THE TEMPLE UNIVERSITY COLLABORATIVE ON
COMMUNITY INCLUSION
of Individuals with Psychiatric Disabilities

Managing Risk in Community Integration: Promoting the Dignity of Risk and Supporting Personal Choice

Bill Burns-Lynch, University of Medicine & Dentistry of New Jersey
Mark S. Salzer, The Temple University Collaborative on Community Inclusion
Richard Baron, The Temple University Collaborative on Community Inclusion

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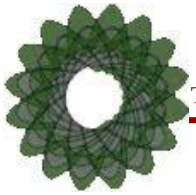

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Chapter 1:
Purpose of this Guide

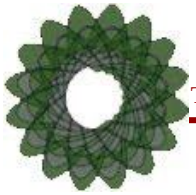
Simply stated, **community integration** is about creating opportunities for increased presence and participation in the community for individuals living with mental illnesses. It is about encouraging and supporting individual choices to actively pursue valued adult roles in life. The purpose of this guide is two-fold:

1. **To assist mental health providers in supporting individuals living with psychiatric disabilities to pursue valued adult roles in the community, that is to say, to adopt a community integration framework to guide service provision; and**

2. **To provide a strategy or template for use in identifying and managing the potential risk persons in recovery may experience as a result of their increased presence and participation in the community.**

Community integration demands that we encourage persons in recovery to expect nothing less than that which individuals living without disabilities look forward to in their lives. The moral imperative aside, these demands find their legal underpinnings with the Americans with Disabilities Act (ADA), the Department of Justice's "Integration Regulation," which requires that people with disabilities have the opportunity to interact with people who are not disabled in services, programs, and activities, and the 1999 *Olmstead* ruling of the U.S. Supreme Court - the landmark decision that concluded unnecessary institutionalization is a form of discrimination prohibited by the ADA. Applied to individuals with psychiatric disabilities, it led to a presidential executive order in which states were required to develop a plan for identifying and moving individuals with psychiatric and other disabilities from institutions into community settings.

This notion of supporting the pursuit of valued adult roles in the community is also a key component in the current climate of transforming mental heath systems to recovery-oriented systems of care. The emphasis on community integration and recovery is important because the system of care that has existed for most of the last century was based on the notion that recovery was not possible, and that basic maintenance and ongoing care of people with serious mental illnesses should be the goal (Anthony, 2000). There have been many developments over the last 50 years that have helped to dispel these beliefs, including the untiring voice and advocacy of the mental health consumer/survivor movement, the empirical research on the variable course of serious mental illnesses, the development of the field of psychiatric rehabilitation, and the successes of many individuals living with mental illnesses in reclaiming valued adult roles in their lives. Additionally, the ADA and the *Olmstead* decision set in motion exciting policy developments in which the promotion of community integration and recovery



were a central focus. The final draft of the President's New Freedom Commission on Mental Health Report: *Achieving the Promise: Transforming Mental Health Care in America* (DHHS, 2003), articulated the following vision:

"We envision a future when everyone with a mental illness will recover…when everyone with a mental illness…has access to effective treatment and supports - essentials for living, working, learning, and participating fully in the community."

We believe that community integration is what recovery is for!

However, a curious juxtaposition in the mental health field has occurred. As we have watched our social service systems evolve through an increased emphasis on recovery, community integration, empowerment, and personal choice, so too, it seems, that our social services structures have devolved to one in which we mostly worry about the risks involved – risks to service users, risks to providers, and risks to the financial stability of our organizations - and not to the broader purposes of working with people to increase their satisfaction with their presence and participation in the community - their quality of life.

