



Well Together

**A blueprint for community inclusion:
fundamental concepts, theoretical
frameworks and evidence**

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WELLWAYS AUSTRALIA



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Note on language

We recognise that language has power, and have tried as far as possible to use neutral terms that put the person first. At times, we have chosen language that is recognised in mental health and disability sectors in order to communicate clearly to readers and allow them to seek out further references.





Laura Collister
Director, Mental Health Services,
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Wellways Australia's vision is of a society where people experiencing mental illness and psychosocial disability, and their families and friends, are understood, accepted and afforded the same opportunities as others to participate in the community. This vision, while first articulated in 1978, still remains relevant today. Many people experiencing disabilities are excluded from valued parts of life – from employment and education, adequate housing, to accessible primary health, and social and community relationships.

The National Disability Insurance Scheme (NDIS) intends to address these challenges. Based on the principles of individual choice and control, it will provide tailored support to individuals experiencing disability to improve social and economic participation.

This publication was commissioned by Wellways Australia to build on our existing knowledge base and ensure the work we do, now and into the future, is firmly grounded in the best available and most contemporary evidence. Its timing is not coincidental. It is explicitly intended, in this new NDIS environment, to provide practice principles to guide our work with people experiencing a range of disabilities. It also provides a foundation that is applicable to the delivery of specialised areas of mental health interventions – such as Prevention and Recovery Care, and Residential Rehabilitation.

This publication, as expected, challenges approaches that focus on illness and impairment. It concentrates on the role of community, strongly arguing that community inclusion is a human-rights issue and that urgent change is needed across the mental health and broader disability sectors. This change will require a reorientation of service providers to mainstream opportunities, a recalibration of power differentials and addressing barriers that currently exist in the community. Many of these barriers reflect the prejudice and discrimination held by the community and service providers alike. It also requires paying attention to the needs of families and carers, and addressing their inclusion into the community.

The publication is aptly titled – *Well Together: A blueprint for community inclusion*.

Wellways Australia already works with a diverse group of people experiencing a range of disabilities. The evidence-based fundamentals articulated in the publication reflect our values and will ensure all the work we do is uniformly oriented towards community inclusion.

We share this publication with the wider sector as we all work to improve the lives of people who have not been well served by traditional approaches, and remain excluded from genuine community opportunities.

A handwritten signature in black ink, appearing to read 'Laura Collister'.

Laura Collister



Community inclusion

a new generation of supports and services

Inclusive communities – ones in which everyone has the opportunity to lead meaningful and satisfying lives – require a fundamental reframing of the ways in which we all relate to one another.

Inclusive communities celebrate diversity and highlight the strength that diversity brings to the community itself, challenging traditional prejudices and the exclusion they foster, while replacing marginalisation with a welcoming embrace. This is a powerful vision of the future, particularly for many groups who have been disenfranchised and marginalised in the past, including people with disabilities. Community inclusion requires a dramatic shift in how the rest of society thinks about the engagement of people with disabilities in the fabric of everyday life.

Community inclusion can best be understood as comprising two essential commitments: first, that all individuals have an opportunity to fully participate in the community; and second, that communities actively seek out and welcome the participation of everyone, valuing each individual's uniqueness and abilities.

These commitments, and the fundamentals required for making them a reality, are embedded in the following principles:

- Community inclusion is an urgent human rights issue;
- Community inclusion is an economic and moral imperative, and creating opportunities for participation in the community benefits all people;
- Community inclusion, and the participation that results from increased opportunities, is an aspect of health, and is facilitated through the provision of supports and by addressing external barriers.

These foundations provide the framework for 11 fundamentals of community inclusion that can serve as a blueprint for a new generation of policies, programs, and practices.

Fundamental #1 Community inclusion is important

While high-quality treatment and rehabilitation services must continue to be available, there should be a prevailing understanding and emphasis on community inclusion among all stakeholders.

Fundamental #2 Community inclusion applies to everyone who experiences a disability

Community inclusion initiatives should ensure that everyone will have the opportunity to work towards community inclusion, even if someone else believes that they are not yet 'ready' for community participation.

Fundamental #3 Community inclusion requires seeing 'the person', not 'the patient'

Each person should be accorded respect: seen by those around them – including disability service providers and community groups – as an individual with unique strengths, problems, interests and cultural identity; and never defined by their impairments or differences.

Fundamental #4 Self-determination and dignity of risk are central to community inclusion

Each person should be empowered to make their own decisions about their community inclusion goals, the supports and services they feel they need to be successful in attaining those goals, and the best ways to identify and responsibly manage any risks that may be involved.

Fundamental #5 Community inclusion should embrace multiple domains of mainstream life

Each person should have the chance to pursue participation in areas that are important to them rather than being restricted by what is available or believed to be important by society.

Fundamental #6 Community inclusion focuses on participation that occurs more like everyone else

To the degree desired by the person, participation should be self-determined, in the community, and should maximise opportunities for interactions with the most diverse group of fellow citizens possible.

Fundamental #7 Community inclusion is strengthened through emerging support technologies, the natural supports of families and friends, and the engagement of peer supports

People should have access to supports that enables participation, including: programs that promote awareness of community resources and develop skills to access these; support to involve families, friends and carers; and peer support.

Fundamental #8 Providing support to family and other natural supports promotes community inclusion

Efforts should be made to strengthen the capacity of families to support community inclusion and experience community inclusion themselves.

Fundamental #9 Environmental barriers to community inclusion must be identified and addressed

Community inclusion initiatives should specify the environmental barriers to community inclusion – among them negative public attitudes, pervasive poverty, and inadequate public transportation – and adequately address them.

Fundamental #10 Community inclusion initiatives for individuals with disabilities maximise the use of mainstream community resources

Community inclusion initiatives should work actively to engage people in the ample mainstream resources that are available to all citizens, connecting people to jobs and schools, clubs and teams, religious congregations and recreational programs used by everyone.

Fundamental #11 Community inclusion requires establishing welcoming communities

Community inclusion initiatives should work with community groups to help establish a welcoming and mutually supportive community, where each individual's participation is valued not only for their uniqueness, but also for the contribution individuals with disabilities can make to enhance their community.



“People don’t need more referrals to mental health services, they need referrals to life and community”
(Rapp, 1996)

Building inclusive communities – ones in which everyone has the opportunity to lead meaningful and satisfying lives and participate as fully as they would like as valued members – requires a fundamental reframing of the ways in which we all relate to one another. Inclusive communities celebrate diversity and understand the strength that this diversity brings to the community as a whole. Inclusive communities also challenge age-old prejudices and the established patterns of discrimination they foster, replacing marginalisation and isolation with affirmation, eager welcoming and embracement.

This is a powerful vision of the future, particularly for many groups who have been disenfranchised and marginalised – cultural, sexual, and ethnic minorities and indigenous communities in particular – and thus it calls for a new generation of policies, programs, and practices that consistently engage us all. But for people with disabilities – mental, physical, sensory, cognitive, developmental, intellectual, or emotional – the evidence regarding community inclusion suggests the need for a still more significant shift: in the expectations people with disabilities have for their own lives and their roles in the broader community; and in how society thinks about people with disabilities and their right to be part of everyday life in the community.

The purpose of this monograph is:

- To clarify why community inclusion is one of the most urgent issues in our work with people who are affected by mental health issues and other disabilities;
- To articulate why community inclusion is a human rights issue, a moral and economic imperative, and a cornerstone of personal health; and
- To identify the fundamental elements of an evidence-based approach for people and organisations that want to create inclusive communities

Community inclusion of individuals with disabilities

Community inclusion can best be understood as comprising two essential, and deeply intertwined, societal commitments: first, to ensure that all individuals have an equal opportunity to fully participate in the community; and second, to establish communities that actively seek out and welcome the participation of everyone, valuing each individual's uniqueness and potential contribution. While the research and advocacy surrounding such a broad concept provides a wide range of approaches and definitions (Simplican, et al. 2010), the definition provided here offers a useful framework for highlighting the responsibilities of both human services providers and local communities to effectively support the meaningful participation of individuals with disabilities in our shared world.

To ensure that all individuals with disabilities have an equal opportunity to fully participate in the community

is a particularly challenging commitment. Those with disabilities, like other marginalised populations, have often been forced to the fringes of everyday life, and human services programs designed to provide support to individuals with disabilities have served to sustain that separation. A generation ago, large institutions dominated the provision of what often became lifetime care for those with disabilities, and more recently even those programs based in community settings have inadvertently built a sub-culture of disability (Estroff et al. 1997) in which those with disabilities lived, worked, and formed personal relationships almost entirely with others like themselves. To ensure that everyone has an opportunity to fully participate in the community calls for a new generation of activism that is focused on facilitating, rather than substituting for, community engagement.

To build communities that actively seek out and welcome the participation of everyone, valuing each individual's uniqueness and potential contribution

broadens the focus of community inclusion, arguing that the responsibilities of human services providers must be met by an equal commitment from all individuals, organisations, and institutions within the community itself. This needs to be a social pact to create welcoming communities that actively seek out engagement and participation of individuals with disabilities – in neighbourhoods and worksites, within religious congregations and recreational activities, and as part of the purpose of both educational institutions and civic groups. Human services groups have a role to play in encouraging individuals and organisations in the community to examine their preconceived ideas about those with disabilities that result in exclusion, and to design more welcoming initiatives. The community itself must also be willing to be proactive in valuing, welcoming and seeking out all citizens for full and meaningful participation.



“People with disabilities far prefer the challenges and potential rewards of participating in the community like everyone else”

It is important to note that refocusing service providers and mainstream organisations on the goals of community inclusion represents a significant challenge to more traditional assumptions about the possibilities for people with disabilities. For generations, there has been an implied or unintended consensus that most individuals with significant disabilities are ill-suited to living meaningful lives in the community – that they wouldn't, couldn't and shouldn't seek inclusion. This monograph will challenge this perception, arguing:

- That they *would* participate in community activities. Despite the safety and security available in today's segregated residential, work and social settings, people with disabilities far prefer the challenges and potential rewards of participating in the community like everyone else;
- That they *could* participate in everyday activities successfully. With encouragement and support, people with disabilities have proven their capacity for real engagement in the world; and
- That they *should* participate in the broader society. Despite others' fears that inclusion would lead to, for example, stress, symptoms, crises and hospitalisations, those with disabilities are far more likely to thrive when real opportunities for participation are available.

There is a growing consensus as well that community inclusion also strengthens the whole community. This consensus is built on two firm foundations, discussed below: first, the advocacy initiatives of individuals with disabilities themselves; and, second, emerging theoretical paradigms that reframe our understanding of the importance of inclusive communities for people with disabilities and their families and carers.

Advocacy

Much of the drive to redefine the relationship between individuals with disabilities and the broader community has come from individuals with disabilities who express their dissatisfaction and unwillingness to continue to be excluded from society. As other traditionally devalued groups – women, racial and sexual minorities, indigenous peoples, the LGBTIQ community etc – have raised their voices in support of equality and inclusion for themselves, so too have individuals with disabilities. Among the first to reconsider the inclusion potential of individuals with disabilities were those in Denmark's intellectual and development disabilities field in the 1950s, which led to the 'normalisation movement' and then the 'social role valorisation' approach of Wolfensberger (1970,1972). Their critique looked at the network of large, impersonal, and sometimes abusive institutions that dominated human service approaches and argued that services should both respect the individuals in their care and support people in establishing and maintaining personally meaningful adult social roles for themselves in community settings.

In the 1960s and 1970s, a powerful movement of individuals with physical disabilities took shape in many countries. Coalitions of disability activists fought for and won passage of legislation that ensured those with disabilities a broad set of rights equal to those enjoyed by everyone else in their nations. Many countries began with legislation to ensure those with disabilities an equal opportunity to benefit from both public and private services, designed to end discrimination in housing and employment in particular, but also to ensure physical access to public spaces and everyday services. In time, regulations and legal decisions recognised the need to promote community inclusion as well, and sought to guarantee that disability programs worked to ensure that individuals had the opportunity to 'interact with non-disabled people to the fullest extent possible'.

Mental health advocates, and particularly those with lived experience of mental health issues themselves, have fought a somewhat separate battle that has attempted to reframe how mental illness is understood and treated. Activists and advocates who have emphasised 'recovery' continue to reform public attitudes, fiscal policies, and clinical and rehabilitation approaches; as well as promote a focus on support for individuals that fosters hope, personal meaning and connectedness with self and others. Recovery also calls for the development of systems of care that respond to individual needs rather than to diagnostic categories, that instil hope rather than anticipate chronicity, and that ensure individuals with mental health issues have the power to make their own decisions. One of the most persuasive definitions of recovery was offered by William Anthony (1993):

"Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness".

The general concept of recovery is notable for its emphasis on the ways in which individuals are encouraged to develop meaningful and engaged lives 'even with the limitations caused by the illness' rather than the traditional reliance on 'cure' as the necessary precursor to broader participation in the community. A focus on community inclusion advances the field and leads to a new generation of interventions by:

- Emphasising human rights;
- Focusing on the community participation and engagement that is associated with living a meaningful life; and
- Highlighting that both human services agencies and the community-at-large must join with individuals with disabilities to forge new inter-dependent relationships.



“Recognising and responding to the human rights of individuals is an immediate, urgent requirement”

Supporting paradigms

There are three broad theoretical paradigms that provide a useful framework for the emerging consensus around community inclusion: 1) *human rights*; 2) *economic and moral development*; and 3) *individual health* – all of which will help to shape the next generation of community inclusion initiatives.

