Habitus and the Embodiment of Disability Through Lifestyle

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One aim of disability studies is to accurately portray the experience of persons who live with disabilities. Often this experience generates knowledge that challenges institutional and attitudinal stereotypes. In this study, disability is conceptualized as a measurable space and place characterized by objective differences among groups. Bourdieu’s concept of *habitus* is proposed as a way to understand how a social space is created and maintained by everyday life experience. Linking Bourdieu’s understanding of social space to the sociology of health lifestyles, the paper further proposes that classes of individuals enact individual and collective behavior that respond to life choice and life chance. Using measures from the Craig Handicap Assessment and Reporting Technique clustered to reveal patterns of community participation 2 years after spinal cord injury, the study offers an alternative way for modeling knowledge of disability as embodied categories of action expressed as differentiated health lifestyles.


Persons with disabilities generate specific knowledge about the physical and social self in a social and physical world (Bury, 2000; Kelly, 2001; Peters, 1995). To the extent that this knowledge gives rise to categories of experience and perception that are different from normative experience, this knowledge may be viewed as nonconforming (Eiesland, 1994; Zola, 1991, 1993). Over the past 2 decades, persons with disabilities have begun to give voice to such knowledge, calling into question the preconceptions and limitations imposed by outsiders who try to define and objectify the experience of disability (Cohen, 1994; Hockenberry, 1995; Murphy, 1990; Oliver, 1990, 1996; Zola, 1982).

The profession of occupational therapy has recognized the importance of this narrative knowledge. Evidence of this may be found in the growing interest in ethnographic and autoethnographic research. However, occupational therapists do not yet have either the tools and language to fully comprehend the insider’s perspective of disability nor its implications for the study of disability (Craddock, 1996a, 1996b). This study aims to add another perspective on disability by drawing on insights from the sociology of health lifestyles (Cockerham, Rütten, & Abel, 1997). Based on the work of the French sociologist Pierre Bourdieu (1985, 1990, 1998), the paper argues that lifestyles experienced by persons with disabilities are a type of “habitus” shaped by constellations of personal, physical, social, and environmental factors. These factors create and shape a type of social space that is perceived as “ways of being” in the world (Kelly, 2001). Using data from the Craig Handicap Assessment and Reporting Technique [CHART] (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992) to describe patterns of community participation in persons 2 years after spinal cord injury (SCI), the study offers an alternative way for modeling what Eiesland (1994) has called the “kinesis of knowledge” (p. 37) as embodied lifestyle categories shaped by the interplay of choice and chance.

Knowledge of Disability

Criticisms about professional knowledge and ideas about disability have come from many quarters (Fine & Asch, 1988; Mairs, 1996; Nagler, 1993; Zola, 1993). Two
of the most frequent criticisms are that professionals are outsiders to the lived experience of disability and that the knowledge they produce does not accurately portray the actual experience of the persons they call their patients or clients.

Insider Versus Outsider Perspectives

It is argued that those who work within the medical or rehabilitation system retain an outsider’s perspective on disability (Nagler, 1993; Oliver, 1996). Definitions used by those who work in medical or social institutions not only drive practice, they also influence how persons with disabilities view themselves (Oliver, 1990). Moreover, how the professionals define disability is central to the way they report disability outcomes. For example, the Functional Independence Measure [FIM™] (Keith, Granger, Hamilton, & Sherwin, 1987) relies exclusively on the opinions of professionally trained experts to measure the extent of disability. In contrast, the CHART (Whitney et al., 1992) uses a self-report survey to determine the extent of social participation and community reintegration.

Recognizing the limitations of agendas that rely on objective measurement alone, professionals have broadened their skills both by adopting revised models of practice and exploring alternative ways of conducting research. For example, the past decade has been a time of innovation within occupational therapy scholarship. This has included perspectives that emphasize participation as the goal of therapy, the environment as a critical factor in determining disability, and the importance of client-centered practice (American Occupational Therapy Association, 2002; Christiansen, 1991; Dunn, Brown, & McGuigan, 1994; Fearing, Law, & Clark, 1997; Law & Mills, 1998). The goal of each of these new tools has been to open avenues for persons with disabilities to become collaborative partners in practice (Law & Mills).

