuals with CFS find that certain medical and psychiatric treatments do help to ameliorate isolated symptoms, as of yet, no uniformly effective treatment for this condition exists (Friedberg & Jason, 1998). A study by Friedberg (1995) found that patients' perceptions of the effectiveness of various medical and psychopharmacological treatments ranged from 8% to 28% (not including alternative therapies). For some of the treatments listed, up to 9% of patients perceived that their conditions worsened with the treatment. While certain medical and psychiatric treatments can be of benefit to some individuals with CFS, the effectiveness of such treatments varies both between and within individuals (Taylor, Friedberg, & Jason, 2001).

By contrast, findings from this study support the possibility that consumer-driven, integrative community-based service systems grounded in principles of advocacy and independent living can fill an ever-widening gap between individuals with emergent disabilities and more traditional health care delivery systems. As further illustration of staff members' pre-intervention knowledge about CFS, over half (62%) attributed the syndrome to biological or physiological causes. Relatively fewer respondents considered CFS as a form of primary depression (26%), as stress-related (34%), or as having a psychiatric or psychosocial cause (19%).

These findings are, in large part, consistent with current biomedical research involving the etiology of CFS. A number of current laboratory studies in the fields of microbiology, immunology, endocrinology, and neurology-related fields suggest that CFS may have biological underpinnings (Plioplys & Plioplys, 1995; Suhadolnik et al., 1994) and can be distinguishable from primary psychiatric disorders such as depression (DeLuca et al., 1997; Demitrack et al., 1991). While these results are positive, over one quarter of the staff members did not appear to regard CFS as a biologically-based illness and were more likely to consider it as stress-related or as a form of depression.

Attributions such as these are not only inconsistent with current research findings (Komaroff et al., 1996), but they could potentially affect the level of responsiveness of service delivery systems and the nature of services that individuals with CFS receive through Centers for Independent Living. For example, it is possible that individuals with CFS might be inappropriately referred for mental health services by uninformed staff that may attribute the illness to psychiatric issues. While high stress has been linked to symptom exacerbation in CFS, stress is not the sole cause or only perpetuating factor in CFS (Antoni et al., 1994). Moreover, research has not consistently demonstrated a

relationship between CFS and comorbid psychiatric disorders (Hill, Tiersky, Scavalla, Laviertes, & Natelson, 1999; Taylor, Jason, & Schoeny, 2001). Given these findings, clarification of these relationships was incorporated into the educational intervention to prevent misattributions about CFS in future service and referral relationships.

Accurate understanding of issues of severity and functional impairment are fundamental when developing responsive service delivery systems for individuals with CFS. It is one of the most debilitating of all chronic health conditions, affecting virtually every major system in the body including neurological, immunological, hormonal, gastrointestinal and musculoskeletal systems (Friedberg & Jason, 1998). It affects all aspects of life and functioning, including occupational functioning, social functioning, and basic activities of daily living (Anderson & Ferrans, 1997).

The responses of most staff members of the Center for Independent Living were consistent with these findings. Seventy-six percent considered CFS as severe or very severe, and over half (61%) considered it highly disabling. While these percentages reflect an awareness of the severity of the illness and service needs of individuals functionally impaired by CFS, almost one quarter (24.3%) and over one third (38.9%) of the CIL staff did not view CFS as severe or as highly disabling, respectively. Thus, the educational intervention also focused upon educating staff about these functional limitations and about the physical accommodations needed by this population (e.g., specialized transportation services, wheelchairs, scooters, and other assistive devices, personal assistants, meal delivery, housekeeping, economic assistance, vocational rehabilitation).

The long-term prognosis of CFS is a complicated issue and an emerging area of study within the research community. While prognosis depends somewhat on factors like fatigue severity, functional capacity, and illness duration (Hill et al., 1999; Taylor, Jason, & Curie, in press), current research suggests that less than 10% of individuals with CFS report substantial improvement over time (Joyce, Hotopf, & Wessely, 1997). In accord, only 21% of the staff members surveyed thought individuals with CFS were likely or very likely to improve over time. Some reported an impression that CFS is progressive (38%). Given what is known about the prognosis and long-term course of CFS in the literature, these findings did not appear to underestimate the legitimacy of CFS as an enduring disability. Similarly, findings regarding anticipated contagion were expected given that the research is equivocal and relatively little is known regarding this issue.

As a result of the educational intervention, all (100%) staff attendees reported that they learned something about CFS that they had not known before. Most (60%) acquired new factual information about CFS, such as learning the symptoms of CFS, potential causes, and necessary accommodations. Two respondents indicated that the intervention helped modify prior beliefs that the illness was caused by stress. One-quarter of respondents provided responses that indicated increased empathy toward individuals with CFS, such as "... [CFS] is an incredibly serious and life shattering condition. It is devastating." Others (15%) gained an increased general awareness of CFS and were able to see

similarities between their own disabilities or symptoms and CFS.

In addition to these findings, most (67%) staff reported a change in opinion about individuals with CFS as a result of the intervention. Nineteen percent indicated that the intervention changed their prior level of awareness of CFS. Twenty-nine percent reported a change in empathy toward those with CFS (e.g., "I have more of an understanding - a very overwhelming situation."). Another 19% reported a changed awareness of the medical legitimacy of CFS (e.g., "I often wondered about the validity of CFS. I accept it as a valid disability now" or "Coming to the realization that CFS is real..."). One-third of respondents reported no change in opinion about individuals with CFS as a result of the intervention.

Because many findings from this study were gathered before the staff members received the educational intervention, they convey optimism regarding the apparent readiness and competency of Centers for Independent Living to work with emergent, invisible disability populations, including individuals with CFS. The many positive findings might be attributable to a number of factors, including that more than half of the staff knew someone diagnosed with CFS (56%) and had read articles about CFS (51%).

Another explanation for their notable pre-intervention knowledge and empathy regarding CFS might involve the nature of the staff members' occupations. The staff members are disability advocates working to support and empower individuals regardless of the nature of their disabilities.

While most findings from this study are optimistic, continued, controlled research and intervention are necessary in Centers for Independent Living throughout the world to prevent misinformation and stigmatizing attitudes toward individuals with CFS and promote effective outreach to this emergent disability population.

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The corresponding author is Renee R. Taylor, Ph.D. University of Illinois at Chicago, Department of Occupational Therapy (MC 811), 1919 W. Taylor St. Chicago, IL 60612; phone: (01) (312) 996-3412; fax: (01) (312) 413-0256; e-mail: <rtaylor@uic.edu>.

Heather Eisele, B.A., can be reached at DePaul University, Center for Community Research, 990 W. Fullerton Ave., Chicago, IL 60614; phone: (01) (773) 325-2063; fax: (01) (773) 325-4923, e-mail: <heisele@wppost.depaul.edu>.

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