Human rights

One of the core paradigms driving community inclusion initiatives over the past two decades has been the growing international recognition that community inclusion for those with disabilities is a fundamental human right. This recognition has been best expressed by the ‘Convention on the Rights of Persons with Disabilities’ (UN Convention, 2006), adopted by the United Nations General Assembly nearly a decade ago, in December 2006, and now signed on to by most national governments, including Australia’s. The Convention noted that approximately 10% (more than 650 million persons) of the world’s population consists of individuals with disabilities, and that most of those with disabilities have been denied their human rights and left to languish on the margins of society.

The Convention makes several important assertions, among many others, about the community inclusion obligations of nations to:

- Promote, protect and ensure the full and equal enjoyment of all human rights and the fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity;
- Ensure that persons with disabilities are not viewed as objects of charity, medical treatment and social protection but rather as individuals with rights, who are capable of claiming those rights and of being active members of society; and
- Promote full and effective participation and inclusion in society, including reasonable accommodations to ensure effective access to community living, communications services, educational opportunities, healthcare, competitive employment, and participation in the economic, political, social, cultural, recreational activities of their communities.

Framing the issue as a human right makes it explicit that these are rights available to everyone with a disability, regardless of the nature, severity or permanence of the disability, regardless of the disabled individual’s identity within other marginalised groups, and regardless of one’s perceived potential. Recognising and responding to the human rights of individuals with disabilities is a formal obligation that cannot be delayed or that can be set on the shelf until everyone else is adequately housed, productively employed or politically enfranchised: recognising and responding to the human rights of individuals is an immediate, urgent requirement.

Economic and moral development

Community inclusion also draws a measure of its theoretical force from the field of economic development, and most notably from the 'capabilities theory' developed by Amartya Sen (1993, 2005) and expanded upon as a moral imperative by Martha Nussbaum (1993, 2000). Sen argues that any nation's economic development should be understood not only by the income of its citizens but also by the degree to which a nation supports each individual's ability to achieve the valued things that they are able 'to do or to be' – their capabilities. The capabilities theory asks:

"Does the individual possess the personal ability, resources, practical means and knowledge required to achieve his or her goals as well as the external circumstances (in the social, economic, and physical environment) to make this possible?" (Burkhardt, 2004)

Capabilities theory has been used to critique societies where social mores and traditions restrict whether someone – a woman, a member of a minority or indigenous group etc – may not have access to resources or opportunities 'equal to others'. For instance, in many countries there are limits on women's roles, including access to an education (to do) or the personal choice to work in a chosen profession (to be). Capabilities theory also raises critical issues for individuals with disabilities, each of whom is likely to need a quite individualised array of supports and services, many of which are typically unavailable even in industrialised nations, with the result that many individuals with disabilities are strong-armed into lives of dependency and hopelessness (Hopper, 2007), less through their disabilities than by the absence of the resources and opportunities they need to achieve what they wish 'to do or to be'.

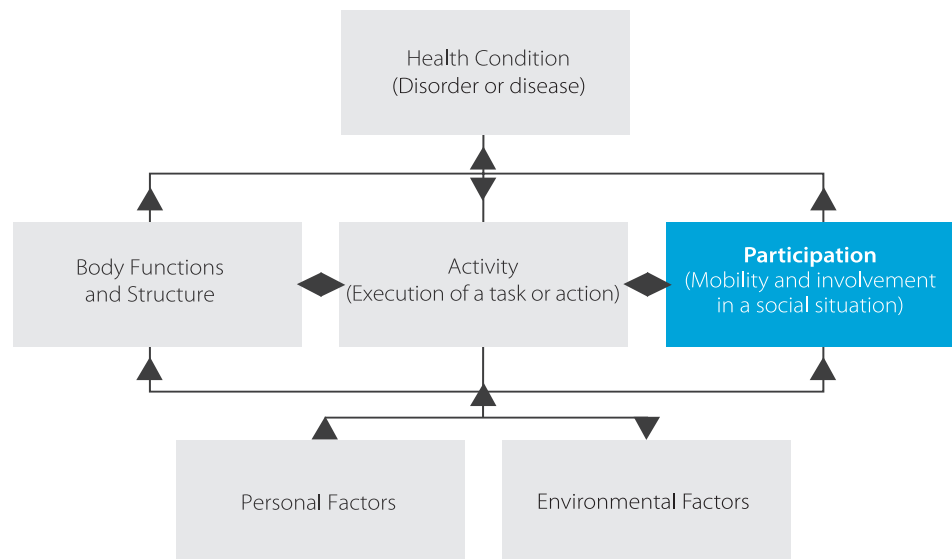
Nussbaum (Creating Capabilities, 2011, 33-34) provides an exhaustive list of the capabilities that individuals – with and without disabilities – ought to be able to claim as their own, including: a human life of normal length; bodily health and integrity; the ability to use the senses in a 'truly human' way and to experience a wide range of emotions; the ability to reason; the opportunity to play; and the chance to participate effectively in political choices. Importantly, she includes within her list of essential capabilities that of 'affiliation – being able to live with and toward others and to engage in various forms of social interaction.'



Health

The World Health Organization (WHO, 2001) developed the International Classification of Health, Functioning, and Disease (ICF) which has become a widely accepted framework for both national and international initiatives related to population and individual health. The ICF shifts public policy development from a narrow and illness-focused view of health to a more holistic orientation that incorporates functioning, rather than viewing it as separate. The ICF identifies three distinct components of health:

- **Body function and structure** – which refers to bodily impairments or symptoms;
- **Activities** – which are defined as ‘the execution of a task or action by an individual (which includes those tasks associated with activities of daily living)’; and
- **Participation** – which is defined as ‘involvement in a life situation’ and is specifically separated from ‘activities’. Participation refers to natural engagements, rather than contrived or manufactured events, in one of four social life domains that typically involve interaction with others in community contexts – domestic life; interpersonal life; education and employment; and community, civic, and social life (which includes religion, politics, recreation, leisure, sports, arts and culture).



“If the barriers to full participation are not intrinsic to the individual but rather are social in nature, it is a matter of social justice that these barriers should be dismantled”

Two aspects of the ICF paradigm are of special importance. First, the ICF utilises a *social model of disability* framework that views health, including activities and participation, as being influenced by the environment. Burkhardt (2004) articulated the essential features of the social model of disability by noting its distinction between ‘impairment (a condition of the body or mind) and disability (the loss or limitation of opportunities to take part in the life of the community on an equal level with others [arising] from the social, economic and physical environment in which people with impairments find themselves)’. She notes that while the older but still prevalent ‘individual model of disability’ ascribes limitations in participation in society to a particular medical condition, leading to well-meaning efforts to change or cure the individual so they can better fit into their communities, the social model of disability focuses on the persistent economic, social and physical barriers that exclude participation of individuals with disabilities. Recognising these barriers is the necessary precursor to actions being taken to dismantle them. Oliver and Barnes (1998) sum this approach up by noting that ‘if the barriers to full participation are not intrinsic to the individual but rather are social in nature, it is a matter of social justice that these barriers should be dismantled’.

Second, the various health domains (ie body function and structure, activity, and participation) are recognised as influencing one another, but also as being independent in the sense that one can experience ‘health’ in one area and not another. One implication of this is that rather than always beginning with efforts to directly address, cure or ameliorate problems with an individual’s ‘body function and structure’, such as symptoms in a mental health context, the ICF framework suggests that interventions can also start by promoting *participation* in community life, which may then improve the individual’s future capacity for community-based activities, and this in turn may positively impact *body function and structure*.

For example, this means that an individual who hears voices might still be encouraged to *participate* in a community event. Although the individual in question might ordinarily keep their distance, attending the event along with a family member, peer supporter or mental health practitioner might positively impact their willingness and capacity to engage in similar enjoyable events that they desire in the future. Participation may ultimately help with their symptoms as well.



Implications

These paradigms – the coherent world view linking human rights, capabilities theory, and the International Classification of Health, Functioning, and Disease – provide a substantial framework and grounding for an increasing emphasis on community inclusion and implementation of a new generation of policies, programs and practices that promote participation of those with disabilities in the community. An emerging commitment among all members of society to seek out, welcome and embrace individuals who have typically been excluded is the vision of the future.

These paradigms, combined with current rehabilitation frameworks and evidence from the field of mental health, lead to 11 fundamentals that can serve as a blueprint for the future development of community-inclusion initiatives. An array of stakeholders – individuals with disabilities themselves, their families and friends, those who provide supports within human services agencies, funders, and, importantly, the wider community – can follow these principles to move community inclusion from a vision to a reality.

Fundamentals of community inclusion

In the following section we describe the fundamentals of community inclusion and provide the theoretical, conceptual and evidence-base underlying the significance of each. As stated earlier, the evidence base that is offered focuses primarily on research focused on individuals with mental health issues, but is applicable to individuals with other disabilities. These fundamentals provide the rationale and underpinnings for promoting community inclusion. Each of the broad statements of fundamentals below is followed by one or more explicit propositions and its supporting research base.

FUNDAMENTAL 1

Community inclusion
is important



“Policies should emphasise and fund community inclusion endeavours on par with programs and practices that target other outcome areas”

Community inclusion is important

Treatment, rehabilitation services and varied supports for individuals with disabilities have often focused on an array of intended outcomes that have not led to community inclusion. For example, services for people with psychiatric disabilities often target a reduction in symptoms or suicide, decreases in hospitalisations or crisis services, or outcomes such as quality of life, wellbeing and recovery. A focus on community inclusion is just as important as these other targeted outcomes.

On the one hand, establishing community inclusion outcomes as a priority underscores it as a human right within the framework of The Declaration on Human Rights for People. This means that the promotion of community inclusion cannot be relegated to secondary status, lagging behind, for example, efforts that specifically target body and function (eg medications to treat symptoms associated with mental health issues) or fiscal efforts to control service use and costs. This further means that policies should emphasise and fund community inclusion endeavours on par with programs and practices that target other outcome areas.

On the other hand, community inclusion is important because it has been so thoroughly overlooked by human services policy and programming in the past, with a significant negative impact on the lives of individuals with disabilities. For instance, there is strong evidence that, despite the downsizing of large mental hospitals, those individuals affected by mental health conditions remain substantially segregated from the mainstream. For example:

- Housing is often clustered in poorer communities where less adequate housing, limited access to human services and other neighbourhood resources, and the problems of crime lead to diminished opportunities for participation (Metraux et al. 2007; Wong et al. 2007);
- Unemployment has remained in the 80%-90% range in most studies (Baron, 2002; Anthony, 1994; NIDRR, 1992), a staggering rate of disengagement from the broader society, while employment programs continue to be underfunded and/or underutilised (Baron, 2002; NASMHPD, 2012; Drake, 2009); and
- Social networks are significantly attenuated, with individuals affected by mental health conditions reporting only one-third the number of other individuals in their social networks (many of whom are mental health staff) as those in the general public (Biegel et al. 1994).

Community inclusion is important primarily because it has demonstrably positive effects on the lives of those with disabilities.





Community participation is beneficial

Community inclusion leads to increased participation in a broad range of life domains that are meaningful to individuals: work; school; leisure and recreational activities; religious and spiritual participation; parenting; dating and other social relationships, among others. The benefits of participation are clear, both for the general population as well as for people with disabilities.

Research in the area of positive psychology has found four areas of participation that are keys to happiness among the general public:

- Meaningful relationships with family and friends – and the deeper the relationships the better;
- Marriage or serious, long-term partnerships with a significant other;
- Religious, spiritual or philosophical beliefs in something bigger than yourself; and
- Working toward goals that one finds enjoyable.

In a related vein, Dolan et al. (2008) articulated areas where lack of participation is associated with unhappiness. These include:

- Separation – having unstable intimate relationships;
- Unemployment; and
- Lack of social contact – not seeing family and friends.

A similar set of findings exist regarding participation for people with serious mental health issues. The following table describes some of these findings by participation domain.