Accompanying the increased presence and participation of individuals living with psychiatric disabilities in the community is a concern for consumer safety and agency liability on the part of many service providers (Rose, 2006). What we are talking about with community integration is often perceived by service providers, persons in recovery, and family members alike, as entailing some degree of risk that many would prefer to avoid or think that provider agencies should not engage in. Unfortunately, in mental health, the term "risk" has come to have negative associations, focusing primarily on issues of diminishing capacity to care for one's self and harm to self and/or others. We know there are risks in working with people with serious mental illness as we move from custodial care to community engagement and integration, but the risks involved are neither so great as many fear nor so inevitable that consumers, families, and providers – working collaboratively – cannot anticipate and then minimize them. On the one hand, the assumptions that persons in recovery cannot manage community life independently or that they are violent is mostly unwarranted. Individuals living with mental illnesses are no more likely than individuals in the general population to commit acts of violence and they are more likely to be the victims of violence over the course of their lifetime (Stuart, 2003). On the other hand, we know that with proper supports and services people can avoid most of the risks of concern. Our societal misunderstanding of the nature and course of serious mental illnesses, the public media's misrepresentation of the potential threat of violence to the community posed by individuals living with mental illnesses, and the difficulty people have in accessing mental health treatment and care all contribute to the continued stigma and discrimination experienced by people living with mental illnesses.

> One of the consequences of the reduction in psychiatric hospital beds and the expansion of services in the community…is media and public alarm about the presence of mental health service users in the community. The tendency towards greater control over people diagnosed as mentally ill appears to be motivated by public concern, fed by some sections of the media, rather than evidence about the best way to ensure public safety (Langan and Lindow, 2004, p. 2).

Herein lies the challenge. Many would say that up until now we have only paid lip service to the ideas of community integration, self-determination, and recovery and that by and large, our programs and services continue to maintain the status quo. Change is difficult; often perceived as fraught with risk, making it difficult to pursue and difficult to accept.

"Adopting a community integration framework and promoting opportunities for increased presence and participation in the community is not business as usual in the mental health system."

The Dignity of Risk

We are transitioning from a system of care that places all of the responsibility for the individuals we serve on the shoulders of mental health providers to one where the people we serve take ever greater responsibility for their own lives and behavior. We do not do this foolishly or light heartedly, but rather with a sense of urgency and in the spirit of collaboration and appropriate concern for the safety and security of the individuals with whom we work. Many suggest that this is a crucial turning point in our service delivery philosophy as self-determination is at the core of what it means to be human. This has become what is known in the disability field as the dignity of risk. We must not only acknowledge that there are risks for persons in recovery as they take more control over their lives and participate more actively in their communities, but we must also encourage them to do so. Robert Perske (1981) states:

> 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.

It is by trial and error through which we learn our most important lessons.

"I suggest to you that that which makes us most human is our ability to enjoy our successes by having the ability to own our own failures."
Chris Lyons

It is in the risk taking that we all experience all there is to being human – the bumps and bruises and the happiness and joys.

> By addressing universal human needs and desires and aspirations, [community integration] poses several risks not usually contemplated by traditional or typical human service systems. By addressing forced impoverishment people with disabilities face the possibility of failure - failure at work or at self-employment. By addressing our connections to our communities people with disabilities face possible rejection. By focusing on the universal human need for friendships and even intimate relationships, self-determination poses the risk of heartbreak. These are the risks that define us as human beings, make us strong and reflective and carry the promise of true community and family membership. With every risk there is a hope of success. With assistance individuals with disabilities including those with intellectual and cognitive disabilities need to face the risks associated with membership in the human race. They need to accept responsibility for the exercise of freedom. They need to understand that the dignity of risk is what makes us human. The possibility of success outweighs the fear of failure in a system of supports that truly values every person and finally aims to re-capture lives lost.
>
> *The Texas Center for Disability Studies, University of Texas at Austin*

We are talking here about taking reasonable, acceptable and prudent risks. We are not advocating, as Perske (1981) says, that people "be expected to blindly face challenges that, without a doubt, will explode in their faces. Knowing which chances are prudent and which are not - this is a new skill that needs to be acquired." This is a key point for service providers and bears repeating here – "this is a new skill that needs to be acquired." Our role will be to acquire the skills necessary to help identify the risks associated with individual choice as reasonable or unreasonable, acceptable or unacceptable and collaboratively develop and implement a support plan to monitor and manage the identified risks (if any). This process will support individuals in achieving their chosen goals and increase their ability to make ongoing informed decisions about their life.

