

Social integration in global mental health: what is it and how can it be measured?

J. N. Baumgartner^{1,2*} and E. Susser^{1,3}

¹ Global Mental Health Program, Mailman School of Public Health, Columbia University, New York, NY, USA

² FHI 360, Washington, DC, USA

³ New York State Psychiatric Institute, New York, NY, USA

Purpose. Global mental health movements increasingly highlight social integration as a key outcome for mental health services. This creates a pressing need to better articulate and measure this outcome. Much of the work in social integration thus far has been in high-income countries (HIC), and is not directly applicable across diverse socio-cultural environments. We discuss promising concepts and measures of social integration with potential for global cross-cultural application. Then, we present some of the challenges of developing measures for global and cross-cultural use, and suggest ways to confront these challenges. Although we focus primarily on adults with severe mental disorders in low- and middle-income countries (LMIC), the questions we raise are also relevant to children, other mental disorders and HIC.

Findings. We identify and describe four distinct conceptual frameworks for social integration that have emerged over the past decade. Then, we discuss the challenge of developing corresponding measures, and the further challenge of developing global cross-cultural measures. We suggest that a key concept shared across much previous and emerging work is *active participation in community and civic life*. As a platform for future development of global cross-cultural measures of this and other concepts, we propose guidelines and present examples of feasible, previously used strategies.

Summary. Emerging concepts of social integration hold great promise, but as yet, there are no corresponding measures suitable for global cross-cultural use. We propose that it is feasible to develop such measures, and that their development will facilitate the advance of community mental health services and the science of global mental health.

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Introduction

Global mental health movements have highlighted social integration as a key outcome for mental health services (World Health Organization, 2007a, b; Collins *et al.* 2011; Maj, 2011; Movement for Global Mental Health, 2011). Although this perspective has deep historical roots (Susser, 1968; Susser *et al.* 2010), its rejuvenation in the past decade has had an impact that is far greater than in past eras. The re-emergence in stronger form was stimulated in part by changes in global human rights policies and mental health programme guidelines in the past decade (World Health Organization, 2007a, b, 2010). It also reflects the increasingly influential consumer-oriented perspective of the mental health recovery movement (Deegan, 1988; Anthony, 1993; Fisher, 1994; Rose, 2001; Bellack, 2006). Many countries now have specific legislation or policies that emphasize the goal of social

inclusion for those with mental illness. Although these countries all fall short, to varying degrees, of reaching this goal, the explicit endorsement of social integration as policy provides important leverage for efforts to achieve it. It also demonstrates the potency of the current movement in this direction.

The call for social integration to be incorporated as a key outcome of mental health services creates a pressing need to better articulate and measure this outcome. This will open the way to building an evidence base for improving social integration, and thereby improving mental health services and the quality of life of people with mental disorders. The need is evident in all countries, particularly in low- and middle-income countries (LMIC) (Patel *et al.* 2007). The bulk of work thus far has been done in high-income countries (HIC), and is not directly applicable across diverse socio-cultural environments. Yet, the greatest number of people and the most diversity in socio-cultural environments are found in LMIC.

Although there are many relevant policies and programmatic guidelines that aim to support and strengthen social integration as a goal for individuals living with severe mental disorders, we draw attention

* Address for correspondence: J. N. Baumgartner, Global Mental Health Program, Mailman School of Public Health, Columbia University, New York, NY, USA.
(Email: jb3219@columbia.edu; jbaumgartner@fhi360.org)

to several signal developments in the last decade. In 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities. Its purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (World Health Organization, 2007b). A general principle of the document is that persons with disabilities, including those with mental disorders, have 'a right to full and effective participation and inclusion in society'. Among other things, this includes a housing environment that prevents isolation or segregation from the community, and participation in recreation, cultural activities and political or public life. The convention's promotion of social inclusion goes hand-in-hand with calls to prevent stigma against those with disabilities and helps provide global momentum for making social integration a measurable outcome of interest for social policies and health programmes (Thornicroft *et al.* 2009).