Table 1: Evidence of the benefits of community participation for people with psychiatric disabilities

Participation domain	Evidence	Citation and population
Employment	Provides structure, opportunity for socialisation and meaningful activity, increase self-esteem and personal mastery, helps cope with symptoms	Van Dongen, C.J. (1996). – Diverse population of people with mental illnesses
	Higher quality of life, higher overall self-rated quality of life, more internal locus of control, and a better global functioning	Eklund et al. (2001) – Persons diagnosed with schizophrenia
	‘Work contributes to the recovery process by providing meaning in one’s life’	Provencher et al., (2002) – Psychiatric disabilities
	‘Competitive work group showed higher rates of improvement of symptoms; in satisfaction with vocational services, leisure and finances; and in self-esteem than did participants in a combined minimal work-no work group’	Bond et al. (2001) – Diverse population
	Formerly unemployed psychiatric patients who obtained competitive employment while participating in a vocational program tended to have lower symptoms, better overall functioning, higher self-esteem	Mueser et al. (1997) – Diverse population
Education	Significant increase in competitive employment; significant decrease in hospitalisations	Unger (1991) – Young adults with long-term mental illnesses
	Significant increase in self-esteem	Cook (1993) – Severe mental illness
	Achieve life goals, self-esteem, empowerment, meaning in life	Mowbray et al. (2002) – Diverse populations
Friendships and marital relationships	Friendships – enhanced quality of life, and ability to cope with life stressors and vulnerabilities	Boydell et al. (2002) – Diverse populations
	‘Social support interactions were significantly associated with better satisfaction with social life. . . while negative interactions were associated with poorer overall life satisfaction, satisfaction with leisure and satisfaction with finances’ (p. 415)	Yanos et al. (2001) – Severe mental illness
	Having a close friend and having a friend providing help were more highly correlated with general life satisfaction. Marital status also associated with higher general life satisfaction	Kemmler et al. (1997) – Schizophrenia

Participation domain	Evidence	Citation and population
Parenting	<p>81% felt that becoming a mother was a positive event. Advantages of having children described by mothers included:</p> <ol style="list-style-type: none"> 1) Child gives love to mother; 2) Mother provides child with a chance to grow and develop; 3) Child provides mother with a chance for personal growth; 4) Children provides roots and immortality; 5) Mother gives love to child. <p>Described how having a child changed your life:</p> <ol style="list-style-type: none"> 1) Motivates mother to be responsible, grow as person; 2) Keeps mother from drugs, deviant lifestyle; 3) child provides support 	<p>Mowbray et al.1995) – 24 mothers with serious mental illnesses</p>
Religion/ spirituality	<p>‘Positively associated with psychological well-being and diminished psychiatric symptoms, and significantly related to recovery, social inclusion, hope, and personal empowerment’</p> <p>‘Religious salience was positively related to empowerment, and religious service attendance was tied to increased use of recovery-promoting activities’</p> <p>Recommendations based on the results:</p> <p>‘Mental health service consumers’ reliance on religious faith and service attendance cannot and should not be dismissed as a symptom of their underlying psychopathology’</p> <p>‘One purpose that religion plays in coping is that one’s faith can provide a sense of meaning and purpose that affords the individual a sense of hope for the future and a source of comfort for the present’ (p. 121)</p>	<p>Corrigan (2003)</p> <p>Yangarber-Hicks (2004)</p> <p>Bussema & Bussema (2000) Diverse mental health populations</p>
Physical activity/ leisure/ recreation	<p>Physical benefits (eg weight loss, reduced risk of diabetes), higher quality of life and well-being, reduce symptoms of schizophrenia</p>	<p>Richardson et al. (2005) Diverse mental health populations</p>



“Recovery and quality of life outcomes are intertwined with the concepts of loneliness and social isolation”

Greater community participation is associated with elevated levels of recovery and quality of life

Recovery and quality of life are key outcomes emphasised in mental health systems around the world. Salzer (2006) hypothesised that increased opportunities to participate in the community would result in actual increased community participation, and thus to improved recovery and quality-of-life outcomes as well. One study involving data from more than 600 individuals with serious mental health issues examined the relationship between community participation, recovery and quality of life (Burns-Lynch, Brusilovskiy & Salzer, in press). Modest, but statistically significant positive relationships were found between the number of days of community participation and recovery and quality of life. In other words, the more someone participated in the community the greater their subjective experience of recovery and quality of life. Stronger relationships were found in areas that individuals identified as important to them.

Community participation increases social contacts that can lessen loneliness and enhance belonging

Recovery and quality of life outcomes are intertwined with the concepts of loneliness and social isolation, and these have become major public health concerns as a result of research suggesting that they are associated with both cognitive decline (Cacioppo & Hawkley, 2009) and greater healthcare utilisation among older adults (Gerst-Emerson & Jayawardhana, 2015). Persons with psychiatric disabilities have consistently been found to have smaller, less satisfying and less supportive social networks than those in other groups (Pattison, 1975). This possibly explains findings that individuals with mental health issues have a more limited sense of belonging to the community (Deweese, Pulice & McCormick, 1996; Granerud & Severinsson, 2006; Prince & Prince, 2002), and that the quality of their social relationship is likely to affect their sense of loneliness (Green et al. 2002). Community inclusion efforts that result in greater community participation are expected to have a positive impact on both loneliness and an individual's sense of belonging, in part because it has been found that social interactions are more likely to occur outside of the home (Yilmaz, Josephsson, Danermark & Ivarsson, 2008). Engagement in community-based activities (Sorgaard et al. 2001), such as recreation and leisure activities that have inherent social qualities (Coleman & Iso-Ahola, 1993), diminishes loneliness and enhance ‘belonging’.

FUNDAMENTAL 2

Community inclusion
applies to everyone
who experiences a
disability



“Research suggests that individuals with disabilities consistently outperform professional, family, and community expectations, especially when real and supported opportunities are available”

Community inclusion applies to everyone who experiences a disability

All persons with disabilities should have access to a full range of initiatives aimed at enhancing inclusion, regardless of others’ beliefs about the severity of their impairments or their perceived readiness for inclusion. Research suggests that individuals with disabilities consistently outperform professional, family and community expectations, especially when real and supported opportunities are available, despite discouraging labels and/or assessments of ability.

Individuals who were believed to be incapable of living in the community consistently have been found to be able to live successfully in the community

Research has found that approximately 50-60% of people who had once been hospitalised in US psychiatric institutions and who had been assessed as chronically in need of inpatient care were found to be ‘recovered’ many years later (22-37 years), as defined by having at least one of the following results: not being recently hospitalised; not having psychiatric symptoms; not taking psychiatric medications; working or otherwise successfully engaging in the community (Bleuler, 1978; Huber et al. 1975; Ciompi & Muller, 1976; Harding et al. 1987; Tsuang, M. et al. 1979).

Additional research which followed individuals who were released from institutions that were closing found similar results. TAPS – the Team for the Assessment of Psychiatric Services – in the UK was created to replace psychiatric hospitals with community-based services. In one study, researchers followed 737 people who went to residential facilities with supports for one year following institutional discharge (Leff et al. 1996) and found that more than 95% were successfully living in the community: there had been only 24 deaths (two by suicide), seven people who had possibly become homeless, and two individuals who went to prison. A series of studies in the United States had similar results. Okin et al. (1995) followed 53 people for up to seven and a half years following discharge to comprehensive, structured residential services. They found that 57% continued to live in the residential settings, 28% moved on to independent living, and only 16% returned to an institutional setting. In terms of service use, 55% needed hospital readmission, but for only 11% of their post-discharge days, while 89% of their post-discharge days were spent outside a hospital or institutional setting. McGrew et al. (1999) followed the final 303 persons discharged from Indiana Hospital for up to two years. They found that 73% stayed out of the hospital and 96% stayed out of jail or homelessness after 24 months.



Aileen Rothbard et al. (1998) followed 321 people discharged from Philadelphia State Hospital, in Pennsylvania (US) for three years. They found that only 20%-30% required rehospitalisation for an average of 76–91 days per year. The median (50%) total treatment costs (health and mental health) per person was approximately \$60,000 a year after controlling for inflation, compared to an expected \$130,000 a year to maintain these same individuals in an institutional setting. In a 10-year follow-up study of this same population (Rothbard et al. 2007) they found that in one year only 18% of participants had a psychiatric hospital admission, with a mean length of stay of 60 days, and that over a 16 year period only 3% were in county jails and only 9% had experienced homelessness.

These same studies also found that people who have been discharged into the community reported having better lives. Leff et al. (1996) found that people who had been discharged from institutions reported appreciation for increased freedom, an increase in friends, and some satisfying contact with neighbours and others in the community. McGrew et al. (1999) examined pre-post discharge assessments for 88 individuals discharged from the Indiana hospital and found that people were equal or better functioning than prior to discharge and experienced consistent improvements in quality of life.

No evidence exists showing practitioners' ability to predict whether or not a specific individual will be able to participate in the community, or how much or when an individual can participate

Prediction at the individual level can be a dangerous undertaking (Aber & Rappaport, 1994). Research aimed at understanding the overall relationship between clinical, demographic, or other factors and future behaviours or outcomes of interest (such as acts of violence, gainful employment, or social success) can be incredibly useful. For example, developing new interventions for adults who are illiterate or individuals with disabilities who are parents, often rests on meeting the identified needs of a group of people with common issues. Prediction of outcomes for a population of people with common issues is based on probabilistic models at a *group level* and, while able to give us a sense of the probability that individuals with specific characteristics may or may not be successful in a given arena, it is by no means deterministic at the *individual level*. This recognition underlies the reality that no practitioner, or others, are able to predict who is 'ready' for community inclusion on an individual basis.

For example, current research demonstrates that 'indirect approaches' and attempts to enhance individual 'readiness' for employment do not typically result in successful competitive employment outcomes for individuals with mental health issues (Bond, 2004). In fact, no specific client factors, including diagnosis, age, symptoms (except the presence of extreme, non-baseline symptoms) and prior hospitalisations, are consistently predictive of employment success (Bond, 2004), while one consistent factor associated with successful employment is motivation to engage in the activity (ie the person says they want to do it) (Bond et al. 2008; Burns et al. 2007; Skivington et al. 2014).

Types and levels of community participation will vary with the unique abilities and motivations of the individual

Those without disabilities participate in their communities in various ways and to varying degrees. Some people choose to work full-time and some part-time. Some people choose to go to a place of worship and others do not. Some like to go to movies or concerts frequently and others choose to go less often or prefer sporting events. Community inclusion will vary among individuals who experience psychiatric disabilities as well (Salzer et al. 2014). That is, to ensure that community inclusion is a valued goal for everyone, each person's unique capacities and interests will need to be understood and accommodated, in the same way in which this occurs in the broader community. For instance, successful competitive employment for some with disabilities may indeed lead to a 40-hour-a-week job, but for others may mean part-time work, while some careers involve a long-term attachment to a particular employer or field even as others choose a variety of short-term jobs etc. University students with disabilities could take a full course load or fewer subjects. The key point to keep in mind is the importance of assuring individuals with disabilities the same choices with regard to participation as others in the community supporting individuals in meeting their desired participation goals without a preconceived notion of what is or what is not possible, desirable, or acceptable.



FUNDAMENTAL 3

Community
inclusion requires
seeing 'the person',
not 'the patient'



Community inclusion requires seeing 'the person', not 'the patient'

Individuals with disabilities should be viewed as valued individuals with hopes, dreams, desires and capabilities like everyone else, rather than as a 'patient' where the focus is solely (or even primarily) on their impairments. This shift in perception is as much an issue for those who work in the disabilities field as it is for community members, and a broad body of research suggests that the ways in which human services staff think about and respond to individuals with disabilities impacts how individuals with disabilities think about themselves and their prospects for participation in the broader society.

Mental health professionals often have negative beliefs and attitudes toward people with mental health issues

Research consistently demonstrates that health care professionals have negative beliefs and attitudes toward individuals with mental health issues. For example, Mukherjee et al. (2002) gathered data from medical students in London and found that 54% viewed individuals with schizophrenia as a danger to others (vs 71% in general population) and 21% said that individuals with mental health issues will 'never recover' (vs 51% in the general population). Lawrie et al. (1998) found that general practitioners in Scotland were less happy to have someone diagnosed with schizophrenia as a patient, and viewed them as more prone to violence, than they were with regard to their other patients.

Similar results have been found among mental health professionals as well. Lauber et al. (2006) surveyed 1073 mental health professionals from 29 inpatient and outpatient facilities in Switzerland and compared their responses to 1737 members of the lay public. They found that psychiatrists reported more negative attitudes than either professionals in other disciplines or members of the general public, and that all professional groups were more favourable to involuntary treatment – rather than community-based care – than the general population. In terms of community inclusion, Magliano et al. (2003) surveyed 714 lay people, 465 mental health professionals and 709 relatives of persons diagnosed with schizophrenia in Italy. They found that:

- 54% of professionals said persons with schizophrenia 'should not get married' (vs 40% in the general public);
- 64% of professionals agreed that 'people with this disorder should not have children' (vs 61% in the general public);
- 27% of the professionals felt that 'patients with this disorder should not vote' (vs 29% in the general public); and
- 79% of the professionals said patients with this disorder are less able to work than other people (vs 77% in the general public).



“Negative beliefs and attitudes among mental health professionals ... can facilitate self-stigma among individuals with mental health issues that may make them less inclined to participate in the community”

Grausgruber et al. (2007) surveyed 460 non-physician staff members from mental healthcare institutions in Austria and found that only 19% of staff would be willing to have someone with schizophrenia take care of their child, versus 11% of the general population, and only 53% of staff are willing to interact with someone with schizophrenia as a fellow employee, versus 35% of the general population.

Two summaries of research about mental health provider beliefs and attitudes towards people with mental health issues reached similar conclusions. Schulze (2007) wrote that ‘...nearly three quarters of the relevant publications (reviewed) report that beliefs of mental healthcare providers do not differ from those of the population, or are even more negative’ (p. 142). Wahl & Oroesty-Cohen (2010) reviewed journal articles published between 2004 and 2009 and found evidence in 14 out of 19 articles that mental health professionals had more favourable beliefs and attitudes when compared to the general population. However, they also found consistently negative findings (that is, worse than the general population) even in those studies with positive findings with particular regard to ‘social distance’, that is, respondents’ reluctance to interact socially or occupationally with people affected by mental health conditions. They concluded that ‘it may be more appropriate, then, to conclude that results are mixed with respect to the nature of professional attitudes toward people with mental health issues.’ This is the same conclusion reached by Schulze in her 2007 review’ (p. 58). Among other things, a primary concern about the presence of negative beliefs and attitudes among mental health professionals is that it can facilitate self-stigma among individuals with mental health issues that may make them less inclined to participate in the community.

The expectations of professionals about individuals with mental health conditions contribute to negative outcomes

The myth of Pygmalion – in which a Greek sculptor falls in love with one of his statues to such an extent that it brings the statue to life – has served as a metaphor for a substantial line of research, primarily in the field of education, of the ‘Pygmalion Effect’. This research examines the extent to which teachers (or presumably any authority figures) who hold high expectations of a person will generate greater performance than expected from that person. More recent research, however, has also examined whether the opposite can also be true: that is, will low expectations of a person result in poorer performance? One recent report in the educational arena finds support for this theory (Boser, Wilhelm & Hanna, 2014). While there is little similar research in the disability field, it is plausible that low or negative expectations that professionals/supporters have for people with disabilities will be associated with lower levels of community participation and inclusion. Similarly, it is believed that how practitioners view the individuals they support will affect what practitioners focus on in their work and target for outcomes. For instance, if practitioners keep in mind the hopes, dreams and desires of people they are working with then they might be more inclined to focus on promoting community inclusion.

