

**“SIMPLY TO BE LET IN”:
INCLUSION AS A BASIS
FOR RECOVERY***

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*THIS IS A REVISED VERSION OF AN INVITED KEYNOTE ADDRESS TO THE 9TH ANNUAL MENTAL HEALTH SERVICES CONFERENCE OF AUSTRALIA AND NEW ZEALAND. “WHOSE DREAMS? WHOSE REALITIES?” SEPTEMBER, 1999, MELBOURNE, AUSTRALIA.

This article takes its inspiration from a poem by Borges, in which the author makes a plea to simply be “let in” without being wondered at or required to succeed. Based on the view that these issues have applied historically to people with mental illnesses—first during the period of the asylum, and now more recently as a result of deinstitutionalization—this article argues for the adoption of a broad conceptual framework of inclusion that, based on a disability paradigm, neither alienates or requires people to succeed. First, the ways in which such a framework augments existing approaches to treatment, rehabilitation, and recovery are outlined. Next, the authors describe the three elements of friendship, reciprocity, and hopefulness as aspects of inclusion that may provide a foundation for efforts toward recovery, and illustrate each of these elements through the stories of participants in a supported socialization program. Implications for future research and policy are suggested based on these data.

This is the best that can happen –
what Heaven perhaps will grant us:
not to be wondered at or required
to succeed
but simply to be let in
as part of an undeniable Reality,
like stones of the road, like trees.

–J.L. Borges,
from *Fervor de Buenos Aires*,
1923/1972

The inspiration for this article comes from the above poem by Borges. Although not addressing mental illness directly, this poem is relevant to the issue of recovery in a number of ways. Specifically, this poem speaks to the ex-

periences and desires of individuals with mental illnesses, both in our tragically regrettable past as well as—we can hope—looking toward a more promising future. First, it is well documented by Foucault (1965) and others (Johnson, 1990; Scull, 1981) how people with mental illnesses, from the Middle Ages to the beginning of the 19th century, were treated as sideshow freaks during their confinement in jails, poor houses, and alms houses through the early days of the asylum. During this period people with mental illnesses were for the most part, in Borges’ terms, “wondered at.” In fact, tickets were sold to the gentry who wanted to spend their Sunday afternoons traveling out to the country-

side to stare, gawk, and muse over the “insane” in their rags, chains, cages, and otherwise stable-like accommodations. During the year 1815 for example, Foucault (1965, p. 68) estimates that there were 96,000 Sunday visits to Bethlehem Hospital alone, for which each visitor paid a penny to see the “lunatics” exhibited by hospital staff.

Ordinarily, we like to believe that these dark days in the history of psychiatry, along with the equally dark days of the 150 years of institutionalization that followed, came to an end with the downsizing and closure of large state hospitals. Despite the best intentions of deinstitutionalization, however, we would suggest that people with severe mental illnesses, from the 1950s to the present day, have instead entered into a period in which they are, again in Borges’ terms, “required to succeed” in order to have their dreams for dignified lives in the community fulfilled. By this, we mean that we have required people to be in remission from the symptoms of their illness before they have been allowed access to normative adult activities such as living independently, completing their education or being gainfully employed, or having mutual, caring relationships. Deinstitutionalization has yet to succeed in “letting people in” insofar as many people with mental illnesses continue to live out the majority of their lives within the artificial settings of community-based programs.

Most community-based programs certainly offer a fate better than lying in soiled clothes in a bed of hay and being stared at through bars by wide-eyed children as if one was an exotic animal in the zoo. A life restricted to what may be considered the psychiatric “ghetto” of community-based programs, however, was neither the dream of the crafters of the deinstitutionalization legislation, nor, we would suggest, is it the dream of most people with mental illnesses. In the vocational arena, for example, a re-

view of outcome studies among individuals with mental retardation found that the average time people spend in pre-vocational activities such as assessments and sheltered workshops *prior* to beginning a job was 47 years (Bond, 1992). A staggering statistic in its own right, this number actually may prove overly optimistic for individuals with mental illnesses, as data consistently have shown that mental illness is associated with the lowest employment outcomes among various disabilities (Drake et al., in press; Marshak, Bostick & Turton, 1990). It is no wonder then why, in their criticism of some community-based services such as prevocational training, peer advocates have come to the conclusion that “pre” actually means never. Experiences with these programs suggest that we expect people to have to stop being psychotic before they can get a job, to have to be more stable before they can return to school, and to have to manage their money better before being ready to live on their own. Given that severe mental illnesses are long-term conditions, and given that there can be an infinite variety of such “have to’s” thrown before people before they reach some elusive ideal of normality (an ideal that most people who do not have psychiatric disabilities also never reach; Davidson & Strauss, 1995; Deegan, 1992), most people with serious mental illnesses have yet to be able to participate in the natural and ongoing rhythms of community life—the dream of deinstitutionalization. Why have we failed to fulfill this dream? And what can we do about it now, almost a half-century later?

In the following, we first describe some of the ways in which the community support approach (Parrish, 1989) of the last 25 years has fallen short of fulfilling the dream of community reintegration. Next, we describe an alternative vision of mental illness as a psychiatric disability and its implications for social policy. Although not offering a perfect analogy

for mental illness, a disability model offers a few insights about elements of inclusion that we suggest push beyond the boundaries of conventional clinical practice. We use examples from a supported socialization program to illustrate three of these elements through the stories of individuals with psychiatric disabilities. Finally, we conclude with a consideration of future directions for research and policy development to create additional pathways to achieve the inclusion of individuals with psychiatric disabilities begun almost 50 years ago.

This Is The Best That Can Happen?

It is widely accepted that there were several successes to deinstitutionalization. For example, the census of state mental institutions in the United States—which had come by the 1940s to be described aptly as “snake pits”—decreased 80% between 1954, when the policy of deinstitutionalization was adopted, and the most recent round of hospital closures in the late 1980s (Johnson, 1990). Such numbers are misleading, however, if one considers that people, prior to deinstitutionalization, may have been institutionalized for a good portion, if not the majority, of their adult lives. Following deinstitutionalization, and accelerated by managed care, lengths of inpatient stays have decreased continually, but readmissions—the same people having to return time and time again—have increased subsequently. In fact, the number of admissions per year has increased by almost 90% over this same time period, with readmissions now accounting for 70% of all inpatient episodes (Kissling, 1994; Klinkenburg & Calsyn, 1996; Wasylenki, 1994; Weiden & Olfson, 1995). If a major goal of deinstitutionalization—the most defining mental health policy initiative of the last half-century—was not just to depopulate overcrowded and decaying state institutions, but also to get and keep people out of psychiatric hospitals, then on this score we must conclude that it has fallen well short of its target.