More recently and from a service user perspective, the 'Cape Town Declaration of October of 2011' by The Pan African Network of People with Psychosocial Disabilities states: '... We want, like everyone else, to vote. We want to marry, form relationships, have fulfilled family lives, raise children, and be treated as others in the workplace with equal remuneration for equal work' (PANUSP, 2011). This document, as well as the UN Convention, reflects not just a lack of social exclusion, but rather a pro-active, participatory ideal.

The World Health Organization (WHO) has in recent years offered ongoing endorsement and broad guidance for countries to promote social integration of people with mental illness. One of the purposes of the Mental Health Policy and Service Guidance Package is to 'assist the reintegration of people with mental disorders into all aspects of community life, thus improving their overall quality of life' (World Health Organization, 2004, 2005, 2007a). Although 'reintegration' is not explicitly defined, the package does state that 'social inclusion for an individual means access to supportive relationships, involvement in group activities and civic engagement' (World Health Organization, 2004). WHO's 'mhGAP Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings' includes psychosocial interventions to facilitate rehabilitation in the community, such as accessing resources, coordinating health and social interventions, promoting social, educational and occupational activities, and increasing inclusion in social activities (World Health Organization, 2010). The mhGAP recognizes that the promotion of social inclusion of people with mental disorders requires cross collaboration among health, employment, education, social and other relevant sectors. The WHO is now launching another

initiative to guide the monitoring of human rights and the quality of services for those with severe mental illnesses (World Health Organization, 2011). The WHO does not, as of yet, provide complementary guidance for evaluating programme efforts to promote social integration at an individual level.

At the national level, numerous countries have policies and programmatic guidance that specifically mention social integration or inclusion as a goal of psychiatric services (DHHS, 2003; Ministério da Saúde, 2004; ODP/SEU, 2004), but the definitions are rarely clear, much less measurable. For example, Brazil has strong policy guidelines that promote social integration (PAHO/WHO, 1990; Ministério da Saúde, 2004) and a rapidly growing system of community-based mental health clinics (Centros de Atenção Psicossocial, often referred to as CAPS). Nevertheless, a client's social integration is not a routinely measured individual level outcome at the CAPS.

These increasing global and national calls for adopting social inclusion or integration as a key outcome for those with mental disorders are a welcome development. They have not yet been accompanied, however, by similarly vigorous efforts to put forward a clear framework for conceptualizing social integration, never mind measuring it. The Grand Challenges in Global Mental Health initiative has recently identified the top 40 challenges in the next 10 years that will make an impact on the lives of people living with mental and neurological disorders (Collins *et al.* 2011). The second most highly ranked challenge is to 'develop culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings'. As we cannot hope to eliminate social exclusion, or rather, promote social inclusion, without more efforts to conceptualize, measure and monitor this important goal, such efforts might be interpreted as integral to this research priority.

To help advance this agenda, this paper discusses some of the more promising concepts of social integration, considers the available measures of social integration and finally, confronts the challenge of developing measures for global and cross-cultural use. We focus primarily on severe mental disorders in LMIC. Much of the review is also relevant, however, to other mental disorders in children and adults. Similarly, much of it is also relevant to HIC, as of necessity, we draw heavily on work done in HIC.

Concepts of social integration

In current parlance, 'social integration' may refer to several overlapping concepts and may have multiple

meanings. For example, recent reviews of the concepts of social inclusion and social exclusion note their conceptual overlap with participation in society and lament the difficulties of obtaining a clear conceptual framework that links personal and contextual factors (Morgan *et al.* 2007; Cobigo & Stuart, 2010). We will highlight four promising efforts to provide a conceptual framework for social integration at an individual level: (1) a disability framework from the WHO, (2) a conceptual framework for community integration emerging from the U.S. mental health services literature, (3) a definition of social integration based on Amartya Sen's Capabilities Approach which has been influential in global human development work, and (4) an alternative framework that includes participation in sub-communities (i.e. enclave communities) as part of an inclusion continuum that consumers may choose for themselves (World Health Organization, 2001; Wong & Solomon, 2002; Ware *et al.* 2007; Mandiberg, 2010). All four frameworks have specific implications for the measurement of social integration among individuals with mental illness. Although concepts and measurement at the community level are equally important, they are beyond the scope of this paper.