If they do not, and focus on impairments instead, they might not promote community inclusion and instead target, for example, symptom stabilisation and maintenance. Salzer and Baron (2014) reported on the use of a narrative exercise to identify 'schemas' – an organized set of thoughts and beliefs that convey a person's way of viewing the world around them – that are held by mental health policymakers and providers about a person diagnosed with schizophrenia. Participants in the exercise were asked to 'write a story about a man named John who is 38 years old and has been diagnosed with schizophrenia. Your story can include anything about how John thinks, feels, or behaves. The story should have a beginning, a middle, and an end'. An analysis of the stories developed showed that there were two core schemas, or story types, that emerged, one referred to as 'John the patient' stories and the other referred to as 'John the person' stories.

The 'John the patient' stories generally went something like this:

John the patient

John was released from the hospital. John got a room at the YMCA. Once a month he would get a phone call from his caseworker. John would spend most of the day sitting in his room. John was afraid to go outside as he felt people were looking at him or talking about him. When John was in the hospital he sometimes felt the same way, but not always. At the hospital they gave him pills and there were people who talked to him, sometimes this made him feel better. John had doctor's appointments once a month at the clinic, sometimes he would go, sometimes he wouldn't because he forgot. They would also give him pills, which he would take sometimes but other times he would forget or he couldn't find them. John thought people were breaking into his room and stealing them. As John got lonelier and more scared he just stayed in his room. He didn't bathe or shave or wash his clothes. When he did leave his room people would point and talk about him because he was dirty and smelled. One day John went out and when people started pointing at him he yelled at them and threatened them. They called the police, who arrested him. After a few days in jail John had a hearing and was sent back to the hospital. This made John feel better. He once again had people who cared about him.

These 'John the patient' stories focus on illness and symptoms (eg fear, loneliness, hygiene), violence, criminal justice involvement, pills, non-adherence and hospitalisations. The expectations are characterised by hopelessness and chronicity, and the target of services is on body function and structure with the hope of achieving stabilisation and maintenance to keep John out of harm's way.



The 'John the person' story went something like this:

John the person

John lived in his country home with his parents and three older siblings. As the youngest child, with three older sisters, he was the centre of his family's attention for many years and enjoyed being the focus of their lives. He was not at all thrilled with the idea of leaving this nurturing environment to enter school, where other children often made fun of him and teased him, but he did! His high school years weren't especially enjoyable, especially compared to his earlier life experiences within his family, so he was excited about the opportunity to begin working at the local McDonald's after graduation. John is not very interested in talking about the time of high school graduation until now, saying that it has been a very difficult struggle, one in which he watched both of his parents die of cancer within two years of each other, and his other three sisters become further distant in his life. He talks briefly about receiving a diagnosis of schizophrenia, and the many doctors, counsellors and hospitals, all of which had different labels and treatments for the problems he kept finding himself in, but he prefers now to focus on his new, one-room apartment that he's just moved to, and the fact that he is the short-order cook at the local Friendly's, working 15 hours a week. John thinks about asking Mary, a waitress on a date, going to his sister's home for a Memorial Day picnic, and saving enough money to buy a cassette player. John is a 38-year-old man who dreams about finding a girlfriend, working more hours, managing his finances, seeing his sisters more and keeping his current apartment.

In this story the impairments associated with schizophrenia are acknowledged, but they are discussed in relationship to John's life, relationships and community. John's individual hopes, dreams and desires are readily acknowledged and are the central focus of the story. The practitioner who would write such a story would have an easier time focusing on community inclusion and maintaining an expectation that John, or anyone else they supported, could successfully participate in the community.

FUNDAMENTAL 4

Self-determination
and dignity of risk are
central to community
inclusion



“Many of our best achievements came the hard way: we took risks, fell flat, suffered, picked ourselves up and tried again”

Self-determination and dignity of risk are central to community inclusion

The opportunity to live, and be heartily welcomed, in the community requires both clear opportunities for *self-determination* and ongoing acknowledgement of the *dignity of risk*. These are not only responsive to the advocacy demands of individuals with disabilities, but also form key elements of effective programs.

Self-determination refers to ‘acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference’ (Wehmeyer, 1996, p. 24). With regard to the challenges of community inclusion, individuals with disabilities themselves should prioritise the types of participation that are most meaningful to them and should determine the degree to which they wish to participate in each. *Dignity of risk* (Perske, 1981) refers to the right to make choices that affect one’s own life even when these choices could, or do, turn out to be mistakes, allowing individuals to learn from their mistakes along the way like everyone else. *Self-determination* and the *dignity of risk* are not always afforded to individuals with disabilities, including those with intellectual, cognitive and psychiatric disabilities. Perske writes, ‘Many of our best achievements came the hard way: we took risks, fell flat, suffered, picked ourselves up and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Persons [living] with [disabilities] need these chances, too’ (1981).

People with disabilities would, could, and should participate in community life

Policymakers and providers, when confronted with the demand for community inclusion of individuals with serious mental health issues, often respond by expressing their doubts that they would, could, or should participate in community life.

The ‘wouldn’t’ concern is typically expressed through the lens of the diagnosis and symptoms, such as anhedonia (inability to experience pleasure from activities) and alexithymia (inability to identify and describe emotions that may interfere with interpersonal relationships) in schizophrenia, or general lack of energy and motivation associated with both schizophrenia and depression. The lack of ‘motivation’ observed by some providers, however, may be less a motivational problem and more the response of people who have been discouraged by clinicians and/or carers from establishing community inclusion goals or who experienced numerous failed attempts at community inclusion that have been thwarted by ineffective supports and/or by environmental barriers. For instance, individuals affected by mental health conditions who want to work may also have had to contend with employer prejudice and discrimination or disincentives to work (which may involve cuts in public economic support or more limited access to health care).



Research, however, suggests that the desire to participate in the community in varied ways is quite strong. In one study, Baron (2003) found consistent expressions of consumer interest in competitive employment, despite widespread professional beliefs that consumers were disinterested in economic self-sufficiency. Salzer et al. (2014) examined how important various areas of community participation, including employment, were among 119 people with a psychiatric disability. These results are presented in Table 2. It is clear from these data that people with psychiatric disabilities would participate in the community.

The ‘couldn’t’ concern is typically expressed when practitioners point out numerous deficits or impairments that are believed to make it impossible, or nearly impossible, for the person to participate. In the mental health context this might include high levels of symptom severity, impairments in cognitive abilities (including problem-solving and memory issues), social skill issues, or other concerns that could limit participation. Contrary to this belief, as was described earlier, there is ample data indicating that people with the most severe impairments can live successfully in the community. Moreover, supports technologies have been developed to assist a wide-range of individuals in their ability to establish a home in the community, work in the community, be educated in the community, and socialise in the community, as described in a later section in this report – all of which make it clear that people with psychiatric disabilities *could* participate in the community.

Finally, the ‘shouldn’t’ concern emerges out of two fears. The first is that participation itself will lead to stress in the life of an individual with a mental illness, resulting in an exacerbation of symptoms, psychiatric crisis, and then re-hospitalisation. The oft-preferred solution – to eliminate whatever produces stress – often eliminates community inclusion as a meaningful goal for both the individual and his/her supports staff. On the contrary, Marrone and Golowka (1999) point out that while work is stressful for everyone, not working, and the resulting poverty, is likely much worse. The second fear is that mistakes can happen when people participate in the community: someone can get lost taking public transport; an unwanted pregnancy or a sexually transmitted disease could result from efforts to support romantic or intimate relationships; or an incident could occur in a religious setting. But studies in a wide-range of areas indicate that participation actually benefits people with mental health issues (see Table 1). Further, while the occasional negative consequence of participation cannot be completely avoided, there are proactive approaches that can be taken to limit the chances that such negative outcomes will occur and to lessen their impact if they do (Burns-Lynch, Salzer & Baron, 2010). As a result, it is clear that people with psychiatric disabilities should participate in the community in ways of their choosing.

Table 2: The importance of community participation

Importance and sufficiency of community participation	Total # of respondents	Importance		Sufficiency (for those who consider activity important)			
		Yes		Less than desired		As much as desired	
		N	%	N	%	N	%
Go shopping at grocery store?	118	114	96%	32	28%	61	54%
Use public transport?	119	109	92%	20	18%	68	62%
Go to run errands?	118	105	88%	19	18%	68	65%
Entertain family or friends in your home or visit family or friends?	118	95	81%	50	53%	40	43%
Go to a barber shop, beauty salon, nail salon, spa?	118	91	76%	44	48%	39	43%
Go to a church, synagogue, or place of worship?	117	90	78%	53	59%	32	36%
Go to a gym?	119	85	71%	56	66%	22	26%
Get together in the community or attend an event with family or friends?	119	85	72%	41	48%	39	46%
Go to a park or recreation centre?	118	84	72%	40	48%	43	51%
Work for pay?	118	83	71%	54	65%	24	29%
Go to a restaurant or coffee shop?	119	81	68%	38	47%	36	44%
Participate in volunteer activities?	119	81	68%	34	42%	39	48%
Go to a library?	119	80	67%	46	58%	33	41%
Go to a 12-step group for mental health issues?	119	78	66%	28	36%	44	56%
Go to school to earn a degree or certificate?	119	75	63%	51	68%	21	28%
Go to a community fair, community event or activity?	118	72	61%	41	57%	29	40%
Go to a theatre or cultural event?	118	68	58%	46	69%	17	25%
Go to a movie?	117	67	56%	47	70%	18	27%
Go to watch a sports event?	119	65	55%	41	63%	22	34%
Go to a zoo, botanical garden, or museum?	116	60	52%	43	72%	16	27%
Take a class for leisure or life skills?	118	59	50%	38	64%	20	34%
Go to a social group in the community?	118	59	50%	38	64%	19	32%
Go to or participate in civic or political activities or organisations?	118	53	45%	36	69%	14	27%
Go to a consumer-run organisation?	118	50	42%	30	60%	20	40%
Go to a 12-step group for substance use problems?	119	48	40%	15	31%	30	63%
Go to another type of support group?	117	43	36%	16	37%	24	56%



Individuals with disabilities have personal preferences about the aspects of community life that are important to them, and those preferences may change over time

The section above outlines reasons that have been expressed for why people with mental illnesses would not be supported to participate in the community in ways that they desire. This section comments on the concern that efforts to promote community inclusion will include encouraging people to participate in areas where they do not want to participate or to a degree that they are not interested. The data in Table 2 simultaneously suggests that people with psychiatric disabilities want to participate in a variety of ways and that not everyone feels it is important to them to participate in every area. For example, 71% report that working for pay is important to them, meaning that 29% indicate that work for pay is not important to them. This occurs in every other domain except for shopping and using public transportation, which most agree is important. In terms of sufficiency, despite the finding that most participation in these domains is limited to a few days at most each month (Salzer et al. 2014), some people are satisfied with the degree to which they participate, as indicated by the column representing the percentage of people who indicate they engage in the domain 'as much as desired'.

Cultural differences represent another arena in which personal preferences are often expressed and which lead to the requirement that human services workers not only interact with those with disabilities in a culturally competent manner, but also are comfortable facilitating community inclusion within culturally varied frameworks. On the one hand, Betancourt and Green (2010) point out that 'research has shown that cultural competence training improves the attitudes, knowledge, and skills... that are related to caring for diverse populations... and also improves patient satisfaction' – important qualities even if, as they point out, there is still little evidence 'that have shown any impact on... health care outcomes' (Beach, et al. 2009; Paez et al. 2009). On the other hand, within systems that truly value self-determination, individuals with disabilities who come from diverse backgrounds – diverse from one another and diverse with regard to program staff – are likely to express culturally varied interests with regard to community inclusion. Programs must be able to respond respectfully and effectively in helping individuals who have different culturally determined preferences with regard to connections with family and friends, different emphases on work or religion, and different levels of commitment to culturally specific cultural or advocacy activities.

Opportunities for self-determination are associated with positive outcomes

While there are no self-determination interventions per se, there are a number of current and emerging interventions where self-determination plays a primary role.

The Wellness Recovery Action Plan (WRAP®) is rooted in the principle of self-determination and involves an individual, often with support from a peer or group of peers, identifying issues that are intrusive or troubling and implementing strategies for coping with or overcoming them, along with a plan for increasing empowerment, quality of life, and the achievement of their own life goals and dreams. One randomised, controlled trial involving WRAP showed it is associated with decreased symptoms and enhanced hope and quality of life (Cook et al. 2011; Jonikas et al. 2013).

A Psychiatric Advanced Directive (PAD) is a process whereby someone develops a written document that explicitly describes what an individual wants to happen if they are determined to be incompetent at some time in the future or are unable to communicate their preferences for care (Appelbaum, 2004; Elbogen et al. 2006; Swanson et al. 2006; Srebnik et al. 2003). PADs often include an expression of preferences with regard to which hospitals or providers someone would, or would not, prefer to be involved in their treatment, which medications they prefer, who they would like to be contacted in a crisis, and the needs that they would like attended to (such as plans for caring for a pet or paying the rent). The presence of a PAD has been found to be associated with greater service engagement and adherence (Swanson et al. 2010) and fewer involuntary commitments (Swanson et al. 2008).

Shared decision-making refers to an intentional and active process in which clinicians and consumers work together to identify service goals, preferences and support plans to help meet the consumers' goals. Shared decision-making requires more than consumer input and signing off on support/treatment plans: research suggests that one end result of a truly shared decision-making process is that consumers are more satisfied with the care planning process and had better recall of the care plan (Woltmann, et al. 2011; Moran et al. 2014).



