From Dependency to Self-Advocacy: Redefining Disability

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Assumptions About Disability


1. It is often assumed that disability is located solely in biology, and thus disability is accepted uncritically as an independent variable. The disability and the person are assumed synonymous, and the cause of others' behaviors and attitudes" (p. 108). Fine and Asch contended that disability is portrayed as the variable that predicts the outcome of social interaction when, in fact, social contexts shape the meaning of a disability in a person's life. Thompson (1982), in reviewing the literature about interactions between persons without disabilities and persons with disabilities, found that these interactions are characterized by anxiety, discomfort, and inhibition. Most persons without disabilities have a predisposition to negatively evaluate persons with disabilities and to have difficulty communicating with them. Thompson then discovered that when children without disabilities were shown pictures of a child with a physical disability (e.g., using crutches or wearing braces), the children without disabilities often assumed the presence of another disability in addition to the one represented in the picture. There was an overall assumption of inferiority in their communicative responses to the pictured children.

2. When a disabled person faces problems, it is assumed that the impairment causes them" (Fine & Asch, 1988, p. 9). The disability is assumed, for example, to prevent a person from securing employment or from going to a restaurant. The person's biological limitations are viewed as being the obstacle rather than the human-made bar-

Attitudes and perceptions about disability are formed during interactions with others and through observation of our environment. Many persons equate disability with dependency, helplessness, and imprisonment. Others embrace the concept of independent living, in which people with disabilities are viewed as self-reliant consumers whose autonomy is not adversely affected by their need for assistive devices or other supports (Denson, 1988). While some persons with disabilities place their hopes in the prospect of cure and recovery, others contend that "rights are more important than cure" (Johnson, 1992b, p. 27).

Throughout this review it is assumed that it is preferable for persons with disabilities to view themselves as being consumers (not patients), adults (not perpetual children), capable of independent living with supports (not in need of institutionalization), contributors to society (not burdens), self-directed (not controlled by others), in need of personal assistance services (not caregiving), and in need of rights (not cures). It is also assumed that learned helplessness is a result of the attitudes of society toward people with disabilities and that a change in attitudes is needed.

This article explores the mechanisms by which people with disabilities redefine the meaning of disability. Policy makers who participated in developing the Americans with Disabilities Act of 1990 (ADA) (Public Law 101-336) redefined disability to one another as they collaborated to write regulations providing access to employment, public transportation, public accommodations, and telecommunications. During the process of implementing these regulations, there is opportunity to change the meaning of disability from one that focuses on limitations in certain social and environmental contexts.

Occupational therapists can play an active role in the redefinition of disability by examining their own attitudes and communication about disability and by becoming advocates who facilitate changes in the environment that increase opportunities for persons with disabilities.
rriers of architecture, discriminatory work practices, or social limitations that are common to all people.

The Arkansas Research and Training Center in Vocational Rehabilitation (1990) cited work by Gerben, Dejong, and others that compares the traditional rehabilitation paradigm with the independent living paradigm (see Table 1). In the traditional rehabilitation paradigm, the “definition of the problem” is listed as “physical or mental impairment, employability skill deficits, functional limitations, and lack of motivation and cooperation” (p. 65). In contrast, the independent living paradigm defines the problem as being “dependence on professionals, relatives, etc., inadequate support services, architectural barriers, and economic barriers” (p. 65). The locus of the problem is traditionally seen as being in the person with a disability. In the independent living paradigm, the locus of the problem is in the environment and in the narrow “professional” attitudes promoted by the rehabilitation process.

“3. It is assumed that the disabled person is a ‘victim.’” (Fine & Asch, p. 10). Outsiders may view an acquired disability primarily as a tragedy, whereas insiders state that they fare better than they would have expected. Fine and Asch pointed out that researchers do not use positive statements made by persons with disabilities to reframe their notions about how people think about traumatic events. Rather, they tend to interpret such statements as indicating the use of psychological defenses (e.g., being in denial) to manage what the researchers assume is not a manageable situation. Some authors presume that the disability itself is the victimizing experience, instead of the reactions or deprivations that people experience because of social responses to their disability.