The International Classification of Functioning, Disability and Health (ICF) is WHO's classification system and framework for measuring health and disability at both individual and population levels (World Health Organization, 2001). This system addresses, and in fact, places significant emphasis on participation in society. The ICF domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. As an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors. The ICF clearly prioritizes social participation in its definition of disability; however, there is a lack of detail about what is encompassed within the 'participation' domain and how it is measured. The complementary assessment instrument, the WHO Disability Assessment Schedule (WHODAS 2.0), measures some aspects of participation in general terms, but in only a few items, thus limiting its ability to more comprehensively characterize an individual's social integration (Üstün *et al.* 2010).

In the U.S. mental health services literature, Wong & Solomon (2002) have proposed a more theoretical and specific conceptual framework for 'community integration' of individuals with mental illness. They define community integration as a combination of physical, social and psychological integration. Physical integration is the extent to which an individual participates in activities and uses goods/services in the

community, while psychological integration is the extent to which an individual feels a part of the community. Social integration has two dimensions – interactional and social network – and it reflects the extent to which an individual engages in social interactions with community members. Much of what they have carefully laid out in this framework is casually mentioned as part of social inclusion/participation/integration in a variety of policy and programme documents. Wong & Solomon (2002) have not proposed a specific instrument to measure community integration. Other researchers have, however, devised strategies for measuring integration based on their framework (Gulcur *et al.* 2007; Yanos *et al.* 2007; Abdallah *et al.* 2009).

A third framework for social integration has been put forward using the Capabilities Approach (Ware *et al.* 2007, 2008). The Capabilities Approach looks at not just a person's functioning (activities and achievements), but also their freedoms – whether they have the opportunities and the environment necessary to function as they wish (Sen, 1992, 1999). As articulated by Ware *et al.* (2007), 'to define social integration, we borrow from the capabilities approach, its emphasis on agency, its developmental perspective, its recognition that individual development is contingent on supportive social environments, and its core concepts of competency and opportunity in delineating the process through which social integration develops'. Ware *et al.* (2007, 2008) identified six personal capabilities necessary for integration (responsibility, accountability, imagination, empathy, judgment and advocacy) and work on a complementary instrument is ongoing. This conceptual work is appealing due to its focus on personal capacity and social opportunity when measuring social integration, which is important for everyone but especially for those living with stigmatized health conditions in impoverished settings. One of the authors, Hopper (2007), has espoused this approach more specifically for redefining social integration and social recovery in schizophrenia.

A fourth formulation for social integration expands upon which relationships and communities should count as contributing to social integration. Sub-communities, also known as enclave communities, of persons with severe mental illnesses may offer consumers other pathways towards social inclusion; for example, friendships formed with fellow members of a Clubhouse Model of psychosocial rehabilitation or activities stemming from a business venture that is run by and/or supports those with mental illnesses. In Mandiberg's review of this alternative approach to social inclusion, he states 'having the option of fully integrating in the broad community, remaining in an embedded sub-community, or moving back and forth between

both allows for far more ways of leading community lives' (Mandiberg, 2010). This concept has implications for how social integration is evaluated in that social relationship and community activities do not necessarily have to be with non-affected individuals. For example, Wong & Solomon's (2002) more detailed definition of social integration indicates that social interactions should be 'culturally normative ... and take place in normative contexts'. Although the intent is that those with mental illness should not be socially restricted to the so-called non-normative relationships and contexts, Leff & Warner (2006) and Mandiberg (2010, in press) highlight that affected individuals should make that choice for themselves.

Despite their depth and promise, none of these frameworks have as yet been well articulated for understanding social integration across diverse contexts. In addition to their strengths described above, this and other important limitations should be considered when determining how to measure social integration among a population with severe mental disorders.