"In the past, we found clever ways to build avoidance of risk into the lives of persons living with disabilities. Now we must work equally hard to help find the proper amount of risk people have the right to take. We have learned that there can be healthy development in risk taking... and there can be crippling indignity in safety!"

Robert Perske

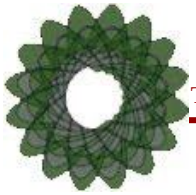
Acknowledging Risk and Supporting Choice

We need to acknowledge that there is some degree of risk to persons in recovery, some risk the agency may experience, and some risk perceived by the community at large. For most of the individuals with whom we work, these risks are likely to be minimal, however, these real or perceived risks – be they fear of the threat of violence, inconvenience, or annoyance on the part of community members; fear of embarrassment, poor community relations, or of some other kind of serious harm on the part of the provider; and fear of rejection, failure, de-stabilization, and/or re-hospitalization on the part of the individual in recovery - must be viewed through the lens of the "dignity of risk" and must be accompanied by a plan of action to be implemented by service providers and the individual in recovery should a crisis arise. These plans ought to give weight to both helping the individual avoid the identified risks, and to helping the individual if something does go wrong.

Challenges and barriers will confront us and the individuals we serve as we support their attempt to move from mere 'presence' in the community to a far more robust sense of 'participation' in community life. Many people have a portion of the burden to shoulder in addressing these challenges and barriers. One significant challenge, that of negative agency attitudes – and of similar resistance to community integration initiatives among clients themselves, their families, and the community - lay in the perception that each effort to heighten client engagement in community life will entail risks that will be difficult for clients to endure, for example, de-stabilization or re-hospitalization, rejection or ridicule, of financial strains or relationship losses. Agencies and families to be sure, are often unwilling to shoulder these risks.

Community attitudes can create substantial barriers to full participation. The negative effects of prejudice in our society run very deep and cut across all of the community integration domains (reviewed in the next chapter). People with almost any disability, often feel invisible and/or unwelcome in the community, thereby limiting job opportunities, social networks, family life, housing opportunities, and religious activity. Public misperceptions about the nature and course of mental illness and of the real risk of threat individuals living with mental illnesses pose to the community contribute to the discrimination and stigma experienced by those living with mental illness. This stigma is likely to cause some community members to have unrealistic fears about exposure to violence, or create annoyance at being inconvenienced while getting on public transportation as an individual in recovery navigates the financial transaction required to get on the bus for the first time.

It is unlikely that persons in recovery, the agency, or members of the community will experience any real or enduring harm as a result of our efforts to increase integration and participation in the community. However, if or when one of these identified risks (or a crisis) does happen, then it is critical that we, the provider and the person in recovery,

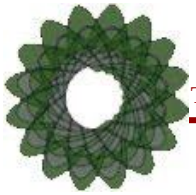


have a support plan to address the issues that arise. All of these "risks" do need to be explored in their individual contexts as they relate to each individual's choices and the supports and resources that are available to them. While it is true that an agency or program can never have absolute control over a situation (nor do we as individuals in our own daily lives), and cannot guarantee success in every endeavor, it can anticipate possible risks, plan ahead, and promote a safe environment while increasing opportunities for people with mental illnesses to participate more fully in their personal recovery, as members of a recovery community, and in activities offered by the greater community as a whole.

"We do not do this foolishly or light heartedly, but rather with a sense of urgency and in the spirit of collaboration and appropriate concern for the safety and security of the individuals with whom we work."