Recently, the World Health Organization (WHO) revised the model it uses to describe disability (World Health Organization [WHO], 2001). In 1980, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) proposed a common language for describing long-term effects of disability (WHO, 1980). From the outset, the ICIDH was criticized by members of the disability movement because it modeled disability as a consequence of disease. Moreover, terminology like “impairment” and “handicap” was perceived not only as being unduly negative, but also as adding to the prejudice that fosters oppression of a minority by the group in power (Fine & Asch, 1988; Oliver, 1990). Members of the disabled community argued for changes to the model that could capture the importance of disability and link it to ongoing life experience rather than to core identity (Bury, 2000). WHO’s new model, the International Classification of Functioning, Disability and Health (ICF), attempts to remedy these faults by changing the core concepts of the model from disease to health and from impairment to function (WHO, 2001). The new model is centered around activity, a broad concept that encompasses both the capacity to perform and the method of performing valued life tasks.

Unlike the ICIDH that it replaced, the ICF was conceived to be nonlinear in form to encourage the modeling of multiple interactions with a multidimensional space and allow for multiple pathways to the same outcome (WHO, 2001, p. 16). It is by design both reflexive and recursive. But where within the space it proposes will the embodied “voice” of the insider be heard? That is a question that remains to be answered.

Narrative and Reflexivity

Narrative accounts of disability have also begun to assume more importance in professional research. These accounts often highlight the differences of insider and outsider knowledge (Bury, 2000; Mairs, 1996; Zola, 1982). Primeau (2003) explored the strategy of reflexivity to develop a better understanding of the distance between the perceptions of insider and outsider. Although it is important to use techniques that give voice to the life situation of the subject, the techniques used by qualitative researchers may not go far enough. This is because the subject of study is also involved in a reflexive project of which he or she may be largely unaware.

Reflexivity as a dimension of the embodied experience can be captured by the words of Pierre Bourdieu, “the real is relational” (1998, p. 3). As applied to disability studies, this means that the real embodied experience of being a person with a disability is continuously shaped and reinforced by ongoing interactions with the physical, social, and personal environments. This is the idea that Verbrugge and Jette (1994) convey in their concept of disablement. It is this ongoing reflexive task that Charmaz (1991) captured in the quotation “moment to moment . . . that is the most comfortable way of living and the only way for me. . . . It just seems to be the simplest, the least wear and tear” (p. 228). And it is the same knowledge that Eiesland identifies when she writes “the corporeal is for persons with disabilities the most real . . . we become keenly aware that our physical selves determine our perceptions of the social and physical world” (1994, p. 31). Thus, even the most rigorous qualitative research involves overlapping layers of reflexive knowledge.
Uncontested and Contested Knowledge

In the field of disability studies, the work of Foucault is often used to bolster arguments involving differences between contested perspectives (Foucault, 1975, 1980; Oliver, 1996; Turner, 1995). Foucault's poststructuralist view that the use of power is embedded in the words that one group uses to describe another encourages the view that persons with disabilities are an oppressed minority (Ritzer, 2000). Foucault's insight that those who retain the power to label also have the power to control appears initially to offer hope to those who would study disability. However, Turner (1995) is quick to point out the limitations in Foucault's perspective. Chiefly, Foucault views the body as the outcome of oppressive knowledge rather than as the generator of nonconforming knowledge. As a result, his work does not suggest how the embodied knowledge of what it is to be a person with a disability can be expressed in a form other than discourse or alternative political rhetoric. Thus, Foucault falls short of providing an avenue through which the real experience of disability can be studied.

In contrast, Bourdieu assumes from the outset that all human experience is shaped by a logic of practice continuously generated by a person interacting with his or her life-world (1990). This logic is different from the logic of a logician because it is not the product of mental calculation, nor is it directly visible (1990, p. 86). Instead, it comprises the taken-for-granted knowledge of being. Nevertheless, the effect of this practice can be verified because it is differentiating—that is, it divides people into different groups based on their actions. Bourdieu terms this logic of practice "habitus." Habitus is the product of a person's history, social position, perception, and symbolic mastery (1977). Unlike habit patterns, habitus is not something that can be modified or changed at will. It exists as part of the social structure in which a person defines himself or herself. It is a kind of virtual envelope within which past, present, and future ways of being are held together and embodied. Bourdieu believed that such embodied knowledge was uncontested because it is generated by the actions and interactions of the person himself or herself within the space he or she occupies in the social world (1977, 1990, 1998).