Available measures of social integration

There is no widely accepted single measure of social integration or social inclusion even for HIC. There are a few stand-alone instruments measuring community (which would encompass social) integration and participation but they have not been widely used (Berry *et al.* 2007; McColl *et al.* 2001; van Brakel *et al.* 2006). Because social integration significantly overlaps with other concepts such as disability and quality of life, studies in LMIC with a stated interest in social integration as an individual level outcome have often used more established instruments that measure these overlapping concepts, sometimes combining elements from these instruments (Chatterjee *et al.* 2003; Caqueo-Urizar *et al.* 2011). In HIC, we also have examples of studies that have used a combination of domains from existing instruments in order to assess community integration (e.g. in the US; Gulcur *et al.* 2007; Yanos *et al.* 2007). Other HIC studies have used *ad hoc* measures based on a conceptual framework for community integration (Abdallah *et al.* 2009).

Perhaps the most common research strategy for assessing individual-level social integration or inclusion has been to use all or part of quality of life and/or disability instruments. For example, the World Health Organization Quality of Life instrument (WHOQOL-100 and WHOQOL-BREF) and the Lehman Quality of Life Interview have been widely translated and used globally (Lehman, 1988; WHOQOL Group, 1998a, b). They include domains such as living situation, family and social

relationships, work/school, daily activities and functioning; some of these items fit with various definitions of social integration. However, these broad quality-of-life (QOL) instruments do not capture important integration elements such as interactions with people you do not know and feeling like you belong to your community. Meanwhile, disability instruments may capture some of these missing elements, but exclude others. For example, the World Health Organization Disability Assessment Schedule (WHODAS 2.0) includes items that assess communicating with people you do not know, joining in community activities and experiencing barriers or hindrances in the world, but it excludes assessing opportunities for forming and maintaining intimate partnerships and raising children, important elements of social inclusion articulated by those living with severe mental illnesses (Baumgartner, 2004; Üstün *et al.* 2010; Pan African Network of People with Psychosocial Disabilities, 2011).

There are a few recent instruments that are less well known but hold promise for future advance. Berry *et al.* (2007) in Australia developed a subjective measure of community participation in order to test the relationship between participation and mental health based on a clear definition of community participation. They defined community participation as encompassing informal social connectedness, civic engagement and political participation and they included 14 items in their scale to reflect different types of participation – from contact with extended family to joining voluntary sector activities to talking about current affairs with family and friends. The authors highlighted that the scale items indicated commitment, initiative and effort, suggesting that community participation relies substantially on being thoughtfully, pro-actively and personally engaged in the community. As a relatively new instrument, there is limited literature on its adaptation or use in LMIC.

The Participation Scale developed by van Brakel *et al.* (2006) is an 18-item measure of client-perceived participation in people affected by leprosy or disability; however, the instrument is meant to be generic and not disease specific. In fact, the instrument is based on the participation domain of the ICF and is intended to be cross-cultural in nature. The scale underwent extensive development with field sites in Nepal, India and Brazil. It touches upon all of the disability domains of the ICF with items such as do you help other people, are you confident to try to learn new things, do you take part in local festivals/rituals and, in family discussion, does your opinion count? Respondents rate their participation in comparison with a 'peer', defined as 'someone similar to the respondent in all respects except for the disease or disability'. Use of this peer concept

allows the scale to be used in a variety of settings with standards of participation being locally anchored. Again, as a newer instrument, its use beyond the field sites is limited but the scale is particularly promising given its use of the ICF theoretical framework and cross-cultural field-testing.

The Community Integration Measure (McColl *et al.* 2001) is a 10-item instrument that comes from work in rehabilitation for those with acquired brain injuries. There are numerous disability-related measures in the rehabilitation literature and while this measure was not developed specifically for mental disorders, we include it because besides the usual items on relationships and activities, it has two items that assess belongingness (I feel like I am a part of this community and I feel that I am accepted by this community). Psychological integration was highlighted by Wong & Solomon (2002) as a key component of community integration and it may tap into issues of social opportunity in accord with the Capabilities Approach to measuring social integration (Ware *et al.* 2008). The Perkins' Sense of Community scale (Perkins *et al.* 1990) is an example of a scale that specifically measures psychological integration.