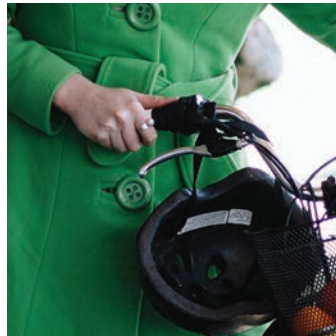
FUNDAMENTAL 4

Self-directed care (SDC) is another type of initiative with many variations that generally allows individuals to maximise personalisation of services by enabling them to identify and select the services they believe will facilitate the achievement of their life goals. Often, SDC involves the following: 1) Consumers identifying treatment/service goals with support from an individual whose job it is to facilitate self-determination; 2) Control over a budget to be used to purchase goods and services to achieve those goals; and 3) The opportunity to purchase traditional services (eg medications, psychiatry care, etc) as well as goods and services outside the mental health system that will help them achieve their life goals and wellness.

One interesting aspect of SDC is that it facilitates the use of 'personal medicine,' which has been described by Dr Patricia Deegan as self-taught, non-pharmaceutical strategies that persons with mental health issues use, sometimes in combination with psychiatric medication, to advance their recovery and improve their lives (Deegan, 2007). Deegan notes that 'there seem to be as many types of personal medicine as there are individuals: fishing, parenting, repairing airplanes, walking, diet, caring for pets, friendship, driving...'. Current research in mental health suggests that participation in SDC programs is associated with greater satisfaction with care (Welder et al. 2015; Doty et al. 2007; Shen et al. 2008), enhanced opportunities for pursuing personal medicine (Snethen et al. 2016), and enhance community tenure and participation, greater functioning, and fewer hospitalisations (Cook et al. 2008). SDC participants also use more preventive care (eg psychiatry and outpatient psychotherapy) and fewer crisis services (Hall, 2007).

FUNDAMENTAL 5

Community inclusion
should embrace
multiple domains
of mainstream life



Community inclusion should embrace multiple domains of mainstream life

Housing and employment are two areas that get the most attention when discussing community inclusion, and they receive the predominant amount of funding that is available. However, it is critical to attend to other areas of community inclusion as well, because they are also important to people.

People find various life domains to be important, yet they report that they are rarely satisfied with their level of engagement in those areas they feel are most important. In Table 2 we presented results from the Salzer et al. (2014) study on the importance of various areas of community participation among 119 people with a psychiatric disability. 'Work for pay' was important to 71% of the respondents. However, a number of other domains of participation were found to be even more important, including: shopping; use of public transportation; running errands; entertaining family or friends and visiting family or friends; going to a barber shop, beauty salon, nail salon or spa; going to a church, synagogue, or other place of worship; going to a gym; getting together in the community; attending an event with family or friends; or going to a park or recreation centre. Work was among the top areas where people were not doing as much as they would like (65% reported working less than they desired), but there was insufficient participation in other areas as well, including worship, working, education, community events, cultural activities, attending a sports event, visiting zoos or gardens, cultural involvements, and taking classes for leisure or life skills. The importance of attending to all domains is further supported by the research evidence presented earlier in Table 1, which describes the benefits associated with participation in each area.



FUNDAMENTAL 6

Community inclusion focuses on participation that occurs more like everyone else



Community inclusion focuses on participation that occurs more like everyone else

As described in Salzer et al. (2014), community inclusion means opportunities for participation in community life that is centred around three questions: 1) Where does the participation take place? 2) Who chooses and directs the participation? and 3) How much does the activity maximise opportunities to participate with others who do not necessarily experience disabilities. The overarching goal is to provide opportunities for participation that is more like everyone else, on each of these three dimensions.

Where does the participation take place?

In answering this question, the opposing endpoints on a continuum of activities are those that take place within mental health institutions and human services facilities vs participation that is more genuinely community-based. Examples of participation within mental health institutions or programs would include sheltered workshops, in-house vocational training workshops, educational classes, or agency-based dances, movie nights, and exercise classes. Examples of community-based participation in these same areas are mainstream job training programs, competitive employment, enrolment in degree-earning programs at local colleges, bingo at a church or community centre, individual membership in a local YMCA gym, or joining a hobby club or citizen action group on one's own or with a friend. Baron has commented on 'the overly warm embrace of mental health systems' (2008) and the tendency of staff to share service recipients' anxieties about participation in the world. Support staff then provide 'substitute' experiences – holiday dinners, group trips to the movies, etc – in which community life is approximated without the sometimes-uncomfortable realities of individual community engagement in the abundant mainstream groups that already exist in most everyday communities.

It is also useful to note that 'community' activities are not necessarily activities that are centred in one's immediate neighbourhood. Sociologists (Putnam, 2000) have noted that in today's world almost everyone has access to a much wider set of 'belonging' options: individuals today may retain close relationships on the phone with family and friends in other cities; many people travel miles to attend a Sunday church service and related social events at a preferred congregation; online interest groups draw people together around shared interests rather than shared geography; and getting together with people with a shared ethnic, religious, or political set of values draws people to one another across traditionally defined community boundaries.



Who chooses and directs participation options?

In assessing who chooses participation activities, the opposing endpoints on a continuum are program/staff-directed vs person-directed. It sometimes may seem expedient for program staff to make decisions about participation, especially in the leisure and recreational domain, because staff are familiar with the activity, tickets for a group are available, the event is close by and easier to get to, or there is a staffing shortage making individualised participation with supports harder to achieve. Such an approach likely does not result in participation in areas desired by all individuals, and every attempt should be made to facilitate individualised and self-directed participation that occurs by fully soliciting an individual's hopes, dreams, and desires, and then responding with individualised supports to achieve them.

How much does the activity maximise opportunities to participate with others who do not necessarily experience disabilities?

This third question refers to opportunities service recipients have to interact with citizens who do not experience disabilities. The opposing endpoints on this dimension are participation primarily with other persons who experience disabilities (separation) vs participation that primarily promotes interactions with other persons who do not experience disabilities (association). Participation that occurs within an institution/agency is de facto separatist, but so are dating websites that are exclusively for people with mental health issues and events where groups of individuals who experience psychiatric disabilities go out into the community together to participate in organised activities. Peer support is a recognised exception to this (and is explored in the next section), but individuals also benefit from opportunities to associate with people with whom they share other interests and identities. Increased opportunities for association result from engagement in mainstream, community-based activities as an individual, with friends and family members of one's choosing or with strangers who may become friends. Again, the issue here is one of opportunity. People can choose separation for a variety of good reasons, but a focus on community inclusion requires that individuals have many options to choose from.

FUNDAMENTAL 7

Community inclusion is strengthened through emerging support technologies, the natural supports of families and friends, and the engagement of peer supports



Community inclusion is strengthened through emerging support technologies, the natural supports of families and friends, and the engagement of peer supports

As discussed earlier, the social model of disability is embedded in the WHO International Classification of Health, Functioning, and Disease. One approach for facilitating community inclusion that emanates from this model is to focus on identifying individual needs that might be associated with community participation and providing supports to address these needs. In this section we briefly describe various types of supports that are available for promoting community inclusion. Our focus is on the supports developed for persons with psychiatric disabilities, but many are also applicable to persons who experience other disabilities. The supports we discuss include those that address intra-individual barriers to inclusion, such as lack of knowledge, acute or high degree of symptoms that might interfere with inclusion, limited skills, and self – and anticipated stigma that may undermine motivation to pursue inclusion. We also discuss supports technologies that are available to assist individuals in acquiring and maintaining participation in desired areas over the long-term. It should be kept in mind that while we focus on supports that generally target change within the individual who experiences the disability, it does not mean that the ‘cause’ of disablement rests within the individual. Changes at the individual level are one way to enhance person-environment fit, but addressing environmental barriers as well, as discussed later, is also critical. In fact, while we are still accumulating research in this area, providing supports at the individual level is beneficial, but is not a panacea for promoting community inclusion. Environmental factors, especially prejudice and discrimination, as well as poverty, undoubtedly play major roles, and may even be more responsible for the lack of community inclusion that we see than the ‘impairments’ at the individual level.

Increase knowledge about community resources

Given the focus of some service systems on symptoms and impairments, it is plausible that individuals with disabilities are less often asked about their desires for inclusion and may lack knowledge about opportunities and community resources that facilitate inclusion. For example, what employment programs exist, in the mental health or other social service system or broader community, that an individual might be eligible to utilise to get back to work? How about educational resources or leisure and recreational opportunities or spiritual opportunities? Knowledge about community resources is viewed as a critical support (Gammoned & Lukens, 2001; Salzer, 2006) and a few examples of interventions that include the identification of community resources, including some involving peers, have been described in the literature (Barbate et al. 2007; Rivera, Sullivan & Valente, 2007; Wasylenki, Goering, Lemire, Lindsey & Lancee, 1993). Another modality that has been used is the development of resource guides that describe the availability of community resources.



One such guide, called the *ICAN PLAY Leisure Manual*, can be found at – <http://tucollaborative.org/community-inclusion/resources/recreation-and-leisure-resources/>. Finally, there has been some research on the use of ‘fairs’, or a specialised event to raise awareness and knowledge about opportunities and resources, to promote greater awareness among individuals with mental health issues about their own physical health conditions, including testing for diabetes, hypertension, and obesity (Cook et al. 2015). Information was also provided to persons who screened positive for a health condition or risk who were also given information about resources available to get help and treatment. A description of how this health fair was created can be found at (<http://www.cmhsrp.uic.edu/download/health-screening-dialouges.pdf>). Dr Gretchen Snethen and other colleagues at the Temple University Collaborative on Community Inclusion used a similar approach to create an ‘Activity Fair’ where community organisations could share information about leisure and recreational opportunities in the community that are available to persons with psychiatric disabilities like any other citizen. The manual for how to develop this type of event can be found at (<http://tucollaborative.org/activity-fair/>).

Offer psychopharmacological and other treatments

While it is clear that individuals with psychiatric disabilities participate less in the community than the general population, it is unclear to what extent this is due to impairments (ie symptoms) vs other factors, especially external barriers. While there is some indication that treatment for depression can enhance work outcomes (Simon et al. 2001), it has not been demonstrated that treatment alone for persons with serious mental health issues enhances community inclusion (Harvey et al. 2004). Nonetheless, it seems reasonable to conclude that evidence-based treatments are an important support to offer in order to facilitate community inclusion.

Enhance community living skills

Individuals with psychiatric disabilities may experience social, problem-solving, and cognitive impairments that may interfere with the development of a positive person-environment fit within many environments. There are a number of evidence-based practices in each of these areas, including evidence that enhanced skills result in greater community inclusion.

Social skills training aims to improve interpersonal abilities by breaking down social interactions into discrete steps and using role modelling, simulated role plays, behavioural rehearsal, corrective feedback, and homework assignments to practice new skills (Bellack et al. 2013; Mueser et al. 2013). The interpersonal skills that are acquired through social skills training have been found to generalise to everyday life (Lieberman et al., 1998; Marder et al. 1996; Glynn et al. 2002; Liberman et al. 2002), especially when they emphasize in-vivo training in the person’s natural living environment (Glynn et al. 2012; Heinssen et al. 2000; Liberman & Fuller, 2000).

Problem-solving training involves teaching a sequence of steps for dealing with various challenges. The steps are: defining the problem, brainstorming solutions, evaluating the solutions, choosing the best solution(s), making a plan to implement the solution(s), and evaluating the success of the solution(s). The evidence base underlying the effectiveness of problem-solving training has primarily focused on reductions in symptoms, although the approach could certainly be useful for individuals as they attempt, for example, to figure out how to become more engaged in their communities (Mueser et al. 2013).

Cognitive Remediation Therapy (CRT) uses a variety of training methods, including computer-based programs, to improve and sustain attention, memory, executive function, social cognition or metacognition. Susan McGurk, an international leader in this area, and colleagues published a literature review (2007) in which they reported that CRT resulted in improvements in the ability of individuals with serious mental health issues to obtain competitive employment, increase skills in addressing interpersonal problems, and enhance the quality of and satisfaction with interpersonal relationships. One recent review by Chan et al. (2015) found that computerised CRT increased workdays in a given year by 19.5 days and earnings by an average of \$959(US) compared to those not receiving CRT. It should be kept in mind, however, that while such gains are significant and economically meaningful, these increases in annual earnings do not bring people out of poverty and may not be considered adequate in terms of achieving full community inclusion (Baron & Salzer, 2002).

Other types of skills training are likely beneficial. Independent living skills that target activities of daily living and instrumental activities of daily living is likely a necessary support, although the evidence in this area is lacking. Asset development and the development of financial skills is also viewed as a promising area for intervention that is important for community inclusion (Cook et al. 2010; Cook & Mueser, 2013).

Reduce self-stigma

People with psychiatric disabilities are devalued by society and experience prejudice and discrimination in all areas of life, from work and housing to social interactions (Overton & Medina, 2008). There is also evidence that mental health professionals have similar beliefs and attitudes toward individuals with mental health issues to the general population (Schulze, 2007; Wahl & Aroesty-Cohen, 2010). People with psychiatric disabilities are aware of such beliefs about them (Phelan et al. 2000), which may lead to anticipated stigma resulting in lack of motivation, avoidance, and isolation. This awareness, combined with a person with a mental illness agreeing with the belief (eg 'People with mental health issues cannot be successful'), self-application (eg 'I have a mental illness and cannot be successful'), harms self-esteem and self-efficacy and is referred to as self-stigma (Corrigan, Larson, & Rüschi, 2009). Reduced interest or effort in community inclusion that some might conclude as being evidence that people with psychiatric disabilities 'wouldn't' participate, discussed earlier, may instead be a result of anticipated and self-stigma.