In this Guide

Included in this guide you will find principles and strategies to promote opportunities for increased community integration, processes for exploring the risks or consequences (both positive and negative) associated with the individual choices people make in their pursuit of valued adult roles, tools to assist in the development of comprehensive support plans to monitor and manage the identified risks, as well as useful real life examples to demonstrate the implementation of a community integration framework. It is our hope that you will find this information useful in designing programs, policies, procedures, and training for your staff, board, volunteers, and those to whom you provide service.



Chapter 2:
Overview of Community Integration

For individuals living with psychiatric disabilities, the concept of community integration has generally been thought of in terms of greater physical presence in the community but not necessarily in terms of participation as full members in the community, in the sense of psychological and/or social belonging. It is important, therefore, that we define and promote community integration as not only the right to live in the community (presence), but also the right to participate in the community with opportunities to live, study, work, and recreate alongside and in the same manner as people without disabilities.

"Community Integration is the opportunity to live in the community and be valued for one's uniqueness and abilities, like everyone else."

Mark Salzer, Ph.D.

A concept in the field of mental health related to community integration that may be more readily familiar to most is that of *recovery.* Current federal, state and local mental health authorities are mandating the transformation of the mental health service delivery system to one that is recovery-oriented. Recovery is defined in many sources as an ongoing process, an individual journey that involves the rekindling of hope, belief in one's self, opportunities for choice and self-determination, the compassionate support of others, of making meaning and finding purpose in one's life, and participating fully in valued roles in communities of choice. In recovery-oriented mental health systems, policies, practices and programs are built on the principles, values, and relational processes that promote and support individual recovery and community integration.

According to William Anthony (1993):

> Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, and goals, skills, or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by mental illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (p. 15).

"The concept of recovery is rooted in the simple yet profound realization that people who have been diagnosed with mental illness are human beings."

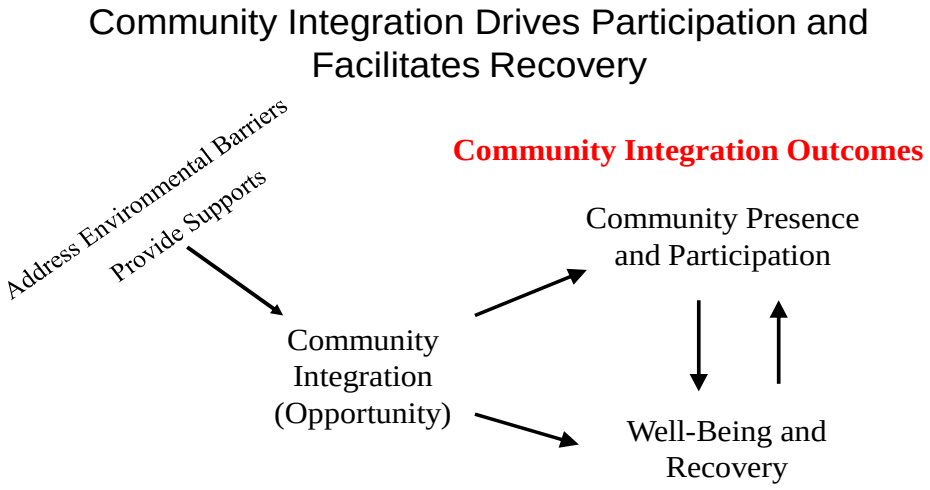
Patricia Deegan, Ph.D.

Patricia Deegan tells us:

> Those of us who have been diagnosed are not objects to be acted upon. We are fully human subjects who can act and in acting, change our situation. We are human beings and we can speak for ourselves. We have a voice and can learn to use it. We have the right to be heard and listened to. We can become self determining. We can take a stand toward what is distressing to us and need not be passive victims of an illness. We can become experts in our own journey of recovery (Deegan, 1996, p. 92).

Community Integration and Recovery

What then is relationship between community integration and recovery? The diagram below presents a framework for understanding this relationship. It is believed that increases in opportunities to live like everyone else should result in increased presence and participation of people with serious mental illnesses in the community – more people working, going to school, developing relationships with peers and non-peers, etc. Increased opportunities and participation should also facilitate an individual's well-being and recovery, and vice versa. This notion is confirmed in preliminary research conducted at the Temple University Collaborative on Community Inclusion, where we have found a positive relationship between the extent to which people feel they have opportunities to participate in the community (integration) and their reported levels of well-being and recovery.