Although items in both QOL and disability instruments capture some aspects of social integration, these items are not sufficient, even in combination, to capture social integration under any conceptual framework. To derive a suitable measure of social integration for global use across diverse contexts, in particular for populations with severe mental disorders in LMIC, investigators will need to significantly extend the items included in QOL and disability instruments, further develop the promising instruments now emerging, or create new instruments. It is unlikely that a single measure will be appropriate and optimal for all situations. Researchers will need to determine their social integration assessment needs and select and adapt instruments accordingly. That being said, we propose that there are central concepts shared by the seemingly disparate frameworks for social integration, and principles that could be followed in adapting any measure of social integration for use among individuals living with severe mental disorders in LMIC.

Development of concepts and measures for global/cross-cultural use

Concepts

We suggest that one key concept that is shared across much previous as well as emerging work, and that could be developed for global use is *active participation in community and civic life*. Participation would ideally include both subjective and objective elements and if

possible, include an assessment of opportunity and means for participation (e.g. access to social situations for meeting new people and financial means for engaging in a particular activity). This concept merges both ability and opportunity. It also goes beyond the concepts encompassed by traditional measures of interpersonal social functioning and social networks (Berkman *et al.* 2000; Burns & Patrick, 2007), in that social integration would include interactions with those whom an individual does and does not know and include participation in a variety of community and civic activities. This concept would include personally meaningful relationships and activities with mutual exchange and would not indicate that independent participation is a sign of greater integration than mutual participation. For example, some instruments highlight the ability to independently do an activity or have a 'normative' relationship (meaning relationships with non-affected individuals) as indicative of better integration. A global instrument should allow for interdependent relationships with whomever a person chooses to associate with the critical element being choice.

Measures

Often, for studies in LMIC without locally relevant instruments, an instrument developed in a HIC is forward translated, and some associated reliability and validity testing may be conducted. At a minimum, researchers should be following WHO guidelines for translating and adapting instruments (Prince, 2008; World Health Organization, 2012). The recommended process includes forward translation, expert panel review, back-translation, pretesting with cognitive interviewing and finalization of the instrument.

Moreover, for measuring social integration, no established instrument is sufficient even in HIC. Therefore, researchers need to take the further step of adapting an instrument to capture social integration in particular context(s). Strategies for doing so are described below.

Future directions

We suggest two key principles for selecting and adapting an instrument for global and cross-cultural assessment of social integration: (1) capture the most essential concepts and (2) balance the need for a standardized global instrument with cultural adaptation. These principles are not prescriptive, but rather, represent central considerations that should be addressed before embarking upon a particular strategy. Depending on the context and the research question, consideration of these principles may lead to quite different approaches. We propose below three alternative strategies that are all compatible with these

underlying principles in some contexts, and illustrate them with examples from the field.

The first strategy is to use an established instrument with a global core of standard questions with an optional module with context-specific questions. For example, this local expanded version might highlight participation in particular aspects of civic life that are culturally valued and deemed important for that context but that are not captured in the global core of questions. To illustrate this approach, we highlight global stigma measurement among populations with severe mental illnesses.

Yang *et al.* (in press) are working on an approach for developing a cross-culturally valid stigma assessment applicable to mental disorders. Although stigma theories and measures have been widely used in HIC, there exists a research gap on cross-cultural measures of stigma (Link *et al.* 2004). On the basis of extensive ethnographic research with Chinese and US-based populations with severe mental disorders, Yang *et al.* (2007) have articulated a new theory highlighting how culture influences stigma. Culture was conceptualized as the activities that 'matter most' to an individual in their local context. To engage in activities that 'matter most' is to identify a person as being of full adult status within a cultural group. What is key is that these daily activities can be empirically identified and operationalized. Stigma was therefore viewed as affecting core capacities for 'personhood' in that stigmatized conditions could threaten what was most at stake for an affected individual.