The most effective interventions are typically those that get to the root cause of the problem. In this case, it is best to target the community exclusion that leads to anticipated and self-stigma rather than trying to help people adjust, cope, or overcome the effects of prejudice and discrimination. However, given the enduring nature of prejudice and discrimination, and the colossal efforts it will take to create change, it is believed to be acceptable to focus on the consequences of stigma – self-stigma being among them, in order to possibly bring about the most immediate impact on community inclusion, while we constantly work to resolve community exclusion, as discussed more later.

Interventions have been developed to reduce self-stigma (Yanos et al. 2015). Two are mentioned here. Honest, Open, Proud (HOP) to Eliminate the Stigma of Mental Illness is a three-session program that helps participants weigh pros and cons of disclosing in different settings, teaches ‘safe’ ways to disclose should the person decide to do so, and helps people craft stories that reflect their disclosure goals. Rüsche et al. (2014) found that participants completing HOP recognised more benefits to disclosure and less need for secrecy, which was related to diminished stress and a greater willingness to ask for help. Corrigan et al. (2015) found that women who completed HOP showed reductions in depression, which was mediated by reductions in self-stigma and stress related to self-stigma. The Ending Self Stigma program (ESS) is a manualised, 8-session group-based intervention that was found to decrease self-stigma (Lucksted et al. 2011).

Evidence-based supports technology

A number of interventions have been developed to enhance community inclusion in targeted areas that have common elements to the degree that we might conclude that a “supports” technology exists. Technology, in this case, is defined as ‘.. accomplishing a task especially using technical processes, methods, or knowledge’ (Merriam-Webster). This common technology is based on the ingredients that have proven successful in increasing competitive employment outcomes: Supported Employment (Becker & Drake, 2003; Bond, 1998; Bond, Drake & Becker, 2010; Burke-Miller, Razzano, Grey, Blyler, & Cook, 2012; Burns et al. 2009; Corrigan, Larson & Kuwabara, 2007); educational achievements (Supported Education) (Mowbray et al. 2005; Soydan, 2004); and independent housing (Supported Housing) (Rogers, 2009; Substance Abuse and Mental Health Services Administration, 2010).

Each of these intervention models share these features:

- Rapid – supports begin as soon as an individual expresses interest in greater participation in a particular area;
- Placement – into competitive jobs, mainstream educational programs, or non-congregate independent housing, for example – is rapidly achieved, with no readiness requirements or pre-placement training or preparation;
- Choice – each individual is given a choice, and options, with regard to what they do and where they do it;
- Mainstream – participation occurs in normalised settings with similar expectations as anyone else engaged in that activity;
- Supports occur in community settings rather than in separate mental health facilities;
- Supports are offered as long as it is needed and desired to sustain participation; and
- Supports are integrated into other services to the degree desired by the individual.

It is believed that this supports technology could be utilised to successfully assist inclusion in the areas of leisure/recreation, spirituality, parenting, intimate relationships/dating, and other participation areas that are desired by individuals.

Natural supports

Natural supports are the relationships that occur in everyday life, such as family relationships and friendships, but also including relationships with co-workers, neighbours, clergy, fellow parishioners, peer relationships, and acquaintances from various settings in which someone finds themselves. Natural supports are differentiated from formal or paid supports, such as counsellors, therapists, line staff, care managers, and paid peer workers. Natural supports contribute to interdependence (rather than dependence) and social belonging, and facilitate dignity and self-esteem. Natural supports are also plausibly more readily available in both possible number and time (eg 24 hours a day, seven days a week) vs paid supports that are limited by funding and typical work hours and susceptible to changes in funding (Walsh & Connelly, 1996). A life that maximises natural supports relative to paid supports is a life more like everyone else's.

Walsh and Connelly (1996) identified eight categories of natural supporters and examined the extent to which each provided supportive behaviours to individuals with psychiatric disabilities.



These are described below verbatim from their article along with the percentage of supportive behaviours provided by the category out of all the supports they obtained:

- **Friends** – acquaintances identified as sharing an ongoing personal relationship characterised by intimacy (38.8% of all supportive behaviours)
- **Family of origin** – biological, blood, and legal relatives, including mothers, fathers, brothers, sisters, and adoptive and step siblings and step parents (17.2%)
- **Informal community relations** – people encountered in activities of daily living but whom the client did not generally know outside of specific and narrow roles (for example, waitresses, mail deliverers, lifeguards, police officers, pharmacists, and store clerks) (10.0%)
- **Work – co-workers, supervisors, and customers** (some respondents identified co-workers as friends, and those responses were not included in this category) (8.5%)
- **Family of procreation** – present and former spouses, as well as children and grandchildren (8.4%)
- **Extended family** – the variety of other family relationships, including aunts, uncles, cousins and grandparents (7.9%)
- **Neighbours** – people with whom a client lived in close enough geographic proximity that they were routinely seen or encountered in daily life (6.3%)
- **Church** – the clergy and their families, church members, and church workers (2.9%)

The discussion of natural supports and community inclusion has been most prevalent in the area of employment. For example, Wehman and Bricout (1999) reviewed research on the use of natural supports in employment settings and concluded that it can be associated with some positive benefits, but should not be considered an effective replacement for supported employment or other paid supports, at least for those with significant impairments. Butterworth et al. (1996) discuss the presence of natural supports as an important outcome of successful employment rather than necessarily being a method for promoting successful employment. Roberts et al. (2010) outline the promise of combining Supported Employment models with structured support to develop a person's natural support network in assisting individuals to get and keep a job.

Some strategies for enhancing natural supports and greater community inclusion include COMPEER, a program that began in the 1960s in which intentional relationships were established through matching of 'clients' (ie individuals with serious mental health issues) with community volunteers, including those with and without a mental illness. Matches commit to meet for at least four hours a month for at least one year and engage in activities that one often does with friends, such as having meals together or meeting for coffee, going to a movie, attending a sporting event, etc.

The founder of COMPEER, Bernice Skirboll, emphasised that 'From the beginning, Compeer's mission has been to help people in mental health care live happier, more productive lives' (2006). A number of positive outcomes have been found for those who participate in COMPEER (McCorkle et al. 2008; 2009), including favourable results from a study that was conducted in Australia (Montclair, 2011). Another Australia-based program, Anglicare Mental Health Project (Barringham & Barringham, 2002) also focuses on connecting people who are 'isolated and vulnerable' with individuals who support them in living their lives in the community. This program also trains community members on their critical role in facilitating community inclusion and what they call 'creating spaces for story sharing' with their match, which enhances shared human connection with one another and facilitates reciprocity, discussed below.

Salzer & Baron (2014) have commented on the importance of reciprocity, in particular, in building strong natural supports. Creating a norm of reciprocity for persons with mental health issues (Matejkowski et al. 2011) and other disabilities requires creating an expectation of 'giving' as well as 'taking' in social exchanges. The concern is that in the process of creating a supportive system we have, in one sense, put people with disabilities too much at the centre of things without asking or expecting any reciprocation based on their capabilities. As Salzer and Baron wrote (2014), 'We ask family members to be more supportive, neighbours to be more accepting, co-workers to make reasonable accommodations, and religious and interest groups to set aside their prejudices; but it is not... all that common that we ask the individual with a psychiatric disability to carry his or her own weight in those relationships if we are serious about building natural supports.'

Our Center created a document that offers suggestions for how to grow natural support systems (http://tucollaborative.org/sdm_downloads/natural-supports-developing-a-personal-support-system/). These include:

- Help people discover and express their interests. Engage them in discussions about possible choices, using inventories where appropriate
- Collaborate and partner with a person's family if he/she is comfortable with this choice
- Identify community resources that fit the person's interests
- Encourage people to participate in social or community activities that are consistent with their interests and culture
- Help people cope with social adversity by recognising potential discrimination.



Peer support

Relationships between people who have had similar experiences is theorised to be beneficial for many reasons (Salzer & Mental Health Association of Southeastern Pennsylvania Best Practices Team, 2002). As a result, there has been a worldwide emergence of a new behavioural health workforce of individuals with mental health issues who are paid to provide peer support (Salzer, 2010). Recent reviews have concluded that peer support is effective for people with mental health issues (eg Chinman et al. 2014; Rogers et al. 2009). For example, Davidson et al. (2012) concluded:

“Thus far, there is evidence that peer staff providing conventional mental health services can be effective in engaging people into care, reducing the use of emergency rooms and hospitals, and reducing substance use among persons with co-occurring substance use disorders. When providing peer support that involves positive self-disclosure, role modelling and conditional regard, peer staff have also been found to increase participants’ sense of hope, control, and ability to effect changes in their lives; increase their self-care, sense of community, belonging and satisfaction with various life domains; and decrease participants’ level of depression and psychosis.”

Peer support might be particularly effective in helping people identify areas where they wish to participate more in their communities, which could be especially challenging after many years of possibly being told that community inclusion was not possible. Peers have also been known to participate in certain activities in the community with someone they are supporting to decrease stress about going to the activity alone or to teach them how to get to the activity.

FUNDAMENTAL 8

Providing support
to family and other
natural supports
promotes community
inclusion



“A substantial amount of research finds that families affected by mental health issues engage in fewer social and leisure activities”

Providing support to family and other natural supports promotes community inclusion

Mental health issues affect everyone who cares about the individual, especially family members (Goldman, 1982). While some of these impacts are positive (Ohaeri, 2003) a substantial amount of research finds that families affected by mental health issues engage in fewer social and leisure activities, experience financial strain and diminished quality of life, and have greater levels of personal and family distress (Lefley & Wasow, 2013) and stigma (Corrigan & Miller, 2004). These can result in their own exclusion and loneliness. A focus on community inclusion therefore requires us to consider the whole family, and challenges services to provide support that enables the development of mutually supportive relationships within families and provides pathways for families and friends to engage in their own journey of recovery (Lovelock, 2015).

Enabling mutual support in families

The impact of mental health crises and subsequent experiences of disability and exclusion on a family can result in individuals being thrust into ‘caring’ and ‘cared for’ roles. These impacts may also result in a sense of loss and grief as a ‘parent’ or ‘partner’ role is obscured and in a deterioration of the mutuality inherent in healthy family relationships (Lovelock, 2015). Wyder & Bland (2014) challenge the notion of the ‘static and enduring role of caregiving’ and suggest that families need support to regain hope, reconnect, overcome trauma and make the journey ‘from carer to family’. The evaluation of Building a Future, an Australian program developed by Wellways (the organisation that commissioned this monograph), found positive outcomes from a family peer education program where families, friends and carers are supported to gain knowledge and skills in relation to their caring role, and supported to focus on their own wellbeing. The group sessions for family members resulted in less worry, tension, and distress, which was maintained at three and six month follow-up (Stephens et al. 2011). The end result of such interventions is likely more energy and community engagement that can contribute to the community inclusion of their loved one.

Strengthening the capacity of families to support community inclusion

Families, friends and carers have a unique role to play in supporting community inclusion because they often have great insight into an individual’s talents and abilities, and their interests, skills, beliefs and ambitions (Machin & Repper, 2013). However, distress, depletion of energy and resources, and loss of hope – as well as their own social isolation – diminishes the ability of families, friends and carers to believe in, advocate for, and contribute to the wellness and community inclusion of their loved ones. A robust literature exists showing that family psychoeducation can have an impact on community inclusion-related outcomes for individuals with mental health issues, in addition to impacting symptoms and relapse (Lucksted et al. 2012). For example, Mueser et al. (2001) found that two different family psychoeducation interventions both had a positive impact on the social abilities of the family member with the mental health illness.



FUNDAMENTAL 9

Environmental
barriers to
community
inclusion must
be identified and
addressed



Environmental barriers to community inclusion must be identified and addressed

The three paradigms that support the community inclusion approach – human rights, economic and moral development, and personal health – each acknowledge that the ‘the social model of disability’ is essential to an understanding of the lives of those with disabilities. Its analysis – that disability is the product of the reluctance of social systems to accommodate, welcome and embrace individuals with impairments to fully participate in the community – draws attention to the array of environmental barriers to community participation that remain either unrecognised or unchanged. In that light, it becomes critical that rehabilitation services not only provide individuals with the supports required to participate in everyday activities, but also address those very environmental barriers that exclude, isolate, and devalue individuals with differences. Although there are multiple barriers, the most serious environmental barriers consistently identified in the disability literature are: 1) Individual disempowerment (Chamberlin, 1997); 2) Sustained poverty (Elwan, 1999); 3) Inadequate transportation (Krahn et al. 2015; Sherman & Sherman, 2013); and 4) public prejudice and discrimination (Corrigan & Matthews, 2003) – a set of perplexing environmental barriers that are deeply intertwined with one another. There is, thus, much to be done by both consumers and providers, particularly in league with one another, to advocate for significant change in each of these arenas.

Individual disempowerment

Individuals with mental health issues are disempowered, with little authority over the treatment and rehabilitation decisions that shape their lives, limiting their ability to move toward personally meaningful community inclusion goals. Many of those with mental health issues – and, it should be noted, their carers as well – have little control over the treatment and rehabilitation services they will receive. Although community-based mental health programs do at least nod in the direction of ‘consumer-centred services’ and joint consumer/provider development of service plans, there is broad agreement that providers continue to assess consumer needs and prescribe treatment and rehabilitation programming with little participation from dispirited and demoralised consumers (WHO, 2010). For instance, in a series of in-depth interviews with individuals with serious mental health issues, Baron (2002) found that while most of those interviewed had worked successfully in the past and expressed strong interest in working in the future, they reported almost no exploration of their vocational ambitions in intake interviews or case management sessions.

The disempowerment of those with disabilities – the lack of ‘agency’ in addressing their needs – is troubling in light of the evidence that when those who do have the opportunity to voice their preferences for treatment and rehabilitation services are far more likely to attain outcomes that are personally meaningful to themselves.