It is perhaps with respect to its other avowed goal, however, that deinstitutionalization has failed more significantly. In the rhetoric of deinstitutionalization, the downsizing and closure of state institutions was to lead to the more noble and humanitarian—if also perhaps ambitious—goal of reintegrating people with mental illnesses into their home communities. As described in the 1960 *Final Report* of the US Joint Commission on Mental Illness and Health, which provided the direction and blueprints for the last 40 years of program and policy development in the US: “The objective of modern treatment of persons with major mental illness is to enable the patient to maintain himself in the community *in a normal manner*” (1961, p. xvii; emphasis added). Even when maintained in the community, many people with serious mental illnesses would argue that their lives are still far from normal. The statistics cited above on readmission rates tell only part of the story. In addition to the problem of the revolving door of recidivism (Cotterill & Thomas, 1993; Davidson, Stayner & Haglund, 1998; Pfeiffer, O’Malley & Shott, 1996), concerns have steadily increased since the 1970s about other unintended consequences of deinstitutionalization. Foremost among these are homelessness and the rising victimization and “criminalization” of people with serious mental illnesses resulting, to cite only one example, in the Los Angeles County Jail becoming the single largest institution within the US housing individuals with serious mental illnesses (LaFond & Durham, 1992; Torrey, 1988; Torrey et al., 1992).

As societal safety nets have worn and frayed, and as benefits and access to health care have constricted, people with serious mental illnesses have found themselves on the margins of an unwelcoming society. There was no “homecoming” for those discharged after lengthy stays at state institutions (Reidy,

1998). Since that time, there have been new generations of individuals who can live neither on a state hospital campus nor in the mainstream community in the normal manner once envisioned. Either such individuals avoid diagnosis and treatment, and remain abandoned and alone on the streets or in the jails, or they succumb to the weight of their disability and its stigma, and resign themselves to a shadow existence in the new backwards of social clubs, halfway houses, and sheltered workshops (Rowe, 1999). No longer “wondered at” for the price of a penny, people with serious mental illnesses can choose to be either ignored, passed by, or the object of others’ fears and distrust. It is no wonder, then, why one out of 10 people with schizophrenia, for example, commits suicide (Drake, Gates & Cotton, 1986). The only other possibility, the only avenue of escape for the nine out of 10 people who do *not* choose suicide, is to try to succeed. To have a normal life, to have their own apartment, to have a job, to have friends, to have their parents be proud of them, to have a car or to be allowed to have sex, they first have to eradicate the visible evidence of their disability. They have to be in remission, they have to have their illness under good control, they have to be symptom-free, they have to be cured.

And yet we have no treatments that can cure mental illnesses. We have no new medications, or psychotherapies, or rehabilitation techniques, which can eradicate mental illness. Medications are being improved, psychotherapies are becoming more focused and disorder-specific, rehabilitative interventions are becoming more effective, but yet still we can neither prevent nor cure mental illness. All the while that we search for the cause or the cure, the outcome literature consistently demonstrates that most people, once diagnosed with a serious mental illness, will experience the effects, side effects, and sequelae of the



disorder for many years to come. Even people who improve enough to be considered recovered will most likely do so over a 15 to 35 year course, no matter how good the treatments are that they receive (Carpenter & Kirkpatrick, 1988; Davidson & McGlashan, 1997; Harding, Zubin & Strauss, 1987; McGlashan, 1988). If we know this about mental illnesses, then why do we continue to insist that people be free of symptoms before they can have their lives back?

Increasingly, peer advocates want to know why they are “required to succeed” in overcoming what we tell them is a chronic medical illness just like diabetes before they can work, live independently, choose their own friends, or return to school. Adolescents with diabetes continue to go to school, continue to pick their own friends, continue to date, and to pester their parents for use of the car. If serious mental illnesses are also prolonged illnesses—like diabetes—and illnesses for which there is not yet a cure—like diabetes—then why do we expect anyone to overcome them? No one overcomes diabetes.

Of course, most people who have prolonged conditions also would argue that their lives are not normal. A blind person obviously cannot see, a deaf person not hear, etc. And there will be some things that people experiencing a serious mental illness will *not* be able to do. There will be ways in which their lives are not normal. The difference here is that we have found ways, both as individuals and as a society, to restore varying degrees of normality to the lives of people who are blind, deaf, or paraplegic, or who have diabetes, despite their deficits or disorders. We post Braille signs on ATMs, have close-captioned television, cut curbs in our sidewalks, and ensure access to public transportation for people in wheelchairs. We allow seeing-eye dogs to accompany blind individuals into restaurants, and provide 6 year olds di-

agnosed with diabetes with age-appropriate coloring books that assure them that it was not their fault that they developed the illness (e.g., from eating too many sweets). It would appear to be only in the case of mental illnesses that we try to eradicate or at least minimize the visible signs of the illness *before* we turn to restoring any semblance of normality to people's lives. And it is thus that we have moved from *wondering at* people with mental illnesses to *requiring* them to *succeed*.

Consideration of these examples suggests that the conventional clinical model of treating the symptoms and sequelae of the disorder prior to attending to the remainder of the person's life may be no more appropriate to mental illnesses than it is to blindness, deafness, or a variety of other prolonged conditions. A rehabilitative paradigm, which may go a step further in promoting adaptation and using existing strengths to compensate for enduring deficits, also may not be sufficient to the degree that it nonetheless targets success as well. In this same vein, we finally suggest that the recovery model emerging within the mental health consumer movement (Chamberlin, 1978, 1984, 1990; Frese & Davis, 1997) also may be insufficient for mental illnesses to the degree that it too requires a person to be "in recovery" in order to be making strides in restoring his or her life. It unfortunately has become commonplace, for example, for some advocates to view themselves as superior to peers who have more obvious disabilities, feeling that they have gone from being a patient, to being a client, to being a consumer, to being in recovery in progressive steps up an empowerment ladder, while their peers have remained on the lower rungs, passive and helpless. But would we ever say, after all, that someone was in recovery from blindness, or deafness, or paraplegia?


