AFTER THE ASYLUM: A BASAGLIAN-INFORMED VISIN OF RECOVERY-ORIENTED CARE

Depois do Manicômio: Uma visão Basagliana sobre o Cuidado Orientado em Recovery

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ABSTRACT: Prior to his untimely death, Franco Basaglia had envisioned a "next step" for the anti-asylum movement to involve working toward the inclusion of persons with serious mental illnesses in the community activities and settings of their choice. The current status of mental health systems both in the U.S. and in Brazil suggest that this remains a central challenge that continues to require innovative and concerted efforts. In this article, I review three directions of system transformation strategies for promoting community inclusion and full citizenship that Basaglia had foreseen but which he had not lived long enough to pursue in earnest. These include addressing discrimination against persons with mental illness, addressing the role of service users throughout the mental health system, and addressing the social determinants of mental health on a societal scale. While the asylums have been effectively closed and promising work has begun in each of these three areas, there remains much more work to be done in ensuring persons with mental illness a meaningful life in the communities of their choice.

Keywords: Discrimination. Community Participation. Civil Rights. Citizenship. Recovery.

RESUMO: Antes de sua morte prematura, Franco Basaglia tinha previsto um "próximo passo" para o movimento antimanicomial envolvendo o trabalho para a inclusão de pessoas com doenças mentais graves nas atividades da comunidade e trabalhos da escolha deles. A situação atual dos sistemas de saúde mental nos Estados Unidos e no Brasil sugere que esta condição continua a ser um desafio central que requer inovação e esforço compatilhado. Neste artigo, eu reviso três direções estratégicas de transformação do sistema para promover a inclusão comunitária e a plena cidadania que Basaglia havia previsto, no entanto, ele não viveu

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o suficiente para ter convicção. Estes incluem começar a lidar com a discriminação contra pessoas com doença mental, começar a abordar o papel dos usuários em todos os serviços do sistema de saúde mental e abordar os determinantes sociais da saúde mental em uma escala societal. Embora os manicômios tenham sido efetivamente fechados e tenha sido iniciado um trabalho promissor em cada uma dessas três áreas, existe muito trabalho a ser feito para garantir às pessoas com doença mental uma vida significativa nas comunidades de sua escolha.

Palavras-chave: Discriminação.Participação Comunitária.Direitos Civis. Cidadania. Recovery.

1 INTRODUCION

> "We must therefore make sure of community participation. Without this it is not possible to go further in this direction … How such participation can be achieved is a problem for the future …" (BASAGLIA,1980. p. 27).

As this passage—written shortly before his untimely death—suggests, Franco Basaglia had already envisioned, over 35 years ago, what would eventually become a central challenge of the next phase of the transformation of the mental health system once the asylums were effectively shuttered. At the time, he was still engaged primarily in persuading his colleagues, at home and abroad, that the closure of mental hospitals was a crucial and necessary step in restoring basic rights to people with mental illness as well as in restoring a properly therapeutic function to psychiatry. He was convinced that as long as doctors and systems of care had access to mental hospitals, and could deposit in them those who were coming into conflict with societal norms and expectations, psychiatry would continue to emphasize its social control function to the exclusion of exploring any other, possibly more constructive and effective, strategies for responding to human distress. As he wrote:

> "Only when the institution is no longer responsible for wide-ranging errors, will it be possible to realize that mental illness is not always chronic and will experience show that the rules of everyday living may actually be reacquired" (BASAGLIA,1980 p. 23).

What Basaglia did not live long enough to see, but which he may also have anticipated (LOVELL, 1986. p. 37), was that community-based programs could come to take on some of the same functions as had once been the performed by the asylum. While in the case of the hospital, containment had led to prolonged, if not permanent, marginalization, in the case of

community-based care, it was marginalization that would possibly come to lead to prolonged, if not permanent, containment. This form of containment was no longer physical in nature, perhaps, but now involved becoming trapped—through discrimination, demoralization, and despair—in a shadow existence in the community; a kind of half-life that Rowe (1999) has aptly described as one limited to "program citizenship" (in contrast to full citizenship). That is, the only places where such people may come to feel that they belong are mental health or other social service programs, whether they be housing, vocational, social, or clinical in nature. Tragically, for these people, the legacy of the asylum lives on through the community-based programs that were developed to take its place, forestalling the day when "the rules of everyday living may … be reacquired." In understanding this risk of the anti-asylum movement becoming stuck in affording people with mental illness only a second class citizenship, it may be useful to recall that, for Basaglia, closing the asylum was only the first step in a prolonged process of including persons with mental health conditions in the lives of their local communities. As he wrote:

> "What about the inmates? In place of their total dependence on the mental hospital, the aim was to re-establish their standing as members of society at large. Patients had to be given back their rights as citizens, both in legal and in economic terms … Moreover, this process of laying the unshakeable foundations of his membership of the social body was the first step, not the last, in the rehabilitation of the former inmate" (BASAGLIA, 1980. p. 187).