However, habitus does more than direct the researcher to look for classes of people responding to an innate logic. It also assumes the complicity of other actors or classes of actors who make and maintain the field of action (Bourdieu, 1998). In this way, it can be linked back to Foucault's fields of power that shape and define disability. From Bourdieu's perspective, the power to generate habitus remains with the disabled themselves rather than with an outside oppressor. Because the action of habitus is always reflexive, it both creates and refines the very social space in which people act. The inevitable conclusion is that persons with disabilities themselves, in their roles of embodied and knowledgeable actors, construct particular lifestyles and, through these lifestyles, refine social definitions of disability and health.

Health Lifestyle and Disability

The word lifestyle was not introduced into English until the early 20th century (Oxford English Dictionary Online, 1997). Although it is often used to characterize behavior motivated by the desire for status and power (Veblen, 1994), or to characterize the effect of hazardous behaviors like smoking or drinking (Lambert, 1998), lifestyle is defined quite differently in the sociology of health lifestyles. The study of health lifestyles asserts that all people exist within a social space that is created and maintained by lifestyle practices. Thus, it offers an inclusive perspective in which all people find a place. Within the boundaries of this social space, lifestyle groups are differentiated from one another by how they are positioned relative to one another (Abel, 1991). They are maintained in position by how effective they are in appropriating and using the resources necessary for them to maintain health (Bourdieu, 1998). The social space that they occupy is described as:

A multidimensional space of positions such that every actual position can be defined in terms of a multidimensional system of coordinates whose values correspond to the values of the pertinent variables . . . knowledge of the position occupied in space contains information as to the agents' intrinsic properties (their condition) and their relational properties (their position). (Bourdieu, 1985, pp. 724–725)

This knowledge of the intrinsic properties of being (their condition) and the relational properties of being (their position) is knowledge that is inscribed in the body (Bourdieu, 1990).

Cockerham (2000) links lifestyle to collective social practices that divide people into classes based on the options open to them. Lifestyles are shaped by the interaction of two sets of conditions—life choices and life chances (Cockerham, Abel, & Lüschen, 1993). Life choices are propensities for enacting particular behaviors; life chances are the opportunities or constraints for enacting particular choices. Therefore, borrowing from the language of health lifestyles offered by Cockerham, Snead, and DeWaal (2002), one may suggest that the health lifestyles of persons who experience disability are collective patterns of health-related behavior aimed at minimizing the effect of potentially disabling conditions and maximizing the capability for social participation. These lifestyles are created
from options made available to people according to their life chances.

From a health lifestyle perspective, lifestyle and *habitus* are complementary concepts that elucidate each other (Cockerham, 2000). Lifestyles serve as sign systems in which the physical body is transformed into social practices to garner cultural capital (Shilling, 1993; Turner, 2001). What is needed in the study of disability is an approach that can uncover the rules that create differences between lifestyles groups and reveal the strategies and resources that hold them in place. For this purpose, cluster analysis and correspondence analysis have been found useful (Clausen, 1988).

**Analysis of Group Characteristics**

Market research affirms the use of clustering techniques that identify distinct market segments (Green, Schaffer, & Patterson, 1988; Romesburg, 1984). Clustering techniques can be used to classify cases into a manageable number of groups. Then, correspondence analysis can examine characteristics that differentiate one group from another. Correspondence analysis is a type of canonical correlation used to model the relationship between discrete variables (Clausen, 1988). One advantage of correspondence analysis is that it depicts groups as they would exist in multidimensional space, thus lending itself to nonlinear analysis of shared characteristics associated with group membership. The technique does not measure the degree of relationship among variables, but seeks to explore multidimensional data for new patterns or relationships (Weller & Romney, 1990). Bourdieu has recommended the exclusive use of correspondence analysis to model the social space of *habitus* and its relationship to the field of power (1992, 1998).