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 FOR YOUR DISABILITY TO
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 CLASSROOM, THE OFFICE,
 THE BUS, AS YOU ARE.”


No more than we would say that someone was in recovery from diabetes.

It would appear that neither a clinical, rehabilitative, nor even a recovery paradigm is adequate to overcome our demand that people with serious mental illnesses succeed in eradicating or mastering their illness prior to rejoining the community. In what ways, then, might we augment these paradigms to afford people a sense of inclusion that is *not* contingent on the eradication of mental illness, and is therefore not out of the reach of many individuals with serious mental illnesses for a major portion of their lives?

As Part of an Undeniable Reality

We would like to suggest that such a model is implicit in the redefinition of "mental illness" as a psychiatric disability in the landmark legislation passed in the US in 1990 under the title of the "Americans with Disabilities Act." What

was most inspiring to the mental health advocates who lobbied for the passage of this Act was not just that the Act passed, but that they won the fight to have mental illnesses included as disabilities, to be covered under the law, with all the same rights and legal leverage accorded to the more conventional examples of physical disabilities such as paraplegia. We have implied such a model ourselves in the above discussion, as we have compared mental illnesses to other prolonged conditions like blindness. What needs to be made explicit about this model, and what we propose will augment the clinical, rehabilitative, and recovery paradigms, is precisely that people with disabilities are *not* expected to "recover" in any usual sense of the term.

The essence of the Americans with Disabilities Act is that people who have paraplegia *not* be required to walk in order to attend school or maintain a competitive job, that people who are blind *not* be required to see in order to ride an elevator, and that people who are deaf *not* be required to hear in order to communicate adequately with their health care providers. As long as they can perform the essential functions of the job, or learn the information, or use compensatory strategies like sign language, their disability is to be accommodated. In the very act of providing reasonable accommodations we are delivering an implicit, but powerful, message to the person. We are saying that although we know that this impairment is not going to go away anytime soon, you still have the talents, strengths, skills, or even potential, to make a worthwhile contribution that justifies the extra effort or expense involved. You don't have to sit at home waiting for your disability to go away to regain your status as a contributing member of society. We will take you into the classroom, the office, the bus, *as you are*.

It is in this way that the notion of mental illness as a psychiatric disability is inextricably intertwined with the notion of inclusion. To the degree that the mental health consumer movement borrowed from the civil rights movements of the 1960s, it also should not stop short of such an expectation of full participation. We provide accommodations so that people with disabilities can participate in the ongoing rhythms of community life, can engage in the naturally occurring activities appropriate to their own normative developmental and personal needs and desires, even while they remain disabled.

And it is true that we have made progress within this policy arena as well as in several other aspects of psychiatry. Through the recent advances in supported housing, supported education, and supported employment, we have begun to enable people to choose, get, and keep their own residences, credentials, and jobs—even while they may remain symptomatic (Anthony, 1993; Becker & Drake, 1994; Carling, 1990, 1993, 1995; Drake et al., 1994; Unger, 1998; Wehman, 1986; Wehman et al., 1991). But these alone do not constitute inclusion (Mechanic & Rochefort, Spring, 1992). In addition to safe and secure housing, education, and employment, inclusion also involves a feeling of belonging, of having a niche or a meaningful role to play in the life of a community. Inclusion speaks to one's overall status as a *citizen*, as a full member of a society of one's peers (Rowe, 1999). What other avenues of civic participation have been off limits to people with psychiatric disabilities unless or until they have succeeded in recovering from their disorder?

Based on our recent experiences with a supported socialization program (Davidson, Haglund, in press), we suggest that there are at least three additional dimensions intrinsic to this

broader sense of inclusion that are not typically or explicitly addressed in existing clinical, rehabilitative, or recovery paradigms. These dimensions involve experiences of: (1) social inclusion through friendship; (2) feeling like a worthwhile human being through meaningful activity, and; (3) hopefulness through an affirmative stance. We suggest that while these dimensions may be implicit in some of these models, they typically remain largely unaddressed, due to the requirement to succeed elaborated above. That is, although these dimensions may be considered important in determining someone's quality of life, the assumption often is that they will be recovered by the person once the treatment process is complete. Alternatively, in the models that give explicit recognition to the importance of some of these dimensions as ongoing concerns requiring focused attention concurrent with clinical interventions, these concerns typically are left up to other providers—and these typically are providers with fewer professional credentials (Davidson & Strauss, 1995).

Rather than viewing these dimensions as ancillary to, or following after, treatment we suggest that these dimensions provide a foundation for people to be able to make substantial use of treatment or rehabilitation. They are not so much the rewards of recovery as prerequisites for recovery. When people do not have hope, a sense of self-worth, and a sense of their own efficacy, they will not be equipped to take on the formidable challenges inherent in attempting to cope with, not to mention recover from, their disorder (Davidson, Chinman et al., 1997). In this way, we have found these dimensions both to provide a cornerstone for improvement, and to be fundamental to the inclusion of people with psychiatric disabilities, whether they show any tangible, measurable signs of improvement or not.

In the remainder of this article, we define what we think it means for people with disabilities to be "let in," and illustrate each of these three dimensions of inclusion through stories drawn from a study of what we have come to call "supported socialization" (Davidson, Chinman et al., 1997; Davidson, Haglund et al., in press; Davidson, Stayner et al., in press; Stayner, Davidson & Tebes, 1996). Each of these dimensions appears to speak to an unfulfilled—but clearly not unarticulated—dream of people with psychiatric disabilities. It has been our experience that in working with individuals to fulfill these dreams, we also find it necessary to revise our current models of "mental illness" and its treatment.

Not to Be Wondered At ...

In one of his children's stories, Ludwig Bemelmans, the creator of the popular *Madeline* series, has a grumpy elephant say to a young rabbit eager to befriend him: "In 75 years of lonesomeness, one would think one could get used to it . . . But one doesn't" (1960). This is the first important lesson that we have learned from individuals with psychiatric disabilities: the continuing value of friendship.