In this article, I would like to suggest that it is the steps that come next that we are still challenged to take at the present time, both in Brazil and in the U.S. I would also like to suggest that these steps are precisely those of "community participation" that Basaglia had identified as a "problem for the future." But despite this pronouncement, Basaglia actually had provided several clues as to what these steps toward community inclusion—or what we are now proposing to describe as steps toward recovering (full) citizenship (ROWE; DAVIDSON, 2016.p. 53)—would entail. I will describe several of these steps in the following, guided by what may be less well known components of Basaglia's vision, and illustrated through examples of some of the advances made—however tentatively or awkwardly—in the U.S. and U.K. within the last two decades.

2 ADDRESSING DISCRIMINATION

> "A community that aspires to be therapeutic must take into account th[e] dual reality [of] the illness and its stigmatization if it is to be able to reconstruct, step by step, the patient's identity as it must have been before society, with its numerous acts of exclusion, and the institution it invented, acted upon him with their negativity" – Basaglia (BASAGLIA,1985, p. 49).

The first step toward community participation is essentially contained in Basaglia's insistence, cited above, that "laying the unshakeable foundations" of a person's membership in society was "the first step, not the last," in the process of rehabilitation. Within the Recovery Movement in the U.S. and elsewhere, this same insistence has been expressed in the central tenet that community inclusion provides the foundation necessary *for* recovery to occur, rather than being reserved for later, when it can serve as its reward (DAVIDSON; RAKFELDT; STRAUSS, 2010). This is a reversal of the traditional, institutional-based, model of recover first and then get your life back, suggesting that it is only in the process of getting one's life back (in the community) that a person can begin to recover. If, in this case, restoration of civil rights is the first step in promoting recovery, then the first focus of these efforts must be to identify and eradicate those societal, cultural, political, and interpersonal forms of stigmatization that continue to keep people trapped in a shadow or second class existence. The first and most crucial way to restore a person's civil rights is to eliminate all of the ways in which he or she is currently being discriminated against.

Basaglia touched on this in the passage opening this section, where he comments on the role of stigmatization and exclusion in replacing a person's own, unique (one could say, "God given") identity with the stereotyped identity of mental patient. He also touched on this issue in describing the process which he and his colleagues engaged in with the Trieste community in the 1970s when he wrote that: "We could attempt to do some therapeutic work [outside of the asylum], but this was not very logical while the situation in society as a whole remained unchanged" (BASAGLIA, 1980 p. 26). In other words, it will remain exceedingly difficulty for former inmates to recover or develop the positive sense of identity separate from the illness or diagnosis that is an essential component of recovery (DAVIDSON,2003) as long as virtually everyone else in that person's life continues to view him or her primarily, if not solely, as a "mental patient." The main way to improve this situation is thus not through traditionally

"therapeutic" means targeting each individual, but through social-political means targeting the community as a whole.

Within the U.S. and U.K., such discrimination against persons with mental illnesses is being addressed on multiple levels and through multiple means, beginning with the passage of federal anti-discrimination laws (e.g., the U.S. Americans with Disabilities Act of 1990) and culminating in public education and media campaigns to "change the conversation" about mental illness launched both by First Lady Michelle Obama (2016) in the U.S. and by Her Royal Highness The Duchess of Cambridge (2016) in the U.K., through the Royal Family's "Young Minds Matter" initiative. At the systemic level, initiatives have targeted community education as well, but have also encouraged practitioners to view engaging with their local communities as part of their role, focusing on fostering more supportive environments outside of mental health sites in which the contributions of persons in recovery are both welcomed and valued (ROWE 2014; DAVIDSON,2016).

Another major initiative that has taken off both in the U.S. and in the U.K., and that is being found to profoundly undermine stigma *within* the mental health system, is the training and hiring of persons in recovery to offer "peer support" in conventional mental health settings (DAVIDSON et al, 1999.p. 165) While this initiative remains controversial both in the peer community (due to concerns about co-optation; DAVIDSON et al. 1997. P. 437-455) and in the conventional mental health provider community (due to concerns about a perceived lack of evidence regarding effectiveness), the number and roles of peer providers have virtually exploded over the last decade, with peer initiatives occurring on every continent with the exception of Antarctica. As evidence continues to accumulate as to the benefits of peer work (e.g., CHINMAN et al, 2014 and DAVIDSON; BELLAMY; GUY. 2012), both mental health clients and mental health clinicians are continuing to be exposed, on a daily basis, to tangible role models that bust stereotypes by demonstrating that recovery is not only possible, but is achievable in a very concrete way.