The remainder of this paper will demonstrate how the foregoing insights about *habitus* and lifestyle can be applied to a particular disability group. It reports the results of a study in which cluster analysis and correspondence analysis were used sequentially to examine lifestyles in 956 cases from the National Spinal Cord Injury Statistical Center (NSCISC).

**Case Example**

SCI can be a severely impairing condition with potential to alter both life choices and life chances. The NSCISC has estimated the incidence of SCI to be 40 cases per million population. Fifty-five percent of injuries occur in young adults less than 30 years of age. This is just the time when people are normally expected to be most active in work, school, establishing a home, or enjoying leisure activities. The NSCISC estimates that there are between 183,000 and 230,000 persons in the United States living with SCI (2001).

The interplay between choice and chance to form lifestyles is relevant in the epidemiology of SCI. This is an injury that occurs disproportionately (81.6%) to males (National Spinal Cord Injury Statistical Center, 2001). Statistics gathered by the NSCISC since 1990 identify the ethnic composition of persons in their data set as 59% white, 27.6% black, and 7.7% Hispanic. More than half (53.4%) are unmarried at the time of injury. Although the majority of persons with SCI have at least a high school education, the education level is generally lower than that of the general population. Twelve percent have educational levels of 8 years or less (Go, DeVivo, & Richards, 1995). When these factors are considered together, they suggest that life-chance factors associated with gender, age, ethnicity, marital status, and level of education may contribute to exposure to SCI. Because these life-chance factors cannot be changed by the individual, they may also have a durable effect on facilitating or constraining lifestyle choices after injury.

**Sample and Methods**

Between the years of 1995 and 2000, the NSCISC collected data from second-anniversary follow-ups with people treated through their system of care. Administration of the CHART assessment was a routine part of the follow-up protocol. Because of reduced federal funding, contacts on the second anniversary were discontinued after September 2000. However, during this 6-year period, data that measured social participation, life satisfaction, and self-perceived health were collected. Over this period, 2,585 second-anniversary contacts were made; of these, 976 cases (37.8%) contained data complete enough for inclusion in this study.

The CHART uses a 27-item interview consisting of five subscales to gather information on community participation (Whiteneck et al., 1992). For the purpose of this analysis, items on the subscales were conceptualized as the building blocks that promote or maintain different types of lifestyle rather than as measures of handicap. The CHART subscales measure physical independence (3 items), mobility (9 items), time spent in occupation (7 items), social integration (6 items), and economic self-sufficiency (2 items). In this study, time spent in occupation was conceptualized as central to the creation of lifestyle differences; physical independence, mobility, and social integration were conceptualized as resources used to construct and maintain lifestyle. Therefore, the variable of occupation (Table 1) was chosen as a grouping factor created by *k*-means cluster analysis. Cluster membership was then reintroduced as a
Results

Table 2 summarizes the overall participation in each of the seven areas of occupation. Three areas, homemaking, recreation, and self-improvement, showed uniformly high levels of participation. Quite a different pattern was seen in the variables of school, work, volunteer work, and home maintenance. Based on these initial findings, it was posited that the study sample as a whole might be composed of three, possibly four, well-differentiated groups. Clusters 1 and 3 accounted for nearly 75% of the study sample, whereas the remaining 25% was divided between Clusters 2 and 4. The occupations that dominated Cluster 1 were homemaking, home maintenance, recreation, and self-improvement (Figure 1). Based on these results, Cluster 1 appeared to be a home-based lifestyle. The activities that differentiated Cluster 2 were nearly the same as those for Cluster 1, but school activities also differentiated this lifestyle (Figure 2). Based on these results, Cluster 2 was identified as a school-based lifestyle. The occupations that differentiated Cluster 3 were volunteer work and paid employment (Figure 3). Cluster 3 was identified as a work-based lifestyle. Cluster 4 showed lower levels of engagement across all areas; its few occupations centered on recreation and self-improvement (Figure 4). Cluster 4 was identified as a leisure-based lifestyle.

During the next stage of the study, lifestyles were examined with correspondence analysis to identify how the resources of physical independence, mobility, and social integration were associated with lifestyle. The advantage of correspondence analysis is that it allows lifestyle and resources to be projected onto a single map as dimensions of unified space. Figure 5 gives an example of how persons practicing different lifestyles experience mobility.