The conventional clinical literature suggests that people with psychiatric disabilities often withdraw, gradually lose interest in other people, and have relatively few, if any, relationships, particularly outside of their own family (Davidson, Stayner & Haglund, 1998; Mueser & Tarrrier, 1998). This literature goes so far as to suggest that people with predominantly "negative symptoms" have become reclusive to the point of being asocial, no longer even desiring or missing human contact (Andreasen, 1984). Spending much of their time alone, we have come to assume that some people actually prefer it that way, that they choose to remain apart from others even when opportunities exist for them to choose otherwise.

Social isolation and severe psychiatric disabilities seem to go hand in hand.

Yet, over 2,000 years of philosophical thought—from Plato (392–348 B.C./1961) and Aristotle (384–322 B.C./1962a, 384–322 B.C./1962b) through Heidegger (1927/1962), Buber (1923/1970), and Levinas (1961/1969)—suggests that human beings are essentially, necessarily, *social* beings; that people are social by nature. If, as Heidegger (1927/1962) for example suggests, our “being-with” others is part of what makes us human, then this must equally be true of people with psychiatric disabilities. Though disabled, they remain as fundamentally human as anyone else and therefore as fundamentally social by nature (Sullivan, 1953). Like Bemelmans’ elephant, they too should be unable to grow accustomed to being lonesome, no matter how isolated and for how long they have been so. In fact, we have found considerable evidence in our analysis of first-person experiences of the social lives of people with psychiatric disabilities to suggest that—no matter how disabled or isolated they appear—they have become neither the “empty shell” depicted in the clinical literature (Andreasen, 1984), nor apathetic about relationships, but consistently and poignantly express both being lonely and desiring love and companionship (Davidson, Stayner & Haglund, 1998).

It was to address this desire for companionship, and to see whether or not people with psychiatric disabilities who were socially isolated and withdrawn truly did yearn for friendship, that we developed a supported socialization program modeled after the “Compeer” program originally developed in New York (Skirboll, 1994; Skirboll & Pavelsky, 1974). Instead of requiring individuals to learn and master social skills, or to stake out their own interpersonal turf within the broader social world in order to establish relationships, we offered them a friend and a small monthly

stipend to cover their social and recreational activities. Even though being socially isolated and withdrawn—in addition to having a severe psychiatric disability—were prerequisites for being invited into the study, we found that 67% of those offered the opportunity to develop a friendship with a peer did so, and with minimal structure or support from project staff members (for details on the program and study design, see Davidson, Stayner et al., in press).

For many of the participants, this was the first true friendship they had experienced since before the onset of their psychiatric disorder, often referring back to their adolescence for examples of similarly mutual and caring relationships. It is true that people with psychiatric disabilities encounter obstacles in their efforts to establish and maintain caring relationships with their peers including, but not limited to, stigma, fears of rejection, formal thought disorder and other impairments, and side effects of medications and other treatments (for a more detailed review, see Davidson, Stayner & Haglund, 1998). This study demonstrated, however, that despite these obstacles people should not, and do not, have to overcome anything in order to have a friend. For the majority of people, all that was required were opportunities to befriend someone, and some encouragement and support to take a risk. Despite many years of lonesomeness, friendships developed from there—naturally and as if people had just picked up from where they had left off before becoming ill—just as for the elephant and rabbit.

And just as they do in real life for those of us who do not have psychiatric disabilities, these friendships took many forms. For people with thought disorders, for example, there were quiet friendships that grew between two people as they gardened or fished together, or as they went for relaxing rides through the New Hampshire hills look-

ing at the fall foliage. Some women shopped together, some men watched and argued over sports. There was very little that was unusual, impressive, or profound about these relationships above and beyond what is unusual, impressive, or profound about any relationship except the fact that these relationships with presumably isolated and withdrawn people developed on their own, and with very little difficulty. The experience, and value, of these relationships perhaps was captured best by one young woman whom we will call Jane¹, who described how her life had changed by virtue of having a partner to do things with. Before she met her friend through the program, she said:

I would open a can and eat right out of the can, because I knew I had to put some food in me, but I had no enthusiasm of wanting to make it because I was going to eat it by myself. The only person I had to talk to was the television. So I would open a can of beans, wouldn't even heat it, because I just knew I had to put food in me... I won't go out to a restaurant because I don't like the emptiness. I mean you just sit there and you buy your meal. It doesn't taste the same as when you're eating it with somebody.

To which the interviewer responded: “It doesn't taste the same?” She continued:

No, because when, like when you go to Burger King. Like on the first [of the month], I can go to Burger King. I've got money. I've got a reason to go in there because I've got money, but I'm alone. I sit down at the table, I eat a hamburger. I'm just eating a hamburger. But when I go in with somebody else, and I'm sitting there at the table and eating it, she'll say “Oh, is your hamburger good?” Then it becomes, the hamburger becomes noticeable, and then your mind starts to think about the taste. But when you're sitting there by yourself, you're just eating

it and then you go out the door... don't want to eat really, because it doesn't taste good when I'm alone. [But] when you go out [and] you're not alone, you're able to eat talking to somebody, so that can of beans could have been in a gold bowl instead of just a plain, cold tin can.

Such is the power of friendship, regardless of whether or not one has a disability. In addition to offering companionship and comfort, such a sense of being-with and belonging among others appears to serve as a first cornerstone of inclusion of individuals with psychiatric disabilities.

Or Required To Succeed

A 64-year-old woman, whom we will call Maxine, who had spent most of the last 40 years in and out of state institutions, was invited to be a part of this supported socialization study. As most participants did, Maxine readily agreed and was eager to take advantage of the opportunity to form a friendship outside of a mental health setting. Although she was put randomly into a "control" condition in which participants did not receive a partner but only were given the \$28 per month stipend, she nonetheless informed the interviewer that she found the project to be a very enjoyable and worthwhile experience. When asked by the interviewer what she had liked about the experience, Maxine replied with exasperation that she was "so tired of taking, taking, taking all the time" from others during her many years of being profoundly disabled and institutionalized. Her every need had been met by others, and she never had anything to offer in return. During her participation in the project, however, her \$28 monthly stipend and the lack of a partner to spend it with allowed Maxine to buy birthday cards for members of her family. And with a simplicity and persistence that was manifested in similar ways by several other participants who did not receive new friends,

Maxine also was able to deepen existing relationships by feeling that she now had something to offer others. For her this occurred, for example, when she was able to attend a family Christmas party for the first time in many years because now she was able to bring small gifts for her grandnieces and grand-nephews. She had stopped attending such parties because she had always received gifts from others but had been unable to reciprocate. As she had said, she was tired of only taking, taking, taking all the time.