3 ADDRESSING THE ROLE OF SERVICE USERS

> "When the movement for change in psychiatric institutions begins to perceive the patient as the principal protagonist in the transformation, then the functions of the treatment staff become clearer" (BASAGLIA,1980.p. 182-3).

One central, but seemingly controversial, sphere for the elimination of discrimination against persons with mental illness is that of the mental health system itself. While I alluded to this challenge above, in terms of a potential benefit of peer support, its profound importance warrants an entire section to itself. A recurring theme of the Mental Health Consumer/Survivor movement that gave birth to the Recovery Movement (CHAMBERLIN, 2014.p.323-336) is that persons with mental illness have to recover at least as much, if not more, from the damage done to them by the mental health system as from that brought on by the illness itself. This recognition is similar to the one Basaglia was quoted to voice at the opening of the previous section, in regard to effects of the "negativity" and "acts of exclusion" exerted upon the person both by society and by psychiatric institutions. Much of the work described in the previous section had to do with broadening the scope of psychiatric practice to take into account the societal context. This section will be devoted to the context provided by the mental health system itself.

Hiring trained peer support staff alone will not be sufficient to eliminate discrimination within the mental health system, as this form of discrimination is inherent to, and permeates, many of the policies and practices that are core to conventional care. Although there is much disagreement and dissension within the mental health survivor/service user community about the nature of mental illness itself (e.g., whether it even exists as an "illness"), one issue upon which everyone seems to agree is that persons who access mental health services should be treated with dignity and respect and should be accorded both the basic human rights, and the associated civic responsibilities, accorded to all other law-abiding citizens. Diagnosing a person as having a "mental illness" in and of itself is not sufficient grounds for terminating, or even limiting, that person's fundamental rights or relieving him or her of any personal or social roles or responsibilities. It is not sufficient grounds in and of itself for calling into question or over-turning his or her own judgment and decision-making, nor is it sufficient grounds for usurping that person's sovereignty in his or her personal or business affairs. And even if the condition in question is disabling in some ways, it is to be understood first and foremost to be disabling in ways that are analogous to physical disabilities; that is, ways in which it impairs functioning in some specific domains (e.g., mobility, vision) while others remain intact. This was the main conceptual shift embedded in the Americans with Disabilities Act of 1990, in which serious mental illnesses were re-defined as "psychiatric disabilities."

In this respect, a disability model may be useful in underscoring the kinds of rights and responsibilities that are to be restored and preserved among persons diagnosed with serious mental illnesses both within and beyond the mental health system. In the U.S., for example, persons with physical disabilities are assumed to retain their personal sovereignty and their cognitive capacities and are therefore entitled to fire or change the personal care assistants who are hired to assist them with activities of daily living. They are to be supported in accessing the same community settings and activities that others have access to, with society having invested significant resources in accommodations—such as wheelchairs, service animals, cutting curbs in sidewalks, widening doorways and installing hand rails in restrooms, and posting Braille signs in elevators—that enable them to do so *while remaining disabled*. The mental health system, in contrast, has generalized what impairments the person may be experiencing, even if on an acute basis, to the entirety of the person's life and functioning and, as a result, has created segregated settings in which such persons' needs may be addressed while they are taken care of by well-intended, but controlling, others. This is one of the ways in which community-based mental health programs have come to perpetuate some of the same attitudes, beliefs, and practices that characterized the asylums they were developed to replace.

How is this situation to be remedied? Once again, Basaglia had pointed to a solution that he did not live long enough to realize. In the passage opening this section, he suggests that it is only when the "movement for change" recognizes "the patient as the principal protagonist" both in his or her own recovery and "in the transformation" of mental health care itself that the functions of the staff become clear. If the person is to remain the "principal protagonist" in his or her own life, and therefore in his or her own recovery (DAVIDSON, 2003), then the roles and responsibilities of mental health practitioners need to change accordingly, primarily shifting to be consultative and supportive in nature. This is the approach which we have attempted to employ in our two decades-long work in transforming care within the State of Connecticut's mental health system in the U.S. (DAVIDSON et al, 2007 and DAVIDSON et al, 2009).