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Table 1. Definitions of Occupational Variables on the Craig Handicap Assessment and Reporting Technique

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Work</td>
<td>Hours per week working in a job for pay</td>
</tr>
<tr>
<td>School</td>
<td>Hours per week spent in school working toward a certificate or an academic degree</td>
</tr>
<tr>
<td>Homemaking</td>
<td>Hours per week spent in homemaking activities such as parenting, housekeeping, and food preparation</td>
</tr>
<tr>
<td>Home Maintenance</td>
<td>Hours per week spent in yard work, house repairs, or improvements to the home</td>
</tr>
<tr>
<td>Volunteer Work</td>
<td>Hours per week spent in ongoing volunteer work</td>
</tr>
<tr>
<td>Recreation</td>
<td>Hours per week spent in recreational activities such as exercise, sports, playing cards, or going to the movies (excludes watching television or listening to the radio)</td>
</tr>
<tr>
<td>Self-Improvement</td>
<td>Hours per week spent in activities such as hobbies or leisure reading (excludes watching television or listening to the radio)</td>
</tr>
</tbody>
</table>


Table 2. Participation in the Seven Areas of Occupation at Year 2 (N = 976)

<table>
<thead>
<tr>
<th>Occupational Area</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>191</td>
<td>19.6</td>
</tr>
<tr>
<td>School</td>
<td>149</td>
<td>15.3</td>
</tr>
<tr>
<td>Homemaking</td>
<td>666</td>
<td>68.2</td>
</tr>
<tr>
<td>Home Maintenance</td>
<td>368</td>
<td>37.7</td>
</tr>
<tr>
<td>Volunteer Work</td>
<td>129</td>
<td>13.2</td>
</tr>
<tr>
<td>Recreation</td>
<td>816</td>
<td>83.6</td>
</tr>
<tr>
<td>Self-Improvement</td>
<td>787</td>
<td>80.6</td>
</tr>
</tbody>
</table>

Figure 1. Profile for a home-based lifestyle (N = 414). Percent of the cluster who report engagement of at least 1 hour per week.

Note. Value = zero.
12 hr in recreation, and 10 hr in hobbies or self-improvement activities.

A small proportion of this group was employed (3.3%), and a smaller proportion was in school (1.6%). One distinguishing feature of this lifestyle was lack of participation in volunteer work. As a group, they were less likely to use high levels of physical assistance from paid or unpaid sources. Although they were more likely to spend 2 to 4 days at home each week, they maintained contact with 1–6 business associates, relatives, or friends. They were also more likely to have 1–4 contacts with strangers each week. Two years after injury, 42.4% of the sample practiced this lifestyle.

The school-based lifestyle. The median annual household income of those who reported a school-based lifestyle was $24,900. As compared with other groups, persons in this lifestyle spent more time in education, and less time in work. In school-based lifestyles, people were more likely to engage in volunteer work, and less likely to use high levels of physical assistance. They maintained contact with 1–6 business associates, relatives, or friends, and had 1–4 contacts with strangers each week. Two years after injury, 42.4% of the sample practiced this lifestyle.
likely to use transportation independently. They were also more likely to enter or exit the home independently and more likely to leave the house more than 5 days a week, to enter and exit without help, and to use transportation. They also were more likely to maintain five or more social contacts each week with friends, and an equivalent level of contact with relatives and strangers. Two years after injury, 12% of the sample practiced a school-based lifestyle.

The work-based lifestyle. The median annual household income for those who practiced a work-based lifestyle was $40,000. The profile for this group showed that, compared with other groups, they were more likely to have attended college prior to injury. Seventy-eight percent engaged in paid employment. They also engaged in volunteer work (41%) and did work to maintain the house (94%). During the average week, they spent 28 hr in employment, 16 hr in homemaking, 9 hr in recreation, and 8 hr in self-improvement. Fewer than 10% attended school. They were less likely to use help from paid or unpaid sources. They were more likely to enter or exit the home independently and more likely to use transportation independently. They were also more likely to leave the house 6 or 7 days a week. They had the highest levels of contact (7+) with business associates. However, they were less likely than the school-based group or the home-based group to have frequent and varied contact with friends, relatives, and strangers. Fourteen percent of the sample could be identified as practicing a work-based lifestyle that included paid or volunteer work.