Disability rights activists contend that the image of the person with a disability as a victim is perpetuated by fund-raising efforts such as telethons. Persons with disabilities are made out to be “nothing more than pathetic burdens to society, whose only desire is to walk” (Johnson, 1992c, p. 5). Activists believe that fund-raising organizers emphasize the victim view of disability to arouse guilt in potential contributors. It is hypothesized that contributors give money because they want to make the persons with disabilities like themselves—not disabled anymore. Johnson pointed out that contributors are less likely to want to help people to be “equal and remain disabled” (1992a, p. 42). Therefore, funds are more often directed toward cures than toward independent living.

The damage done to persons with disabilities when they are portrayed as victims is immeasurable. Children may learn to depend on their benefactors as their only thread of hope, and may grow up believing they cannot live independently or work unless they are cured first. People are expected to be stuck in an eternal mourning period because they do not look or move like everyone else. Instead of taking the victim view, disability rights activists are advocating for society to give them what they need to live with their disabilities. “Rather than regret the unchangeable fact that we can't wash or dress ourselves, why not join in pressuring our government to provide funding for someone to do such tasks for us . . . ?” (Hershey, 1992, p. 28).

“4. It is assumed that disability is central to the disabled person's self-concept, self-definition, social comparisons, and reference groups” (Fine & Asch, p. 11). Persons with disabilities are presumed to make downward social comparisons to preserve their self-esteem, or to search for persons with similar disabilities with whom to compare themselves. Thompson (1982) cited Goffman as arguing in 1963 that even stigmatized persons discriminated against others who appeared to belong to the same group. This discourse is perpetuated by media images of persons with disabilities, which are often used to insinuate that all persons with disabilities are similar.

### Table 1

<table>
<thead>
<tr>
<th>Item</th>
<th>Traditional Rehabilitation Paradigm</th>
<th>Independent Living Paradigm</th>
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<tr>
<td>Role of person with disability</td>
<td>Patient/Clien</td>
<td>Consumer</td>
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<tr>
<td>Role of service</td>
<td>Professional</td>
<td>Peer Consultant and role provider model</td>
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<td></td>
<td>Prescriber and manager of treatment</td>
<td>Helper and advocate</td>
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<td></td>
<td>Controller of access to services Diagnostian</td>
<td>Mentor</td>
</tr>
<tr>
<td>Definition of problem</td>
<td>Physical or mental impairment Employability skill deficits Functional limitations Lack of motivation and cooperation</td>
<td>Dependence on professionals, relatives, etc., inadequate support services Architectural barriers Economic barriers</td>
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<tr>
<td>Locus of problem</td>
<td>In the individual with a disability</td>
<td>In the environment</td>
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<td>In the medical model, the rehabilitation process and the narrow “professional” attitudes they can promote</td>
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<td>Solution to problem</td>
<td>Intervention by rehabilitation professional Evaluation and training Home and job site modification</td>
<td>Peer counseling</td>
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<td>Advocacy</td>
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<td>Consumer control</td>
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<td>Removal of community barriers and disincentives</td>
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<td>Who has ultimate control</td>
<td>Professional</td>
<td>Consumer</td>
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<tr>
<td>Desired outcomes</td>
<td>Maximum activities of daily living (ADL) Gainful employment Psychological adjustment Improved motivation Completed treatment</td>
<td>Self-direction</td>
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<td>Least restrictive environment</td>
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<td>Productivity (social and economic)</td>
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Note: Based on the work of several authors, including Gerben and Dejong (1981, p. 31). Reprinted with permission from Vocational Rehabilitation Services in Independent Living Centers (1990). Hot Springs, AR, Arkansas Research & Training Center in Vocational Rehabilitation.
Redefining Disability

Scotch (1988) discussed barriers to political activism faced by persons with disabilities. A prerequisite to such activism is "a redefinition of disabilities as impairments that are limiting only to the extent that constraints are imposed in the physical and social environment" (p. 166). Hahn (1985) identified three distinct definitions that have been used in the formation of government plans and programs for persons with disabilities.