Salzer, M.S. (2006). Introduction. In M.S. Salzer (ed.), Psychiatric Rehabilitation Skills in Practice: A CPRP Preparation and Skills Workbook. Columbia, MD.: United States Psychiatric Rehabilitation Association.

At its core, community integration is about increasing opportunities for presence and, equally important, participation in the community for individuals living with psychiatric disabilities. Our task is to collaborate with individuals to create real opportunities for

participation and integration in the valued social, vocational, community, civic, and family roles of their choice. After all, recovery is about hope – hope of finding meaning, purpose, and satisfaction in one's life. How better to pursue that meaning, purpose, and satisfaction than through participation in valued adult roles in the community?

The Community Integration Domains

The community integration approach recognizes that many people with psychiatric disabilities have not participated in community life simply because of their disability: either the community has closed its doors or mental health systems have gone too far in providing alternative opportunities within the psychiatric milieu. Working toward broader community integration means addressing both sets of these issues, but doing so also means recognizing that there are a wide range of opportunities to participate in the life of the community, what we refer to here as 'domains' – housing, employment, social life, family, religion, civic activity, recreational activity, and financial independence, etc. These are all the areas of life in which most people connect to other individuals and everyday organizations in their communities. In this section, we look first at the historical patterns of exclusion across several domains, and then at the risks that integration may suggest.

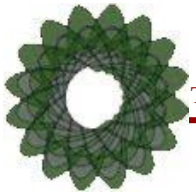
Patterns of Exclusion

Historically, people with psychiatric disabilities have often had limited opportunities to participate in community life, across several domains:

Housing – A good deal of research (Carling, 1990; Dear & Wolch, 1987; Metraux, Caplan, Klugman, & Hadley, 2007; Wolch & Philo, 2000; Wong & Stanhope, 2009) confirms that many of those with serious psychiatric disabilities live in substandard housing in challenging neighborhoods, often isolated from family, friends, and services. Many people continue to live in group living situations when they would prefer smaller settings or more independent apartments, and still, others have tired of renting and want to own a home of their own. Community resistance to both group living and independent apartment programs continues.

Education – Many consumers, and particularly those who want to return to work, have been unable to finish their educations when their illnesses have been most acute, and then have difficulty returning to school – to GED classes, community colleges, career colleges, or universities – as they recover. Educational levels among consumers are lower than among their non-disabled peers, and discrimination in academic settings is common (Kessler, Foster, Saunders, & Stang, 1995; Megivern, Pellerito, & Mowbray, 2003; Murphy, Mullen, & Spagnolo, 2005; Stodden & Dowrick, 2000; Unger, 1999).

Employment – While individuals with psychiatric disabilities say that they want to work, no more than 25% are working or looking for work. On the one hand, supported



employment programs have proven effective at helping people return to work; on the other hand, many of those jobs are in entry-level, part-time, short-term, and poorly paid positions, and most people with psychiatric disability have difficulty finding programmatic support for their employment aspirations (Baron & Salzer, 2002; Becker & Drake, 2003; Bond, 2004; Crowther, Marshall, Bond, & Huxley, 2001; Lehman et al., 2002; Mueser, Becker, & Wolfe, 2001; Mueser et al., 2004; Salzer & Baron, 2009).