Being able to buy trinkets for children may seem trivial on the surface. It is no coincidence, however, that other participants derived the same gratification from these kinds of gestures made possible by their participation in the program. In fact, the second important lesson we learned from this study came largely from our interviews with control condition participants, who suggested to us that there is at least one element that a relationship has to possess in order for it to transform tin cans into gold bowls: it must be between two individuals who are on the same level and who have something of value to offer each other. This is in contrast to the majority of relationships participants had before the project, in which they, like Maxine, felt that they were "taking, taking, taking" all the time from others and either not able or not allowed to give anything back. Although the therapeutic boundaries established for clinical work were meant to protect clients from being exploited, they also appear to have the unintended consequence of imprisoning people within the sole status of recipient; in effect, denying them the opportunity to learn through the clinical relationship what it is that they have to offer others. Yet it is precisely this element of "giving back" that appears to matter most in differentiating reciprocal friendships from the relationships people have with mental health

providers and with family members; the latter being characterized in the clinical literature as asymmetrical, due to the fact people receive more than they are able to give to their families (Davidson, Stayner & Haglund, 1998). Having something to offer in return appears to afford people the sense of being cared about as a worthwhile human being, as opposed to a "charity case" (Davidson, Stayner in press).

As this difference in being a recipient and being a peer may at first be hard to discern, we provide an additional example of another participant in the control condition of our study. This participant, a middle-aged man who had a 20-year history of bipolar disorder and alcohol abuse, whom we will call Tom, expressed a very similar sentiment in describing how he used his monthly stipend to enhance his existing relationships with family and with acquaintances he had made through attending Alcoholics Anonymous meetings. By contrasting the experiences where he felt that he had something to offer with his life before the program, Tom helps us to appreciate what is at stake for people who feel they are taking more from others than they are able to give back. First, Tom describes his previous experiences of family gatherings as follows:

For years I've hated Christmas because... [that's] the time that everybody gets together and everybody talks, and everybody sits at the table and they start listing their accomplishments. And I don't have very many I can list. I'm in school, I'm in college, you know. Big deal. I'm only taking one course a semester. My brothers and sisters took double courses during the semester. I've got a brother who's a lawyer. I've got a brother who's going to be a priest. I've got a brother who's an insurance actuary. These are all high paying, real respectable type jobs. And then you look at me and what have I got and what am I doing? And

it's very hard to try to compare yourself to these people, and everybody's getting together on a holiday and...they're usually comparing themselves like "I've done this" "well, I've done that" and I don't have much to say about what I've done. And what I do say, I don't like saying, because you know, just because of how things are.

To which the interviewer inquired: "Just because of how things are?" Tom continued:

Yeah, like "I didn't go to the nut-house this month, I guess I'm doing pretty good." You know, what do you got to say?

With his participation in the project, however, Tom discovered a sense of self-respect and self-worth through his ability to reciprocate. When asked what he did with his small monthly stipend, Tom replied in terms very similar to those used by Maxine:

Well, I went to buy my father a Christmas present. I bought my mother a birthday present. I was able to buy cards for my brothers' and sisters' birthdays. It was just little things like that that mean so much. Because when you've got no income at all coming in, you know, that seven dollars, you can stretch that out a long ways to enable you to have a pretty good time. I enjoy myself by making other people happy also. I'm tired of being the one that's "Oh, we'll get Tom a Christmas card or we'll get Tom something for Christmas," but Tom can't return the favor. Well, Tom is able to now. I was able to get little trinkets for my nieces and nephews for Christmas. It wasn't much, but I didn't feel like I was on poverty row anymore.

Not being on "poverty row" also enabled Tom to participate more fully in gatherings with his peers from Alcoholics Anonymous; gatherings that in the past he had been unable to enjoy

due to his feelings of being inferior, due to his "charity case," recipient status. As Tom explains:

I belong to AA. I don't know if you're familiar with AA or not, but...most times after meetings, they'll go down to the restaurant, and everybody will have coffee and eggs or coffee and toast or something like that, and for so long... I could never contribute to my own coffee or french fries or whatever I was going to get. So, when I had the money, the extra money, I was able to treat them for a change. And that felt good. I didn't feel like a user. I felt like I was able to pull my own fair share, pull my own weight you know. And that made a difference.

For our present purposes, there are at least two striking elements to Tom's story. First, as also implied by both Jane and Maxine, a relationship in which a person feels that she or he is pulling his or her own weight appears to assist the person in coming to appreciate his or her worth as a human being. Within the context of a caring relationship, through the eyes of the other, people are able to reflect on and come to value their own contributions. Tom described this process in terms of his improvements:

A lot of the times I don't realize my own advancements. It comes about through friends. I'll run into somebody, they'll say, "jeez remember when you wouldn't go out of your house? Now you're going to meetings. Now you're coming down to coffee with us. And now you're doing this or whatever." That's basically how I learn that I'm doing things is through other people's comments.

A second element is that what people have to contribute to these relationships varies tremendously with the nature of the relationships themselves. In the examples provided above of people gardening or fishing together, what each party may have contributed was their

silent companionship—an important contribution that anyone can appreciate who has noticed the difference between being home alone and being at home with one's loved ones, even when involved in independent activities in distant rooms. In addition to giving parts of themselves, there are many ways in which people can make worthwhile contributions to the lives of others without achieving paid, competitive employment. Outside of sheltered workshops and day programs, however, such avenues remain largely unexplored. Recent examples of voter registration drives (Goode, October, 1999), volunteer experiences (Woodside & Luis, 1997), and mutual support initiatives (Davidson et al., 1997; Mowbray, Moxley, Jasper & Howell, 1987) suggest that there is much more that we can do to afford people with psychiatric disabilities opportunities to appreciate being engaged in their own labor. Whether or not that labor succeeds at turning a profit, it appears to provide an additional cornerstone for the broader inclusion of individuals with psychiatric disabilities.