The medical definition emphasizes limitations on physical functioning. "From a medical perspective, disabilities are treated as separate diagnostic categories rather than concentrating on the common problems of disabled people" (Hahn, 1985, p. 88). Liggett (1988) described the postivist view of the politics of disability, which is similar to the medical definition. In this view, "disability presents itself as a problem of definition. The issue becomes one of indicating the relevant physical impairment" (p. 264). Liggett pointed out that this view makes disability into a scientific problem, which leads to a search for more precise information, which then leads to recommendations for reform based on increased monitoring of persons with disabilities. Liggett asserted that this approach creates a society of perpetual assessment and further separates and causes distinctions between persons with and without disabilities.

The medical model encompasses a concept of the sick role, which requires patients to surrender their autonomy to professional direction and devote all of their efforts to complete recovery. Several disability groups have used the term medicalization of life to describe the practice of professionals trying to control the lives of persons with disabilities. Biklen (1988) pointed out that persons with disabilities are often regarded more as perpetual patients or clinical subjects than as objects of discrimination. From the medical definition perspective, "the problems of disability arise from physical flaws within a person rather than from defects in an adaptive environment or society, and solutions to these difficulties must be sought primarily through individual rather than collective efforts" (Hahn, 1985, p. 89). The medical orientation has therefore imposed growth of a unified social and political movement of citizens with disabilities.

Another definition of disability described by Hahn is the economic definition. Instead of emphasizing physical functioning, this approach suggests that a disability can be described as a health-related limitation in the amount or kind of work that can be performed. The application of the economic definition to policy decision making has resulted in problems in vocational rehabilitation programs, in the disbursement of Social Security Income and Social Security Disability Insurance, and in policies that are plagued by disincentives that discourage recipients from seeking rehabilitation and regular employment.

Hahn believes that the basic problem is the assumption, embedded in most rehabilitation and disability policies, that the ability to work is determined principally by a person’s functional capacities. "Most rehabilitation programs are designed primarily to effect a modification of the disabled individual rather than an alteration of the environment — or the workplace — in which (s)he may be located" (Hahn, 1985, p. 91). Little consideration has been given in the past to the possibility of altering job expectations to accommodate the needs and skills of employees with disabilities. Title I of the ADA has now addressed this issue, requiring that, as of July 26, 1992, employers with 25 or more employees must provide reasonable accommodation for employees with disabilities who need it to perform the essential functions of their job.

Hahn offered the new sociopolitical definition of disability as an alternative to the medical and economic concepts. Fundamentally, Hahn stated, "this model implies that disability stems from the failure of a structured social environment to adjust to the needs and aspirations of disabled citizens rather than from the inability of a disabled individual to adapt to the demands of society" (1985, p. 93). Therefore, the devaluation of persons with disabilities has not resulted from a lack of productivity or from their alleged biological inferiority. On the contrary, this inequality has resulted from society’s reluctance to recognize the dignity and worth of these human beings or to grant them civil rights as members of a political community.

The sociopolitical definition is compatible with Liggett’s interpretative view of the politics of disability (1988). Liggett explained that meanings are produced during human interactions and that language practices work to produce disabled identities. Disability can appear or disappear as an identity, depending on context or social conditions. The medical and economic definitions are based on professional assessments, but the new sociopolitical definition of disability is derived from the concrete experiences of persons with disabilities and the discourse in and about those experiences.

If meaning arises out of the process of interaction between people, then it is essential that persons with disabilities become connected with one another against other stigmatized persons, satisfying themselves according to the degree to which their stigma is apparent and obtrusive. In contrast to this view, Fine and Asch pointed out that a "woman who is paralyzed may be as likely to compare herself with other women her age, others of her occupation, others of her family, class, race, or a host of other people and groups who function as reference groups and social comparison groups for her" (p. 12).
other to establish their own meanings and expectations for themselves, communicate with persons without disabilities about their life experiences, and organize themselves as a group to open new avenues for interaction with policy makers.