The Perceived Devaluation Discrimination (PDD) scale is the most widely used measure of internalized stigma (Link *et al.* 1987). On the basis of the Modified Labeling Theory, this scale refers to 'cultural conceptions of mental illness'; however, there has been minimal research towards culturally adapting the theory or the associated PDD scale for use in LMIC. Yang *et al.* (in press) have proposed to adapt the PDD and its 'universal' elements of stigma by developing a new culture-specific module informed by their earlier work on what 'matters most'. The approach would employ ethnographic methods highlighting the 'what matters most' perspective with established psychometric strategies to achieve cross-cultural validation of a new instrument utilizing multiple field sites in LMIC. In brief, the approach would include (1) open-ended qualitative interviews on the PDD scale to elicit the key culture-specific activities that are threatened by stigma among affected individuals, their relatives, and community members; (2) generating and administering a long version of a 'culture-specific' stigma module with affected individuals based on the qualitative analyses; (3) conducting cognitive interviews with affected individuals on the instrument to reduce the

module items down to the 12 most salient; and finally (4) conducting reliability and construct validity analyses with an emphasis on determining whether this new culture-specific module increases the predictive validity of the PDD. Although this summary is over-simplified, the outlined steps highlight the importance of combining quantitative and theoretically derived ethnographic methodologies to generate a new module to add to an existing instrument.

A second strategy is to significantly adapt an existing instrument so that the result is a context-specific instrument uniquely tailored for a particular culture, or even develop a wholly new context-specific instrument. Bolton (2001a, b) and Bolton & Tang (2002) have developed an approach for developing culturally specific instruments that starts with gathering input from the local community about the area of interest for measurement. The approach includes conducting ethnographic interviews with community members, and 'free-listing exercises' to ascertain locally recognized grief symptoms (for a depression instrument) or to learn about tasks important to local people (for a functional assessment instrument). Free listing provides a rapid entry point for understanding a cultural concept by asking a wide variety of informants to generate a list of items and/or ideas associated with the concept.

In one instance, this approach was used to develop a depression scale tailored to a particular culture. Bolton (2001a, b) was examining the criterion validity of the Hopkins Symptoms checklist depression section in the absence of a gold standard (i.e. diagnostic interview by a clinician). The qualitative methods he employed for adaptation, in particular free-listing, resulted in a new instrument with some items removed and others added in order to create a scale specific for Rwandans and their experiences with grief. This approach has subsequently been used for other depression scales in Africa (Bass *et al.* 2008).

In another instance, the approach was used to develop a brand new instrument for functional assessment (Bolton & Tang, 2002). Through a process of free-listing with key informants for specific tasks and subsequent validity and reliability testing in Uganda and Rwanda using community-based surveys, two different functional assessment scales were developed – one for each country, reflecting locally valued tasks. This strategy was further developed for a study in northern Uganda aimed at measuring local mental health syndromes (Betancourt *et al.* 2009). The resulting Acholi Psychosocial Assessment Instrument was a new culturally specific measure of depression-like, anxiety-like, and conduct problems among war affected adolescents in northern Uganda (Betancourt *et al.* 2009).

The two strategies described thus far are both feasible for developing measures of social integration. In the case of social integration, using the first strategy, it would be beneficial to conduct qualitative interviews about what it means to be socially integrated with individuals affected by severe mental disorders, their relatives as well as community members. Using the second strategy, approaches such as free-listing could be applied. Both these strategies, however, require substantial time and resources in order to conduct the necessary qualitative data collection and analysis.

A third strategy is to administer instrument items such that participants respond by comparing themselves against their peers. This peer comparison concept was used in van Brakel's Participation Scale described above, and an earlier example can be found in the measurement of socio-economic status in the WHO Ten Country study of schizophrenia (Jablensky *et al.* 1992; van Brakel *et al.* 2006). The approach has not yet been used extensively for developing global cross-cultural measures, but is promising because it could generate a global scale with the same items that could remain relevant across diverse contexts. An important advantage is that it may be far less costly than the two other strategies, especially for studies that encompass many contexts.

Conclusion

A high priority for global mental health is to promote social integration of individuals with mental illnesses. To do so requires a conceptual framework for social integration and corresponding measures of it. Emerging conceptual frameworks for social integration hold great promise, but as yet, there are no corresponding measures suitable for global cross-cultural use. We have presented four distinct frameworks that have emerged over the past decade, available measures that bear at least some correspondence to them, and strategies that are feasible for developing better measures. We have also identified a key concept that is shared across much previous and emerging work and that is amenable to measurement: *active participation in community and civic life*. We maintain that it is feasible to develop global cross-cultural measures of social integration, and that their development will facilitate the advance of community mental health services and the science of global mental health.

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