What Heaven Will Perhaps Grant Us

Within psychiatry, spirituality has become like sex: everybody has it in some form or other, but somehow we have come to think that we are not supposed to talk about it. People with psychiatric disabilities, like most everyone else, do talk about it, however, if we let them. And what they talk about is a sense of meaning and perspective that cannot be captured in any other way than to appeal to spiritual traditions, because it occurs at such a basic level of existence. If defined sufficiently broadly, most people would agree that they have had glimpses into such basic dimensions of life from time to time, whether or not such experiences are understood within any established religious framework. In addition, most people will be able to identify with the role this dimension plays in the lives of people with psychiatric disabilities,

being able to appeal in their own experience to the healing or restorative power of having a broader perspective on life and death, particularly at times of great grief or joy. Although we all may be able to identify with such experiences and understand their importance in the lives of others, we cannot provide anything else to substitute for them. Like with an effective sense of self and sense of self-worth, we cannot simply give such experiences to someone else (Davidson & Strauss, 1992). At best, we can provide access and opportunities, and help others to prepare themselves for such experiences. Albeit elusive, these experiences nonetheless form the basis of the third lesson we have learned from individuals with psychiatric disabilities: the importance of hope.

We describe this dimension as elusive because of its characteristic *receptive* quality. That is, while the basic experience of awe, wonder, unity, beauty, or the sacred that forms the basis for hope is described differently within each tradition, in most if not all traditions this experience is understood as one that is bestowed upon the individual; it is not an experience that one simply can have at will. You cannot simply instruct someone, for example, to “have hope.” In fact, it typically is of the essence of such an experience that it requires more than oneself and one’s own efforts, that it reflects a whole that is larger than any given individual. Within the Christian tradition, for example, this dimension is perhaps best captured by the notion of “grace” which involves the unconditional receipt of the blessing of creation. As defined by contemporary theologian Frederick Buechner: “Grace is something you can never get but can only be given. There’s no way to earn it or deserve it or bring it about any more than you can deserve the taste of raspberries and cream” (1973, p. 38). In Judaism there is a similar concept of the gift quality of life, which affirms that life is

given to all of creation to be sanctified and cherished. The shared sentiment of these traditions is represented well in the first book of both the Judeo and Christian Bible, the book of *Genesis* [1:31], in which it is written in relation to creation: “. . . and God saw all that He had made, and behold, it was very good.” Although Eastern traditions typically articulate their views on the nature of existence in what might appear on the surface to be more “negative” terms, such as those of nothingness, emptiness, and nonbeing, the state of acceptance or insight (e.g., “Buddha-mind”) offered by these traditions similarly involves an affirmation of all of creation as a divine oneness. Here, too, is the conviction that life, at its most fundamental level, is “good.” Such an act of affirmation underlies, and provides the basis for, the experience of hope.

As we found in the experiences of friendships and “giving back” (i.e., making meaningful contributions), experiences of affirmation take on many forms in the lives of those with psychiatric disabilities, just as they do for everyone else. Many individuals speak directly about the importance of faith and religious practice in their lives, as the things that “kept them going” when all else, and everyone else, had failed them. Others address this same dimension much less directly, however, and in the kind of concrete and seemingly trivial terms we have seen already in the examples of friendship and reciprocity. That is, affirmation of life may be experienced in ways that parallel Jane’s experience of tasting her hamburger or Tom and Maxine’s experiences of buying birthday cards for their relatives. Life for all of us may, in fact, be experienced most poignantly precisely in these kind of concrete details, even though we often may overlook or take for granted their significance (Strauss, 1996).

One example of a mundane experience that contained within it profound, life-

affirming, meaning was provided by a young woman in our supported socialization study, who connected such experiences to her own sense of recovery. Although she described differing from her partner in very significant ways—drawing contrasts, for example, between her partner’s busy absorption in planning her wedding reception and her own preoccupation with how she would get through a trip to the grocery store without “freaking out” (Davidson, Stayner et al., in press)—she described enjoying these differences on the whole because of the glimpses they gave her into a life beyond her disability. As she described:

We always had a good time whenever we went out. We saw a movie, and it was fun, you know. Then I realized. . . hey, I can have more fun too. It just opened my eyes that there are other things to think about besides mental illness. . . It was just realizing that, you know, I could go places and have fun, that life isn’t one big horror.

This young woman’s realization that life isn’t just one big horror may not seem like a profoundly affirmative stance to those of us who have not experienced a prolonged period of disability. Set within that context, however, this is precisely what the first steps toward such an affirmation appear to look like in the experiences of those we have interviewed. To understand how this kind of realization can amount to an affirmation, one first has to appreciate that to many people with prolonged psychiatric disabilities life, in fact, has become almost exclusively the “one big horror” to which this woman referred. As she described, many people have become absorbed in the life into which their illness and its treatment have drawn them, and have closed their eyes to anything other than their disability. In addition to being extruded to the margins of the community to within the restricted boundaries of their own dis-

ability and the broader, but still circumscribed, mental health system, many people who have endured long periods of disability have come to view themselves fundamentally as mistakes, as nonpersons, as not having a right to exist in and participate among the community of their peers. For these individuals, life has become a “big horror” as they have become a failure of a human being.

Reversing this process and coming to believe again that one belongs among a community of one’s peers usually involves a series of incremental steps. Although at times easy to overlook or perhaps even imperceptible, we suggest that such steps, nonetheless, are crucial to providing a basic foundation for the experience of hope; an experience that underlies the possibility of there being any improvement in the course of a person’s illness (Davidson & Strauss, 1992). In order to take responsibility for the “work of recovery” there has to be a sense of personhood outside of the disability, no matter how small or limited it may be initially, to provide the person with a place from which to begin to address the illness itself (Deegan, 1993). Securing such a foothold beyond the disability requires the elements already described above: feeling like you are cared about by others as a worthwhile human being who has something to contribute. Within the context of having experienced life as a big horror, we suggest that for these elements to provide a springboard for hope, people also have to have a sense that it will be worthwhile to take the risks of taking steps forward; and all steps forward, no matter how small, entail risks. Risk-taking requires either confidence or faith in oneself, and if one has neither, then one must find an alternative foundation for a sense of hopefulness. This sense may be regained by people with prolonged psychiatric disabilities through such experiences as going out to the movies, tasting

fresh raspberries and cream, or, as in the case below, enjoying fried clams and “bottomless” cups of iced tea on a hot summer day.