Providing individuals with choices – in living arrangements, employment opportunities, social or cultural activities, religious connections, or other areas in which personal choices tend to differ from person to person – has significant impacts not only on treatment/rehabilitation follow-through, but also on service satisfaction and goal achievement (Corrigan, 2002). The degree to which traditional human services presuppose a ‘doctor knows best’ orientation constitutes an important environmental barrier.

The consumer movement has long argued for a wider interpretation of the demand for empowerment – for voice. On the one hand, consumers have suggested that individual programs can be strengthened by the participation of service consumers at the programmatic level, helping to define what types of programs and what service philosophies are likely to be most responsive to the needs of the client base (Chamberlin, 1979; Leete, 1988; Chamberlin & Rogers, 1990). This can be achieved by seeking and supporting the participation of consumers in agency planning, research and program development. On the other hand, consumers want a stronger voice in the design of public policies, the allocation of public funds, and the establishment of clear system goals. There is evidence as well that consumer advocacy can effectively shape public priorities and policies in ways that promote both autonomy and community inclusion (Eaton et al. 2011; McColl et al. 2003; Hutchinson et al. 2007; Bramley & Elkins, 1988; Weafer, 2003; Tsuda, 2006; Siska, 2006; Gureje, 2000).

Sustained poverty

Poverty is a pervasive barrier to community inclusion for many individuals with disabilities. The evidence on the pervasiveness of poverty among individuals with significant impairments is compelling (Elwan, 1999; Annual Disability Statistics Compendium, 2015), and the link between poverty and disability is clear, although to varying degrees around the world.

There are several ways in which disability generates poverty. First, disability creates a need for specialised equipment, expensive care, ongoing supervision, or expensive medication requirements that strain the wallets of both the individual and his or her family. Second, those with disabilities experience dramatically higher rates of unemployment. Those with serious mental health conditions, for instance, experience staggeringly high rates of unemployment (80%-90%) that has persisted for decades (Anthony, 1994 NIDRR, 1992), while most estimates of unemployment for those with other disabilities hover in the 60% range. This leaves most individuals with disabilities, even in nations where disability entitlements are available, living at or near the poverty level. Third, long-term unemployment itself contributes to the further impoverishment of the individual with disabilities, as his or her connections to supportive networks diminish or disappear over time, cutting the individual off from the types of no-cost assistance which such natural supports can provide.

“Those with serious mental health conditions experience staggeringly high rates of unemployment (80%-90%)”

Poverty has many implications for community inclusion. It confines individuals with disabilities in inadequate housing in impoverished communities (Park et al. 2010), which attenuates opportunities to interact with persons who are employed who might assist them in obtaining work (Baron & Salzer, 2002) and increases their exposure to social problems like crime and substance use (Byrne et al. 2013) that might lead to further isolation. Poverty also places significant restrictions on the funds available to make many types of community participation possible – transportation to a job site, admission to the movies, university fees, tickets for a sporting event, participation in a church-sponsored trip, appropriate clothing for community activities, etc. While service providers often look for low-cost or free opportunities for those they serve to participate in everyday activities, this often requires group attendance, which in turn may draw negative attention and further segregate group members who may be arriving in a marked van or seated together in low-cost seating, etc. Those who can more comfortably afford to participate in the community on their own often do so, and benefit more easily from a sense of belonging and the opportunity to meet new people and make new friends beyond the framework of their social service agency.

Inadequate transportation

Limited transportation options make community inclusion more difficult. Participation in community activities, particularly within an expanded understanding of ‘community’ as stretching beyond one’s own local, walkable neighbourhood, requires access to transportation. Individuals with disabilities often find themselves unable to get around independently because of their limited financial resources (which limits car ownership as well as the use of public transport options), the unavailability of car-owning friends and family with the time to be of assistance, and either inconvenient public transport options (Field & Jette, 2007). Limited public transport is only imperfectly available, and while this makes life difficult in urban areas it is a profound problem in outer suburban and rural areas, in which public transport is severely limited or altogether absent (Field & Jette, 2007; National Organization on Disability-Harris Interactive, 2004; SAMHSA, 2004; Harris Interactive, 2004).

Surveys of individuals with mental health issues, for instance, identify the ways in which participation in community life, including getting and holding a job, living within a comfortable neighbourhood, or joining a religious congregation or athletic club of one’s choice, requires access to transportation resources that are simply unavailable (National Center for Health Statistics, Centers for Disease Control, 1994). A range of options have developed over time that suggest alternative approaches, such as using volunteer drivers, helping individuals to get a drivers’ licence and look for charitably oriented low-cost car loan and car maintenance programs, or working with other human services networks with similar transportation challenges to develop collaborative solutions. In many communities, however, the most consistent source of transportation support is a segregated one – the agency or program ‘van’ that inadvertently advertises the users’ impairments and creating an additional barrier to full and meaningful community participation.



This singularly pragmatic issue stymies many community participation plans, and even those with strong, engaged family and other natural supports may also struggle to get around. Help with transportation needs, for instance, has been a significant cost centre for many of the self-directed care programs in the mental health field in which individuals are empowered to spend service dollars in ways they prefer (Snethen et al. 2016). Transportation issues are often resolved in these programs by using program funding to pay friends or neighbours, who do have a car and the time, to provide transportation to and from community events.

Public prejudices and discriminatory behaviors

Acknowledging and addressing prejudice and the resulting discrimination is critical to successful community inclusion. The distinction between ‘prejudice’ and ‘discrimination’ is an important one to note:

- Prejudice is a negative attitude or orientation towards a group based on a set of beliefs (ie stereotypes) about the group that are predominantly negative and may or may not be demonstrably false
- Discrimination refers to the policies and individual behaviours that result from prejudice that often restrict opportunities for those with disabilities from fully participating in community life

There is a wealth of research (eg Link & Phelan, 2001; Shain & Phillips, 1991) documenting the widespread negative stereotypes and prejudice with regard to those with disabilities. Although those with physical or intellectual/development disabilities face similar challenges, public perceptions of those with mental health issues are particularly troubling, and pose real challenges to the prospects of community inclusion. Communities are convinced that individuals with mental health conditions are imminently dangerous (Cocozza & Steadman, 1975; Martin et al. 2000), incapable of holding onto a job in the competitive labour market (Lennan & Wyllie, 2005; Stuart, 2006), and unsuitable in a variety of everyday roles – as neighbours, worshippers, team members or friends. While these are long-standing stereotypes, common around the world, there is strong evidence that contemporary public discourse has been profoundly affected by ubiquitous, negative media narratives. Sensationalistic news stories (Wahl, 2003; Coverdale et al. 2002) suggesting a strong link between violence and mental illness, misrepresents the documented reality that those with a history of mental health conditions are no more violent than their non-mentally ill neighbours, and leaves a strong anxiety among the general public. And fictional stories on television and in the movies that emphasise the ‘disturbed’ perpetrators of violence leave most viewers with a distorted sense of the risks that they feel are implicit in establishing more inclusive environments (Gerbner et al. 1980; Signorelli et al. 1995).

Public education programs to challenge these prejudices have been shown to have only limited impact over the years. Media-based initiatives, especially public service announcements, have not proven especially effective (Barringham & Barringham, 2002), and more personal approaches, such as lecture series, personal presentations by individuals with disabilities themselves, coordinated 'mental health education campaigns' targeted to religious groups, employers, recreational programs, etc, are expensive to implement and difficult to assess. Today, there are hopes that public attitudes toward those with disabilities will begin to shift as an increasing number of people have one-to-one contact with someone with a mental illness as a co-worker, family member, neighbour, and team member, for instance. This has been theorised as shifts in public attitudes toward other marginalised groups are realised.

Efforts to shift public attitudes in a more positive direction are critically important in part because of the impact that they have on the formation of policies that discriminate against the community participation of individuals with mental health issues. It has not been unusual in the past for public housing or competitive job applications to inquire about one's history of mental health problems, for instance, and in many places one's eligibility to vote or sit on a jury are formally restricted if one has a history of mental illness (Hemmens, 2002). Park et al. (2006) documented that mothers with psychiatric disabilities are three times more likely to lose custody of their children, plausibly without a clear indication that their children are at any greater risk of harm (Kaplan et al. 2009; Mathis & Giliberti, 2000).

Negative public attitudes and discrimination have a broad impact both on the way in which individuals with disabilities are treated in public settings and the ways in which these unsatisfactory interactions affect the willingness of those with disabilities to pursue their inclusion goals. That is, when individuals with disabilities are aware of public prejudices they have a tendency to avoid interactions and retreat to the segregated social environments provided by human services agencies. One study (Power & Bartlett 2016) reported on the verbal and physical abuse experienced by those with learning disabilities just walking through their neighbourhoods, and their increasing reluctance to leave the house, reporting that 'non-verbal feelings, looks and stares and behaviour... were the reverse of being welcomed with open arms'. Another study reported that 'although loneliness and social isolation are highly prevalent among those with severe psychiatric disorders, they are frequently reluctant to participate in community resources and activities due to fear of rejection' (Elisha, Castle & Hocking, 2006; Perese & Wolf, 2005). All of this suggests that what practitioners often report as a 'lack of motivation' for community inclusion is a realistic response to the persistence of prejudice and discrimination that has not yet been sufficiently challenged by the champions of community inclusion.



FUNDAMENTAL 10

Community
inclusion initiatives
for individuals
with disabilities
maximise the use
of mainstream
community
resources



Community inclusion initiatives for individuals with disabilities maximise the use of mainstream community resources

Although the past decades have witnessed a significant shift from a reliance on institutional care for those with disabilities and toward community-based services, most community-based care remains structured around 'in-house' segregated activities, nestled within agencies in the larger community. Certainly disability agencies have been motivated by concern for the individuals they support, but these segregated environments, including partial hospital/day programs, sheltered work settings, educational courses, organised social events and exercise equipment, often re-create participation experiences and supports that are readily available in the broader community. Effective community inclusion initiatives seek to strike a better balance between 'in-house' programming and supporting the individuals they serve in their utilisation of mainstream resources that are available to all citizens.

Disability service providers need to establish 'supported pathways' from segregated services to the use of mainstream services within community settings

Disability providers have traditionally been reluctant to use mainstream resources for several reasons:

- **Funding** – patterns of public funding for disability services often encourage 'facility-based' programs by reimbursing provider agencies based on the level of participation of service recipients in agency-centred activities or 'facility-based' activities, and this served as a disincentive for agencies to re-define services and re-configure staff roles to support the utilisation of mainstream resources;
- **Program design** – providers may find 'in-house' programming easier and less expensive to develop, supervise and sustain. A well-run agency's regularly scheduled activities that permit staff to work predictable hours rather than continually responding to individual consumer needs and varied schedules of mainstream resources appeal to already overwhelmed program administrators;
- **Community resistance** – facilitating the use of mainstream community resources poses two additional problems. First, mainstream agencies may resist the new demands placed on them by the participation of individuals with disabilities. Second, disability providers remain unskilled in working with mainstream agencies to overcome that resistance, or assist service consumers in doing so;
- **Consumer resistance** – some recipients of services, as noted in the section above, may express a preference for 'in-house' vs mainstream participation, wary of public reactions to their presence in public spaces. Service recipients are often deeply appreciative of activities within environments they perceive as safe, in which they can be open about their issues without fear of prejudice and discrimination.



The United Kingdom's Centre for Community Inclusion (2009) argues that while 'in-house' supports and services may serve a time-limited purpose, to promote inclusion we need pathways from segregated service provision into mainstream services: on-site participation solely for people with mental health issues may reinforce segregation unless it is part of a clearly supported pathway to mainstream services accessible to everyone.

A wider and deeper array of supports and services are oftentimes readily available in the community that do not need to be replicated by segregated 'in-house' programs

Community inclusion programs address an array of life domains, yet for each domain there are numerous opportunities to shift from a continuing reliance on disability-specific settings and make greater, facilitated use of mainstream programs. While urban communities often provide an expansive number of opportunities, even small towns and rural areas provide some resources that can be an alternative to agency-based participation and support. This requires staff to be familiar with non-disability community resources and to be comfortable working with those community resources to facilitate consumer use of those resources.

A quick review of community resources available in Australia in key life domains makes the point:

- **Housing** – a far broader and better array of housing opportunities exist beyond those provided in specialised settings. Australia has more than 20,000 registered real estate agents, who could be relied upon to identify accessible apartment rentals and inexpensive homes (and public low-cost home ownership programs) beyond the more limited reach of disability agencies (reia.asn.au);
- **Education, training and employment** – almost every community offers a variety of educational opportunities and job training programs. Australia has 43 public universities and a large network of non-profit and for-profit job training career colleges and other job training programs that might begin to replace in-house job training programs (en.wikipedia.org/list_of_universities_in_australia);
- **Recreational programs** – most communities have a variety of recreational programs – in both public and private settings – in which individuals have opportunities to join a gym, pursue a hobby, or express their artistic interests. For example, Australia has 73 YMCA recreational centres across the country that offer multiple recreational, cultural, and job training programs (ymca.org.au/what-we-do). Moreover, the Australian Government has committed \$1 billion to the National Stronger Regions Fund (NSRF) to enhance the sports and recreational infrastructure in the country – a list of websites for each state listing these facilities can be found here (<http://www.health.gov.au/internet/main/publishing.nsf/Content/sport-and-recreation-facilities>); and

- **Religious and spiritual connections** – for those whose religious and spiritual participation typically takes place in a specific setting such as a church, synagogue, or mosque, these places can be an important recovery resource and staple of mainstream community life for many. Australia has, for example, more than 13,000 churches alone, offering those with disabilities a chance to participate in both the spiritual and the social life of a chosen congregation along with their neighbours (mccrindle.com.au). Lists of synagogues (https://en.wikipedia.org/wiki/List_of_synagogues_in_Australia_and_New_Zealand) and mosques (https://en.wikipedia.org/wiki/List_of_mosques_in_Oceania) are also available.