Persons With Disabilities as a Minority Group

Disability rights activists have explicitly and implicitly identified themselves as a minority group. Several authors have alluded to the usefulness of this distinction to increase political power for achieving equal rights for persons with disabilities.

Those who seek more independence in their lives often find their efforts stifled by limited physical access, social rejection, and insufficient economic support. Such conditions exemplify the meaning of marginality: People with disabilities are institutionalized, segregated, and undereducated, physically excluded from public places, and underemployed. Any other group subjected to these circumstances would most likely be characterized as a minority. Yet the more common tendency has been to view people with disabilities as (a) victimized by a disabling condition and (b) in need of treatment—not of rights. (Biklen, 1988, p. 128)

Biklen has maintained that this perspective keeps the person with a disability from being seen as a minority group member. Hahn (1988) agreed, stating that "a principal problem in establishing the concept of disabled persons as an oppressed group has been the prevalent assumptions of their biological inferiority" (p. 41). Johnson (1992c) quoted Herschey as stating:

The disability rights approach views disability as a natural phenomenon which occurs in every generation, and always will. It recognizes people with disabilities as a distinct minority group, subject at times to discrimination and segregation. . . . But also capable of taking our rightful place in society. From this perspective, people have rights, which society must guarantee. (p. 7)

The idea of acceptance of persons with disabilities as a minority group is as entwined with discussion of civil rights as it is with redefining disability. Scoch (1988) asserted that ensuring access to public buildings or public services may be viewed either as a social welfare benefit or as a civil right. The former connotes dependency and implies that persons with disabilities must earn the approval of their providers by conforming to their expectations. Help is given as a qualified and grudging form of aid. Scoch further notes that "providing access as a welfare benefit invites rationing of accessibility, for welfare is typically given and withdrawn based on the limits of generosity of the giver rather than according to the needs of the recipient" (p. 169). When access to societal institutions is defined as a right, it becomes virtually unconditional. Fine and Asch (1988) maintained that if persons with disabilities were perceived as having the same rights to mobility and life's opportunities as persons without impairments, we would be compelled to rethink the view that access is a gift or charity that can be withdrawn when things are tight.

Hahn (1985) went a step further in declaring that civil rights issues should not be based on economic analysis of disability. Analysts who assume that full equality is not economically feasible seek to transform a question of rights into a problem of economic calculation. "Missing from this equation is a recognition that the existing environment produces undue advantages for the nondisabled as well as disadvantages for disabled citizens" (p. 98).

Disability rights activists who have been involved in political action and those who write for leading disability rights publications have adopted the minority group approach and are working to redefine disability in a manner similar to Hahn's sociopolitical perspective. Their efforts have culminated in what is known as the independent living (IL) philosophy, upon which Centers for Independent Living (CILs) are based.

Independent Living

Denson (1988) described Independent Living as "a concept, a policy, a set of community based services and programs, and a civil rights movement" (p. 12). Independent living is "the freedom to participate in the community fully and to have access to housing, transportation, health care, employment, and education. . . . IL is reflective of a self-determined and self-directed lifestyle which permits the individual to make meaningful choices and solutions" (p. 12).

The history of IL as a consumer movement, according to Denson, is based on the efforts of persons with disabilities seeking their rights in society. The values of the movement are consumer sovereignty, self-reliance, and political and economic rights. Persons with disabilities (consumers of services), not professionals, are the best judges of their own interests and are best qualified to organize and operate their own programs. Consumers "must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled" (Denson, p. 13).

All Centers for Independent Living are expected to provide essential core services that include a specified range of community development services and direct consumer services. Community development services include "community needs assessment, interagency coordination, systems advocacy for needed community change (especially the development of needed services resources), technical assistance, public information and education, outreach, and community initiatives" (Hayworth & Monoghan, 1992, p. 2). Direct consumer services include "Information and Referral, Peer Consultation, Individual Advocacy, and IL Skills Training, as well as other services determined to be locally appropriate" (Hayworth & Monoghan, p. 2).