Dave is a 64-year-old man with over a 40-year history of psychiatric disability, in combination with a more recent history of serious medical problems that further compromise his functioning. Upon enrollment into our supported socialization study, Dave was matched with a female partner near his own age, a woman we shall call Florence. Dave’s friendship with Florence provides a good example of how the dimension of affirmation that we are trying to capture can at times appear in ways that are barely perceptible. In Dave’s case, these experiences arose within the context of an extended period of institutionalization followed by a prolonged period confined to a nursing home. Suffering from a severe and recurrent depression, Dave had experienced persistent suicidal ideation, and had come to view life as “one big horror” in much the same way as the young woman described above. Initially, Dave began to accompany Florence on excursions only as a result of her persistent encouragement, but soon found these experiences to provide a stark contrast to his usual preoccupation with his own misery. He describes:

She took me to places I had never been before. For instance, we made . . . I’m ashamed to admit this, but I had lived in Connecticut for 18 years and I had never even seen the Connecticut coast. So we made several forays down to the Connecticut coast and took some nice long drives through the various towns, saw the beautiful old summer homes, stopped at a place where there was a really nice view of the ocean, and just sat there for a while and talked. And I remember one time in particular. I had never been to Masquawmacut, and so we went to Masquawmacut and Florence came equipped. When I am at my best in

terms of being mobile, I have a brace that I have to wear, and I have to use crutches. I get along fine, but those are things that are absolutely necessary for me to have in order to ambulate. . . . But getting back to Masquawmacut, [Florence] had thought of everything. She had brought this huge beach umbrella, and the tide was high so we only had to walk a very short distance. Oh, I don’t know, 15 feet maybe, and we were almost where the water was lapping in, and I was having a great deal of difficulty in the sand, and so Florence arranged for the kids that were lifeguards down there to give me a hand, and they did. And she always had the beach chairs which came out of the trunk and were unfolded. . . . and it was just really nice. And we sat there that day I have no idea how long. . . . whenever Florence and I went someplace, it was always calm, peaceful. . . . I was getting away from things, and it was just wonderful.

“Getting away from things” and spending time with a thoughtful and caring friend in a calm and peaceful setting appeared to begin to provide an antidote to Dave’s despair. As he described:

Getting away helped. That helped a lot. . . . I felt immeasurably better after that outing. . . . [Wherever we went] I knew I was going to have a good time. And I also knew that I was going to go to a restaurant that I’d be very happy with. The best restaurant on the shore that we went to, and I still, when I mention it, Florence laughs, was called the Fish Tail. . . . and it goes without saying that it’s a seafood restaurant. And we went in there, and it was very sort of countrified, homespun, comfortable. And, as it turned out, we got menus which were unusual. I don’t remember how, but they were unusual menus, in fact, I kept mine. And I didn’t see fried clams on the menu and I couldn’t believe it. This is a seafood restaurant? No fried

clams? I don't think so. So I said to the waitress: "No fried clams?" And she said: "We just got them in today. That's why they're not on the menu." So I said: "Ah-ha! That's what I'd like." So that day we started off with, I think they said, the menu said, a "mug" of clam chowder or maybe seafood chowder. In any event, it really was a mug with a handle. And then... when the clams came, I was overwhelmed. It was this huge mound of clams and french fries and cole slaw. And the clams were so fresh and so lovely, I think without a doubt there were the best fried clams I've ever had. Ever, ever, ever. And I come from Boston, and there's a lot of seafood restaurants in Boston, and I've been to them, but none of these have equaled these fried clams. They also had a real nice perk at the restaurant that I've never seen anyplace else, and that was—this was a very hot day—and Florence and I are both iced tea aficionados, so we both ordered iced tea. And we didn't even have... it came in a huge thing and we were parched, so we dispatched those in record time and lo and behold, the waitress came over and filled both of our glasses again. And we looked at each other, and sort of said, sort of shrugged, and we drank that down pretty quick. And, this was all before we had a thing to eat, and when the glasses were empty, they were no more than empty, but the waitress came and filled them again. And so I said this time, I said to the waitress: "This is unheard of in my experience." And she said: "Well, everyone has bottomless coffee. We have bottomless iced tea." So I don't know how many glasses I had. I certainly outpaced Florence by a country mile, but I love iced tea... and oh! it was just wonderful. It was really a lovely day. Just a lovely day.

We have quoted this passage at such length in order to attempt to give some sense of the subtle, yet rich character of

these kind of experiences of affirmation; experiences that begin to provide people with psychiatric disabilities with a perspective beyond the limits of their illness. This affirming perspective on the aspects of life outside of their disability, on those "other things to think about besides mental illness," provides individuals with a foundation for hope and possibly for improvement in their condition. While not necessarily being religious in nature or content, such experiences of *joie de vivre* do seem to entail an affirmation of the goodness not only of the experience itself or of its object, but also of the subject of the experience as well. As captured concisely in a common phrase used by Christians in the Southern US, such experiences seem to convey to their participants the lesson that "God didn't make no trash."

As mentioned above, such experiences cannot simply be willed to occur; there is a receptive, "grace" like quality to them for which people can, at best, only prepare themselves. It also appears to be the case that such experiences must be appreciated on their own terms and for their own sake, or else they are ruined. In other words, we cannot set out to have such experiences, or to provide them for someone else, in order to instill hope, promote recovery, or fulfill any other function. Despite this fact, and despite the fact that such experiences may seem to disappear as suddenly and inexplicably as they appear, we have found experiences of affirmation to leave a residue or legacy in their wake. Although they cannot be produced at will, and perhaps also cannot be explained or understood fully, they do seem to have an impact on the person, his or her sense of self, and his or her life. In Dave's experience, for example, his enjoyable interactions with Florence came over time to improve his mood, change his attitude toward life, and alter his perspective on suicide. As he recounts:

My life certainly was different [before]. I did not think that I was going to live to be 120. I did not think I was going to live very long; in fact, I wasn't sure that I wanted to. Now I feel totally different. I don't know how much or little my friendship with my partner has contributed... I can't quantify it... but certainly my life was enriched by my partner. And I think if one's life is enriched by whatever, then that is going to change your perspective on life and death.