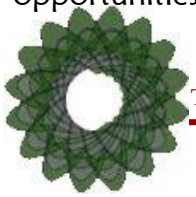
Health Care – Many people diagnosed with mental illnesses also struggle with serious physical health issues, including heart disease, high blood pressure, and diabetes: not surprisingly, research (Druss & von Esenwein, 2006; Gill, Murphy, Zechner, Swarbrick, & Spagnolo, 2009; Green, Canuso, Brenner, & Wojcik, 2003; Kelly, Boggs, & Conley, 2007; Lambert, Velakoulis, & Panelis, 2003; Manderscheid & del Vecchio, 2008; Nasrallah et al., 2006; Parks, Svendesen, Singer, Foti, & Mauer, 2006) suggests that people with serious mental illnesses die, on average, 25 years earlier than those in the general population. Yet many people with mental illnesses have no doctor they see regularly and few participate in health awareness programs.

Leisure and Recreation – This domain is all too often forgotten in community mental health practice, even though research demonstrates the benefits of both physical and social forms of recreation (Daumit et al., 2005; Davidson, Shahar, Lawless, Sells, & Tondora, 2006; Ellis, Crone, Davey, & Grogan, 2007; Goodwin, 2003; Petryshen, Hawkins, & Fronchak, 2001; Rudnick, 2005). These benefits include improvements in physical health, increases in self-esteem; improvements in energy and activity levels, and reductions in stress and symptoms. Yet most people with psychiatric disabilities make little use of the clubs and gyms and ball fields and public parks in their neighborhoods.

Spirituality/Religion – Religion and spirituality are often associated with recovery, from both substance abuse and psychiatric disabilities (Corrigan, McCorkle, Schell, & Kidder, 2003; Fallot, 2001; Gartner, 1996; Schumaker, 1992; Sells et al., 2006), and nearly half of those with mental illnesses report that spirituality is an important part in their recovery process. Yet many people with psychiatric disabilities do not participate in the religious life of the congregations in their communities or find their way to other spiritual settings, and still others who do attend services never really connect to other parishioners.

Civic Engagement – Many of those with psychiatric disabilities are concerned about the world around them – about the safety of their neighborhoods, the needs of children in their city, the direction of the country – and would like to be involved in civic organizations that gives them a chance to feel a part of something beyond the confines of the specialized world of psychiatric disability (Temple University Collaborative on Community Inclusion, N.D.; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Volunteering provides a wonderful opportunity to connect to the community, yet few consumers make that connection.

Family and Friends – Some of the domains described here provide individuals with opportunities for participating in valued social roles; however, research indicates (Albert,



Becker, McCrone, & Thornicroft, 1998; Borge, Martinsen, Ruud, Watne, & Friis, 1999; Corrigan & Phelan, 2004; Holmes-Eber & Riger, 1990; Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001; Nicholson, Biebel, Williams, & Katz-Leavy, 2004; Parks, Solomon, & Mandell, 2004) the people with serious mental illnesses have much smaller social networks, are less satisfied with their relationships, and experience much greater loneliness than those in the general population. Finding ways to regain social roles – as children, as parents, as brothers and sisters, uncles and aunts, and friends – has been tremendously difficult.

The Risks of Integration

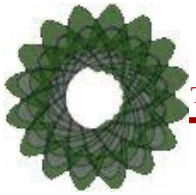
While community resistance and the prejudice of realtors, employers, educators, and others play a part in these historic patterns of exclusion, there is also fearfulness – on the part of clinicians, family members, communities and consumers themselves – about the risks that integration, in any or many of these domains seem to pose. What are these risks, and how serious are they? It can be useful to think of the risks of community integration in four broad categories, each with its own array of consequences:

Rejection – Many times we worry that the individual with a psychiatric disability will be rejected in community settings – ignored, isolated, or even ridiculed. We worry that either community prejudice or the awkward social skills of the individual will result in social rejection, and that this in turn may lead to the consumer's depression or – worse – decompensation. While everyone runs these risks in a new social situation, we worry more about the reaction to and response of consumers.

Failure – While we all know that failure is often necessary for individual growth, we don't want to 'set people up for failure' – whether at the job or in an independent apartment or in a bowling league – if we feel they are not yet ready to succeed or able to manage failure without a loss of hope, a decline in confidence, and a growing passivity. Learning from failure sounds good in the abstract, but raises real concerns for people who have struggled to succeed in the past.