The principles of adult learning suggest that individuals with disabilities make more progress in mastering the skills of community engagement within real-world environments than in specialised and/or segregated settings

Adult learning principles (Bandura, 1963; Knowles, 1973; Kaufman, 2003) argue that adults learn best by active engagement in the real world, and that solving real problems in the here-and-now is more effective than learning in simulated settings or classroom exercises. Individuals – and not just those with disabilities – struggle to transfer learning in specialised environments to the less predictable and more unforgiving settings of everyday life. Even those in-house disability programs designed to train service recipients for independent functioning in the mainstream have had difficulty demonstrating that they have assisted service recipients in moving along a *supported pathway* to community inclusion. For instance:

- **Supported employment programs** which challenge traditional *train-then-place* approaches with a *place-then-train* rapid engagement of participants in ‘real jobs for real pay,’ consistently report superior job placement and job retention results when compared with other in-house training programs (Cook et al. 2005);
- **Housing first programs** which eliminate ‘readiness’ assessments and step-wise approaches in housing (in which the service recipient moves from shelters to group homes, then to small-group supported apartments, and then to independent living) move individuals rapidly into their own home, and report not only better consumer satisfaction but also longer independent tenure (Patterson et al. 2013; Nuechterlein et al. 2008);
- **Social skills training** that relies upon in-house classes to teach and practice the skills needed for successful social interactions report only modest results when individuals graduate from class and move on to real-world social interactions (Wallace et al. 1980; Dilk & Bond, 1996), and consumers report greater social success when joining gyms, church choirs, or local arts classes (TU Collaborative on Community Inclusion, 2015).



Disclosure of an individual's disability in community settings must remain a personal decision for each individual

Everyone wants a bit of privacy in their lives. Choosing what, when, and to whom to reveal aspects of one's personal life is a matter of personal choice. Some individuals are quite open about their private lives, while others reveal very little. For those with disabilities, however, revealing one's disability is a more complex issue. In the context of community inclusion and its emphasis on the individual's active engagement in community activities, deciding what, when and to whom to disclose information about one's impairments is particularly important. These decisions about disclosure must always remain solely those of the individual with the disability. Their right to privacy with regard to what they may well regard as a deeply personal, even intimate, aspect of their lives, is inviolable.

In some circumstances, of course, the issue of disclosure is moot. Many job placement programs are explicitly serving people with disabilities populations and are clear with potential employers about the impairments of those placed, as well as the supports the program will be providing to both employee and employer. Individuals who seek the support of a university's disability services office are clearly seeking assistance – and often accommodations – on the basis of an identified condition. And the mental health practitioner or peer specialist who interacts with a recreational program in the community to seek assistance from the community program itself in supporting the participation of individual with a disability are necessarily clear that the individual they are assisting has a mental illness of some sort.

Many individuals prefer to be more discreet, and an agency can be helpful in many ways without directly working with a mainstream provider within a more explicit framework. Agencies can help people prepare for job interviews, anticipate what it will be like to attend a church function, or help identify educational resources, without usurping the individual's preference to 'fly under the radar' in terms of not disclosing an impairment. Some individuals may be embarrassed or rightly fear discrimination, while others would prefer that new friends (or co-workers, or team members, etc) accept them as individuals first, before they share some of the details about their mental health histories. There is evidence that individuals with psychiatric disabilities, for instance, were not rented an apartment, hired for a job, or welcomed into a religious congregation on the basis of their illness (Rüsch et al. 2005; Granger et al. 1997). Indeed, research confirms that most of those with mental health conditions recommend against early, or indiscriminate, or complete disclosure (Granger, 1995; 1996) because neighbours might become wary from such disclosures, job advancement can be stymied, and social relationships can be tainted.

For others the disclosure of their mental illness is a 'badge of courage' – a bold pre-emptive strike against prejudice and discrimination. Human services providers working toward community inclusion must respect each individual's decision and support his/her community inclusion ambitions within either a disclosure or non-disclosure framework – for, indeed, these are decisions that other members of the mainstream are making every day about various aspects of their own lives.

FUNDAMENTAL 11

Community inclusion
requires establishing
welcoming communities



Community inclusion requires establishing welcoming communities

While substantial strides toward community inclusion can be made by human services agencies by facilitating inclusive goals, re-directing service recipients toward community resources, and challenging both the prejudice and the resulting discrimination faced by individuals with disabilities, the responsibility and success of community inclusion ultimately rests within communities themselves. Individuals and organisations in mainstream communities must begin to overcome unrealistic fears and long-standing concerns in order to express a more affirmative and embracing approach toward the full participation in the community of individuals with disabilities. Each setting, be it a neighbourhood, worksite, religious congregation, amateur sports club or university and classroom, must work toward both genuinely valuing diversity and consistently making it a reality by seeking out and welcoming individuals with disabilities.

Powers and Bartlett (2015) talk about welcoming communities as those that 'cultivate greater connections between people with disabilities and other people in their local communities', and see it as part of a general social shift toward valuing the many manifestations of diversity. They note that in both Canada and England there has been an emerging interest in 'The Big Society' and the UK's position that '... we want society – the families, networks, neighbourhoods and communities that form the fabric of so much of our everyday lives – to be bigger and stronger than ever before' (Gov. UK, 2009). To move towards these types of communities that welcome individuals with disabilities requires a sustained approach beyond the usual commitments and competencies of human services agencies.

Welcoming communities rely on individuals and organisations in the mainstream as additional and important resources for supporting community inclusion

Although provider agencies' responsibilities with regard to promoting community inclusion can be substantial, through roles such as identifying community resources, encouraging and supporting service recipients' participation in community activities, and problem-solving emerging issues, they need not face these challenges on their own. In addition to the participation of families, friends and peer specialists, individuals and organisations in the mainstream are often willing and able to offer supports to new participants with disabilities to help facilitate their engagement in community life. Employers in many countries are aware of their responsibilities to hire individuals with disabilities on a non-discriminatory basis and to provide them with whatever 'reasonable accommodation' they may require to succeed at work (Paetzold, 2005; Fabian et al. 1993, McDowell & Fossey, 2015). Universities have expanded their offices of disability services and the training they offer to faculty and staff to address disability issues among the student body (Salzer et al. 2008). And recreational programs often are prepared to provide supports to disabled participants on an individualised basis (Iwasaki et al. 2010; Richardson et al. 2005).



While there is not a substantial amount of research with regard to either the prevalence or impact of the active engagement of individuals or organisations in the community that provide support, there are inspiring anecdotes:

- In one setting, for instance, a religious congregation was concerned about the slightly disruptive behaviour of a group of new congregants with psychiatric disabilities and turned to individuals in their existing 'social affairs committee' to contact each of the new parishioners to offer to meet with them individually beforehand, sit with them during services, and introduce them to fellow congregants afterward – all of which made everyone more comfortable with inclusion (personal communication, Baron, 2007);
- The owner of a wool store in a small town was approached by a psychiatric rehabilitation agency and asked if she would consider leading a sewing class once a week at the agency for a small group of interested woman, and while the owner declined because of her busy schedule, she did suggest that the interested sewers at the agency might want to join her already-established sewing class on Thursday evenings, along with a staff members to facilitate connections with other classmates (TU Collaborative on Community Inclusion, 2015); and
- A consumer-based program contacted a local 'get out to vote' campaign to suggest they would like to help register individuals with mental health conditions in hospitals and community mental health settings before the next election, but were asked by the broader campaign leaders if, instead, the consumer volunteers might prefer to individually join existing voter registration teams, which would then also visit community mental health programs and local hospitals as they canvassed for voters (David & Baron, 2010).

Individuals with disabilities often create their own 'safe spaces' within community environments, and these can be further supported by providers

The allure of 'in-house' participation, of course, is that they provide their own 'welcoming community' for people with disabilities, ones in which there is little embarrassment about a disability and no fear of physical harassment or verbal humiliation. They are safe spaces for people who are very at-risk for physical and verbal violence. But consumers have often created 'safe spaces' within the community themselves. Powers and Bartlett (2015), writing about the widespread closure of day programs for those with learning disabilities in the UK, found that those who might have felt 'abandoned' to fare as best they could on their own in the community then created new 'safe spaces' for themselves where they hung out at a 'fish and chips' shop and interacted with the owners and customers on a casual basis. Others went to coffee shops and library meeting rooms to get together and interact with other customers and attended community meetings and sports events on their own or with a few friends. Human service providers can help to sustain these initiatives through encouragement and training community members and natural supporters in how to facilitate the development of inclusive 'safe spaces' in community settings, although such efforts have yet to be fully exploited.

“There is compelling evidence that individuals who feel ‘connected’ to a community of others ... are better able to avoid both physical illness and emotional stress”

Welcoming communities are stronger communities

Communities that go beyond the everyday expectation of understanding and tolerance and actively reach out to individuals with disabilities strengthen the social fabric of community life. Many of the arguments for community inclusion made here emphasise that participation in community life is both a human right of individuals with disabilities and an opportunity to benefit from the opportunities and satisfactions that participation can bring. However, the hope that ‘welcoming communities’ will flourish – that individuals and organisations in the mainstream will more consistently acknowledge those rights and support those benefits for individuals with disabilities – can only be sustained if communities see the benefits to themselves of a more inclusive environment. Many countries have sustained a gradual widening of their understanding of the benefits to their social and economic environments by a more inclusive approach to disenfranchised groups at-risk for devaluation. But the benefits to community life from community inclusion initiatives of various types has proven difficult to evaluate, and the evidence base here is largely anecdotal. Business owners who feel the workplace has been strengthened, college deans who believe student perspectives have been widened, religious groups which feel the congregation itself has been strengthened (David & Baron, 2010; Illinois Department of Commerce and Economic Opportunity, 2007; United States Chamber of Commerce, 2012). The absence of confirming data points both to the need to expand community inclusion initiatives and to measure its impact on the community more closely.

At the moment the interest in promoting ‘welcoming communities’ emerges more from a human rights perspective rather than data. However, there is compelling evidence that individuals who feel ‘connected’ to a community of others – families and friends, co-workers and neighbours, etc – are better able to avoid both physical illness and emotional stress (Berkman, 1984; Dohrenwend & Dohrenwend, 1984; Lazarus & Folkman, 1984), and that whether this is characterised as the development of ‘personal communities’ (Wellman, 1982), ‘social capital’ (Putnam, 2000), or one connection to ‘social networks’ (Hirsh, 1988) – this sense of connectedness to the world around us provides emotional, material and information support that has positive impacts on the self-esteem, life opportunities and physical survival of everyone in the community. Expanding that sense of connection to everyone in the community broadens and strengthens the social network.

DiMarco and Colombo (1988) defined a social network as ‘... a willingness of members of the community to reciprocate in their support for one another as part of a stable structure, and in which there are not only shared values but also joint participation in shaping the community’. This suggests that for welcoming communities to become a reality then, as we mentioned earlier, individuals with disabilities will need to reciprocate – giving as well as taking – if they are to be firmly embedded in the social networks of community life. And it is this contribution to the world around them, as much as the benefits they receive, that is at the heart of community inclusion.



NEXT STEP

A blueprint for action

The background is a solid blue color. In the lower-left and bottom-right areas, there are several overlapping circles of varying shades of blue. One circle in the bottom-right corner features a pattern of concentric, slightly offset lines, creating a ripple or target-like effect. The circles are semi-transparent, allowing the underlying blue to show through.



“Service recipients, professionals, carers, families and community allies – are ready to move forward...”

A blueprint for action

Change is notoriously difficult, both for individuals and for organisations. The changes in policies, programs and practices (as well as in the attitudes and traditions on which they are constructed) that are called for by these fundamental concepts of community inclusion constitute a challenging call to action that requires change for all stakeholders – policymakers, providers, carers and persons with disabilities.

These changes are increasingly understood to be not only necessary but also urgent. Nonetheless, institutional inertia often keeps change at a distance. The most frequent arguments against the changes called for by a genuine commitment to community inclusion can be readily articulated. One can hear these themes all the time:

- *We already do this;*
- *We need evidence that this will work;*
- *The people we serve are happy with the care we provide; and*
- *There is no funding to pursue these new directions and meet these new demands.*

But few of these objections to change hold up to scrutiny.



“What is needed is a shift of funding from outdated programs to those that address individual needs to actively participate in the fullness of contemporary life”

‘We already do this’ rings hollow when one looks at:

- The clustered residential impoverishment of many of those with disabilities;
- The staggering rates of unemployment of those with intellectual, physical or emotional impairments;
- The attenuated social networks of this disempowered class of citizens; and
- The lack of engagement in civic activities, recreational programs, social settings, or religious organisations.

‘We need evidence that this will work’ has a ready answer, in part because our disability systems have rarely fully promoted community inclusion. We could have evidence if we really try it. And we do have evidence from supported technologies in the employment, educational and housing fields that demonstrates when given opportunities to participate in community life, people with disabilities have sustainable successes.

‘The people we serve are happy with the care we provide’ is challenged in two ways. First, there is a growing recognition that current programs have unwittingly promoted complacency and hopelessness among service recipients. Second, the chorus of younger people with disabilities who manoeuvre to avoid safety-and-stability oriented programs until they have located – and/or advocated for – the types of programs that offer them supported pathway to engagement in the mainstream of life.

‘There is no funding to pursue these new directions and meet these new demands’ can be turned on its head by noting that what is needed is a shift of funding from outdated programs to those that address individual needs to actively participate in the fullness of contemporary life.

The theoretical framework is in place, an initial set of fundamental concepts can be drawn upon to shape this next generation of policies, programs, and practices and a growing consensus of people – service recipients, professionals, carers, families and community allies – is ready to move forward.



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