Like friendship and a sense of being a worthwhile contributing member of society, evidence of the basic goodness of life and of oneself as a human being appear to be required before people can take up the "work of recovery" (Deegan, 1993). This evidence offers the person a sense of what might be possible beyond the limits of his or her disability, and provides both the motivation and confidence needed for taking the risks entailed in exploring this new terrain. In this fashion, the hopefulness cultivated through experiences of affirmation appears to provide a third cornerstone of inclusion.

CONCLUSION

Like Stones of the Road, Like Trees
Despite the potential utility of the disability paradigm outlined above, we recognize that we have yet to find a perfect analogy for serious mental illness. Serious mental illnesses differ both from diabetes and from other chronic conditions such as blindness or deafness in a number of important ways. Unlike diabetes, for example, many people with psychiatric disabilities improve over time, may regain or even enhance their functioning, and may no longer require the medications that helped them to achieve stability earlier in the course of their illness (Harding, Zubin & Strauss, 1987). Also unlike deafness or blind-

ness, psychiatric disabilities may impair an individual's judgment and ability to function to such a degree that other individuals may have to step in and make decisions for the person on at least a temporary basis. These and other complexities set psychiatric disabilities apart from other prolonged conditions in ways that limit the utility even of the disability paradigm promoted above. We would suggest, however, that there are many lessons to be learned from the application of a disability model to mental illness, and that a more adequate model has yet to be articulated.

The particular lessons with which we have been concerned in this article have to do with a few additional pathways to inclusion that can be afforded to people with psychiatric disabilities, and the importance of these pathways in providing a foundation for the improvements that may then be brought about through the person's more active participation in treatment and rehabilitation. These lessons instruct us that "being let in" to the community often is experienced by people with psychiatric disabilities at the concrete level of not having to eat your hamburger alone, being able to buy birthday cards for relatives, and being able to enjoy bottomless cups of iced tea on a hot day. These examples should not be taken to suggest that recovery is a simple or straightforward affair. Rather, the mundane nature of these examples—actual examples drawn from the lives of participants in a supported socialization program—is meant to illustrate that the process of restoring citizenship may be much more within our reach than we may have imagined. At least the first few steps in this process appear to require subtle, yet important changes in the ways in which we envision the role of the person with the disability. The processes of moving from recipient to peer, from charity case to contributing member of society, from hopeless to hopeful, can begin at the

very basic level of mundane acts like sharing lunch with a friend, going out to a movie, or buying a present for a loved one.

Although such "micro-decisions" (Davidson & Strauss, 1995) cannot be made by anyone else *for* the person with the disability—as it is in part the action of making the decision that is so crucial to its restorative power—we can do much better in affording people opportunities to make such decisions on a day-to-day basis. We also can do more in providing the *in vivo* supports that may be required for these actions to be successful, as we have begun to do in the areas of housing, education, and work (Anthony, 1993; Becker & Drake, 1994; Carling, 1990, 1993, 1995; Drake et al., 1994; Unger, 1998; Wehman, 1986; Wehman et al., 1991). Even if these supports do not bring about a cure, they have begun to prove their effectiveness in increasing community tenure and quality of life. We suggest also that they can be instrumental in increasing the motivation and internal resources for the efforts entailed in participating actively in one's own of recovery (Deegan, 1993).

These lessons suggest that we need to explore additional ways for people with mental illnesses to experience being let in to their communities of choice *even while they remain disabled*. In addition to conventional clinical and rehabilitative tasks, this will require community development work and the cultivation of "mediating structures" that cut metaphoric curbs into the social sidewalks of the mainstream community (e.g., Bellah, Madsen, Sullivan, Swidler & Tipton, 1991; Berger & Neuhaus, 1977; Ferguson, Hibbard, Leinen & Schaff, 1990; McKnight, 1987, 1992). In the end, however, a disability paradigm also promises to challenge at a more basic level our view of mental illness and its treatment. If we no longer either wonder at or require people to succeed

in order to be valued members of the community, how will we come to view them differently? When mental illnesses are no longer allowed to pose such formidable barriers to inclusion, how will the lives of individuals with psychiatric disabilities change?

We end with these unanswered questions. They bring us to the edge of our current understanding, beyond which we are left to imagine a world in which the lingering dichotomy between those with mental illnesses and those without is eradicated, and with it any residual notions of "normalcy." Should this aspiration seem out of place in a discussion of mental illness, consider again the example of blindness. There was a time in the general culture, not so long ago, when blindness usually involved profound disability, unemployment, poverty, and marginalization. A common perception of what it meant to be blind was captured in images of disheveled, malnourished people wearing dark glasses, selling pencils in front of the post office. These days, it is more appropriate to consider examples of blindness to be Ray Charles, Stevie Wonder, or Jose Feliciano. Of these people we might say that they just happen to be blind, in addition to being brilliant musicians, songwriters, and singers. We suggest that our current level of understanding of psychiatric disability is similar to the earlier understanding of blindness, confused as it was with the added impact of disenfranchisement and alienation. We have yet to envision a day in which mental illnesses—once divorced from poverty, oppression, and marginalization—will be considered something that "just happens" to people in addition to being other things like musicians, writers, or friends (Davidson, Haglund et al., in press). Role models like Mike Wallace, Art Buchwald, William Styron, Alma Powell, and Tipper Gore are only just beginning to appear in the public eye. How will we conceptualize and treat mental illnesses when they

provide as common a perception as the homeless person asking for cigarettes on the street corner? At this point, we can only imagine.

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¹ All participants provided written informed consent for enrollment in the supported socialization study, and also provided permission for their interviews to be used in published papers. Names and identifying characteristics were changed nonetheless, however, to protect participants' privacy.

NOTE

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WORK ON THIS ARTICLE WAS SUPPORTED BY PUBLIC HEALTH SERVICE GRANTS #SM47644 AND #SM51916 FROM THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION.