

Simply to Be Let In ...

Inclusion as a basis for recovery

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*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 1923/1972

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.

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 experiences 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. 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 deinstitutionalisation, 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. Deinstitutionalisation 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 deinstitution-alisation legislation, nor, we would suggest, is it the dream of most people with mental illnesses.

In the vocational arena, for example, a review of outcome studies among individuals with mental retardation found that the average time people spend in prevocational 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 in before people 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 deinstitutionalisation.

Why have we failed to fulfil this dream? And what can we do about it now, almost a half-century later?

Is this the best that can happen?

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 ten 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 ten 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.

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.

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

loneliness, 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.

Social isolation and severe psychiatric disabilities seem to go hand in hand. Yet, over 2000 years of philosophical thought - from Plato to Levinas - suggests that human beings are essentially, necessarily, social beings; that people are social by nature. If, as Heidegger 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 & 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 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 loneliness, 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.

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 grandnephews. She had stopped attending such parties because she had always received gifts from others but had been unable to reciprocate.

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.

As we found in the experiences of friendships and 'giving back' (ie. 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. 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).

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, 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.

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 described by others, enjoying fried clams and 'bottomless' cups of iced tea on a hot summer day.

Conclusion

Despite the potential utility of the disability paradigm outlined, 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 blindness, 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. 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 and being able to buy birthday cards for relatives.

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 socialisation 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, 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. Even if these supports do not bring about a cure, they have begun to prove their effectiveness in increasing community tenure 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 process of recovery (Deegan, 1993).

These lessons suggest 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.

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 marginalisation - 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.