The Rehabilitation Act of 1973, as amended in 1978 (PL. 95-602), directly supports independent living. Section 504 of the Act established that it was illegal for persons with disabilities to be excluded from any program receiving federal financial assistance. Section 503 prohibited job discrimination because of a handicap. In 1978, comprehensive services for independent living were mandated under Title VII of the Rehabilitation Act. Consumer participation was mandated in all aspects of independent living programs. For the first time, vocational rehabilitation services were expected to extend beyond traditional counseling into housing and other services that would enhance the ability of a person with a disability to live independently. Also in Title VII, funds were allocated to provide services to persons with severe disabilities who may not be regarded as having potential for employment.
was still "necessary to make laws to mandate citizen access and participation" (Denson, 1988, p. 14). Opportunities were available to persons with disabilities, but they were often inaccessible.

The ADA focuses on accessibility. The language of the ADA establishes Americans with disabilities as members of a minority group who "continually encounter various forms of discrimination, including outright intentional exclusion" (ADA, Sec 2, Findings and Purposes) due to societal barriers. The ADA mandates the elimination of discrimination in employment, public transportation, public accommodations, and telecommunications. By placing its emphasis on environmental accessibility, the ADA contributes to the redefinition of disability.

Disability rights activists emphasize the importance of the community development obligations of CILs. Some CILs become too involved in providing services to individual consumers because it is easy to get funding that way. Roberts (1992) stated, "More important than being service providers is being advocates" (p. 23). However (1992) agreed, stating, "There is often a tendency to advocate on behalf of a consumer, without engaging him or her in the process... this approach encourages continued dependence, which is contrary to the CIL philosophy" (p. 1). Advocacy is needed on the individual level, the group level, and the systems level. Mistrer (1992) warned, "When you don't do systems advocacy, there's not enough time, there's not enough money. There's no way you can serve everybody in your community who's up against the system" (p. 25).

Advocacy Skills Training

Balcazar, Seekins, Fawcett, & Hopkins (1990) defined empowerment as being "the process by which people gain more control over decisions that affect their own lives" (p. 282). Group advocacy has been an important feature in the empowerment process. Advocacy organizations have served as important mediating structures between individual causes and proposals and governmental responsiveness. Additionally, by being involved in advocacy activities, people can develop a critical world view during their struggles and come to believe in their own ability to act.

Darling (1988) provided insight into the process by which persons with disabilities develop their own advocacy skills. Darling discussed parental entrepreneurship on behalf of a child with a disability and the process by which the parent talks to himself or herself about the meaning of the child's disability, then decides on what actions to take. The information presented can be applied to persons who themselves have disabilities. Regarding the adoption of the role of parental entrepreneur, Darling stated, "As with other social roles, this role is learned through interaction with others" (p. 141).

According to Darling, parents often begin with a lack of experience with disability and a specific set of values and expectations about parenting that do not include disability. They have been socialized to respect the authority of the professional, and they often submit to professional dominance. They are in a state of anomie (uncertainty and lack of definitional clarity) and meaninglessness that is often caused by information control by professionals. Parents experience powerlessness, because professionals control not only information about the diagnosis of their child's disability but also the treatment.

Darling identifies turning points, which are interactions that push parents away from complacency and pull them toward increasing involvement in movements for social change. These turning points include (a) interactions with familiar significant others (expressing both unhelpful and helpful attitudes); (b) acute, painful experiences (as in situations of medical error or of blatant discrimination); (c) interactions with new significant others (such as members of a parent group); and (d) media experiences (newspapers, magazines, and television).

The socialization of parents into the entrepreneurial role, according to Darling, occurs through three main avenues. First, parents engage in intense interaction with elders and new significant others. Darling believes parents "become increasingly committed to activist goals after frequent, intense, and long exposure to parents who have already internalized those goals" (p. 154). Second, parents evolve into activist roles through trial and error, learning from experience. After successfully challenging an authority, they are more likely to try again. Third, parents learn the activist role through formal training. Formal courses in advocacy might include training in demonstrating, letter writing, lobbying, and community education. Formal training might also include the use of books and manuals on topics such as legal rights and assertiveness.