Beginning with what the process of recovery appears to involve, we have worked backwards to identify what roles practitioners need to play in educating, empowering, and supporting the person's own efforts to manage his or her condition while reclaiming a full and meaningful life in the communities of his or her own choice. Following an extensive review of the research literature, Slade and colleagues have concluded that recovery involves at least

five core processes: 1) Connecting with others; 2) Having a sense of hope and optimism about the future; 3) Having a positive sense of identity; 4) Having a sense of meaning in life; and 5) Being empowered to take care of, and advocate for, oneself (21). In order to promote these five processes, recovery-oriented care focuses on: 1) nurturing relationships that afford people a sense of belonging and self-worth; 2) instilling hope and offering role models of the reality of recovery through exposures to others in recovery living meaningful lives; 3) being strength-based (as opposed to deficit-based), focusing on the person's efforts to develop and maintain a positive sense of identity apart from the illness or disability; 4) supporting the person in pursuing activities from which he or she may derive a sense of meaning and purpose; and 5) educating and empowering people to exercise self-care and their rights to citizenship and social inclusion. How this work becomes integrated with, and ultimately transforms, clinical practice remains a work in progress, but the interested reader is referred to previous publications which aim to describe these approaches in more depth and detail (e.g., TONDORA;DAVIDSON,2006, and DAVIDSON et al, 2009, and DAVIDSON et al, 2016, and TONDORA et al, 2014).

It is not only at this level of providing recovery-oriented care to individuals, though, that persons with mental illnesses must be viewed as protagonists. It is equally crucial that service user leadership and input be invited and integrated at the levels of programming and policy. Service user advocates have adopted the slogan from the Disability Rights Movement of "Nothing about us, without us!" They have insisted on playing substantive roles in developing and evaluating programs and in designing and implementing policies and managing systems of care. Inroads have been made thus far primarily in the domains of peer support and other peer-delivered services (e.g., respite care) and service user-led and other participatory approaches to research and evaluation (e.g., WALLCRAFT;AMERING; SCHRANK, 2009). While much work remains to be done in involving service users similarly in policy and system design and management, Brazil has the advantage of having a history of broader stakeholder involvement in this area than many other parts of the world, and thus has this as a strength to build on in the future (COSTA, 2016. P. 44).

4 ADDRESSING SOCIAL DETERMINANTS OF MENTAL HEALTH

> "How [community] participation can be achieved is a problem for the future, which is again likely to turn out to be a political and a class problem" (BASAGLIA, 1980. p. 27).

When service users do become involved in service provision, program development, or system design, one of the first issues they raise is precisely the one Basaglia pointed out in the now completed passage above: that the major obstacles many persons with mental illness face in attempting to become involved in the lives of their communities are political and social class-related rather than psychiatric in nature. Increasing recognition of the important roles played by such issues as poverty, discrimination, unstable housing, trauma, and prolonged involuntary unemployment in exacerbating and perpetuating—if not also precipitating or causing—mental illnesses has given rise to the relatively new field of research into the social determinants of mental health (COMPTON; SHIM,2016). The programmatic and policy-related work being carried out in this area could be considered one more way in which society needs to be changed as a precondition for the therapeutic work of psychiatry of be effective, but the magnitude of changes required in this area is of course considerable and may seem daunting.

Surely, I am not suggesting that the limited resources currently available for mental health care be redirected to addressing poverty, unstable housing, and unemployment on a broad, societal scale. What this emerging field of research does suggest, however, is that these factors play crucial roles in engendering and perpetuating disability and chronicity and must be addressed at a societal level if we expect to see progress in improving outcomes for persons with mental illness in any substantive way. The mental health system has acknowledged the importance of these issues in theory, and has taken initial steps in this direction through such advances as supported housing, supported education, and supported employment. But these rehabilitation strategies continue to target individuals and must be complemented with more programmatic efforts to address these determinants of health on a broader scale. In this respect, mental health leaders must advocate for justice and equity as fundamental values for reform, joining forces with like-minded practitioners and stakeholders from other fields in becoming "change agents" beyond the traditional boundaries of their own disciplines (DAVIDSON, 2014. P. 41).

5 CONCLUSION

The anti-asylum movement has been very successful in closing mental hospitals and returning persons with serious mental illnesses to the communities from which they came. Where there continues to be significant room for improvement, though, is in enabling these persons—as well as present and future generations of people who never set foot in an asylum —to maintain valued social roles and a fundamental sense of belonging to these communities even *while* they may be experiencing profound distress and functional impairments. Early intervention programs cropping up around the globe promise to get effective treatments to young people early in the course of illness to prevent the secondary disability that results not only from the effects of the illness itself but also from the discrimination and social isolation that continue to be associated with mental illness. Hopefully, it will prove to be easier and require less time and resources to keep a person engaged meaningfully in his or her community while learning how to manage his or her condition than to have to support the person in re-integrating from the margins. But for even these efforts to be successful, considerable work has to be done in eradicating stigma and discrimination so that young people will access care, and making the care they receive responsive to their everyday life struggles and needs, addressing those issues that most concern them and their loved ones as they strive to retain, or perhaps have to recover, their full citizenship within a caring and compassionate community.

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