The leisure-based lifestyle. The fourth lifestyle differs markedly from the others, showing less variety in types of occupation, less mobility, and lower levels of social contact. The median annual household income of those practicing a leisure-based lifestyle was $15,600, the lowest of any of the lifestyle groups. The lifestyle profile for this group showed that, compared with other groups, they were more likely to have been unemployed or not in school when injured. They were more likely to be black. They were more likely to be older when injured. The only occupations they reported with any frequency each week were recreation (6 hr) and self-improvement (8 hr). They were more likely than all other groups to use more than 4 hr of paid or unpaid assistance. They were less likely to use transportation independently, less likely to enter or exit the home independently, and less likely to leave the house more than 2 days a week. They were likely to have one to two contacts with friends and relatives each week, have no contact with strangers, and have no business associates. Two years after SCI, nearly one third of the sample (31%) could be identified as practicing a leisure-based lifestyle.

Discussion

The experience of 976 persons with SCI shows that distinct lifestyle types are evident 2 years after SCI. Intuitively, it seems obvious that life chances limit some life choices. This same pattern is reported in the health lifestyles literature (Cockerham, 2000; Cockerham et al., 2002). Those who were unemployed at the time of injury would be less likely to enter the workforce within 2 years when compared with other groups. Thus the leisure-based group, with their associated life-chance differences, shows a constraining life-chance effect on the life choices of mobility, physical independence, and social contact. Similarly, the younger school-based group shows a profile in which age and previous school enrollment sets up a different lifestyle pattern.

Bourdieu (1998) suggests that one’s position in social space generates and maintains cultural capital. In this regard, it is easy to see how youth, ethnic background, and previous life experience may work together with mobility, physical independence, and social integration to create different embodied experiences of disability. It might be tempting to assume that some of these lifestyles could be transitional; that is, the volunteer work reported by the school-based participants might provide an entrance into the job market, or the home-based lifestyle might represent a temporary time out from future work-based or school-based activities. However, these second-anniversary contacts represent only one moment in time. There is no evidence to either support or refute the durability of the lifestyle types suggested in this analysis. Nevertheless, therapists may recognize the “story” of each lifestyle as consonant with their own clinical experience of the clients with whom they interact. This lends face validity to these styles as general typologies.

The methods suggested in this paper answer Bury’s plea for a “mid-range approach between a wounded story teller and an overly politicized conception” (2000, p. 182). However, it is important to remember how easily typologies can turn into stereotypes. No inference should be made that these four lifestyle types exist except in relation to each other (Bourdieu, 1985, 1992, 1998). This is in
keeping with Bourdieu's insights about the reflexive and differentiating nature of habitus. By no means should acknowledgment of these hypothetical lifestyle classes be used to reward or punish those who create them. At its best, lifestyle must remain a value-free concept. This study of each of the four groups offers a tangible record of embodied life experience, and each lifestyle deserves to be honored for its own integrity.

On the other hand, this paper does suggest that the story of persons with disabilities can be read in the patterns of how they respond to life chances and use resources to create the lifestyles that promote health. Although the terminology used instruments like the CHART may still retain some degree of an outsider bias (Bogden & Biklen, 1977; Fine & Asch, 1988), this gives all the more reason to refine existing tools and explore new methods based on the insights offered through the health lifestyles approach. What persons with disabilities do in their daily lives constructs the experience of disability. This knowledge is uncontestable because it arises from an innate logic of practice that is used both by individuals and by groups. By accepting this as true, professionals will begin to view persons with disabilities not as an oppressed minority whose future is shaped by a discourse they do not control, but as those who embody their own discourse and teach it to others.

Acknowledgments

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Endnotes

1Since 1991, two issues of the American Journal of Occupational Therapy have been devoted entirely to the topic of qualitative research (see volume 45, issue 3, and volume 57, issue 1). In addition, therapists including Shirley Carr (1991) and Ann Neville-Jan (2003) have recounted stories of the disabling effects of their own conditions.

2Recent revisions to the CHART have made this list more descriptive and more sensitive to multiple life roles. The current study was completed when the initial form of the CHART was used by the NSCISC.

References