Balcazar et al. (1990) listed some of the skills that are included in curricula that have been developed to train citizens to become effective advocates. "They include skills such as personal leadership, group management, problem solving, identification and discussion of community issues, negotiation, knowledge of the political power structure and parliamentary procedures, and knowledge about how to use local resources" (p. 282).

The Role of Occupational Therapists in Redefining Disability

The Michigan Department of Education/Michigan Rehabilitation Services Independent Living Source Notebook (Hayworth & Monaghan, 1990) lists independent living occupational therapy services as one of six basic consumer services offered by Centers for Independent Living. (The other five services are telecommunication device for the deaf [TTD] relay, information and referral, case management, peer services, and skills training.) Occupational therapists can contribute to the redefinition of disability by examining their work practices with consumers and striving to operate within the independent living paradigm, as opposed to the traditional rehabilitation paradigm (see Table 1). The therapist in the independent living paradigm is a consultant, helper and advocate, rather than a diagnostician or a prescriber and manager of treatment. The consumer is or becomes self-directed, and both the consumer and the occupational therapist work to remove community barriers and disincentives.

This paradigm could involve an uncomfortable shift for occupational therapists who work in settings in which they are expected to provide direct services to large numbers of consumers, especially when fees for service are involved. Advocacy can be time consuming and therapists may believe they do not have
the time to spend on such community-based services as the availability of personal assistance services or accessible and affordable housing. Yet these are the types of services that empower persons with disabilities and redefine the meaning of disability. As consumers become self-reliant, they may become advocates and consultants for their peers. As they experience success in their new roles as personal advocates, they may be able to move to systems advocacy, potentially affecting public policy decisions. The presence of a self-reliant consumer in the community has more effect in redefining disability and changing public policy than the presence of an occupational therapist without disability advocating on behalf of consumers.

Occupational therapists may need to educate themselves in order to feel prepared for advocacy training. They may do so by reading disability rights publications, such as Disability Rag, This Brain Has a Mouth, or newsletters published by Centers for Independent Living. Occupational therapists may also redefine disability for themselves by becoming involved with local disability rights groups and developing friendships with people with disabilities who view disability from an independent living perspective. They may further educate themselves by studying state and federal civil rights legislation for people with disabilities and by confronting and educating people in their community who are not in compliance with those laws. This is an important step in the empowerment process. When an occupational therapist has experienced success with facilitating a change in his or her community, the therapist will gain confidence in his or her ability to be an advocate for persons with disabilities. This experience will give the therapist a personal sense of the process by which consumers become empowered.

Finally, occupational therapists can contribute to redefining disability by facilitating interaction between persons with disabilities, the general public, and public policy makers through avenues such as disability rights newsletters, advocacy groups, peer consultation, candidate forums, and hearings dealing with disability rights issues. These suggestions for occupational therapists are by no means complete. They are intended to illustrate the need for occupational therapists to educate themselves about their own attitudes and behaviors with respect to disability rights. Therapists are reminded to be aware that they are continuously redefining disability to themselves and to others by their actions and in their oral and written communication about disability.

Summary

People continually redefine the meaning of disability for themselves through interaction and interpretation. Negative assumptions about disability result in low expectations for persons with disabilities and contribute to policies that keep them in isolation and out of the mainstream of life. Disability rights activists have begun to strip away some of these old stigmas and assumptions by redefining the meaning of disability to themselves and to others, and by organizing themselves into groups for purposes of discussion, education, and protest. Their efforts have resulted in improvements in attitudes about and opportunities for persons with disabilities. They need to remain vigilant to maintain the rights they have won, as well as to address new issues.

Those who are interested in equal opportunities for persons with disabilities need to become advocates. Persons with disabilities learn to advocate for themselves through interaction with others who are committed to activist goals. They also learn through trial and error, gaining strength as they experience success, and they learn through formal advocacy training. Occupational therapists can actively contribute to the redefinition of disability through self-reflection and through advocacy training.

References


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