Embarrassment – Consciously or unconsciously, staff and families and consumers themselves worry about whether the consumer in new situations will embarrass them. Sometimes this is only a mild concern, but sometimes – particularly for agencies that have to worry about public perceptions of their programs – it is a more serious concern. Will consumers 'ruin' relationships with neighbors, or an employer, or a volunteer site – all questions that impact on the agency's ability to thrive.

Dangerous Consequences – And, sometimes, there are still more serious fears – that the consumer will be physically or emotionally damaged, or display threatening or suicidal behaviors, and in one way or another raise questions about the appropriateness – for them and the community – of pursuing integration as an individual or programmatic or



public policy goal. We worry about these things in general, but we worry about the consumer with psychiatric disability in particular.

Yet, a quarter century of community-based mental health care suggests that we worry too much: while some people are rejected and do fail or cause embarrassment, and while there is the occasional 'incident' – for the most part individuals living with psychiatric disabilities thrive in the community and are better able to rebound from setbacks with surprising resiliency. At the heart of this document is the belief not only that disappointment is relatively rare, but also that effective planning – recognizing the risks involved and taking steps to better insure success and respond to the occasional failure – can make integration a reasonable and responsible goal.

"The possibility of success outweighs the fear of failure in a system of supports that truly values every person and finally aims to re-capture lives lost." The Texas Center for Disability Studies *University of Texas at Austin*

Community Integration: A Road Map to Recovery

The application of the community integration framework could be thought of in terms of the table illustrated below that we refer to as the *Roadmap to Recovery*. It provides a clear strategy for increasing opportunities for community integration and recovery. To create opportunities for community integration, we have to identify the institutional barriers that block community participation, and we have to help people develop the individual supports needed to move forward in each area of their choosing. We maintain that all the domains are of equal importance. However, their true weight will be determined individually by the people with whom we work. The table has three columns: Community Integration Domain, Barriers, and Supports. Listed under Community Integration Domains are housing, employment, education, leisure and recreation, social roles, peer support, health status, citizenship, self-determination and spirituality and religion.

Community Integration: Roadmap to Recovery

CI Domain	Barriers	Supports
Housing		
Employment		
Education		
Leisure/ Recreation		
Social roles		
Peer support		
Health status		
Citizenship		
Self-determination		
Spirituality/Religion		

At the policy level, one might use this roadmap to identify the barriers that people with serious mental illnesses face in each of the domains in order to develop strategies for addressing the barriers. It would also facilitate the listing of current supports that are funded in each domain and specification of what additional supports that might be needed.

At the agency level, one might use this roadmap to identify the barriers that people face in each of the domains and develop strategies that the agency can take to address these barriers in the community. The agency also could use the roadmap to ensure that they are offering the full range of supports, or utilizing already existing community supports, to increase the community integration of the persons in recovery that they support.

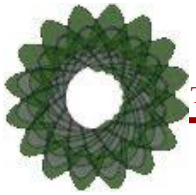
At the program level, a director or manager would use this framework to identify barriers that a specific person in recovery experiences and develop strategies that they could take to address these barriers. They could also use it to review the supports they offer and consider how they might fill some gaps in supporting people in areas where they are not currently providing support.

Finally, individual providers can use this framework to consider the barriers that an individual they are supporting faces in the community and determine how they might be able to address those barriers, in addition to providing necessary supports.

Conclusion

Community integration means that we take seriously the promotion of self-determination and choice in all decisions. It means that we promote independence rather than dependence, but also ensure that peer, friendship, family, and professional supports are available if the person desires them. It means that we provide mobile supports as much as possible in order to get people out of agencies. It means that we promote the use of mainstream resources whenever possible, and address the barriers that limit opportunities of persons with psychiatric disabilities from using these resources.

"Recovery is about hope – hope of finding meaning, purpose, and satisfaction in one's life. How better to pursue that meaning, purpose, and satisfaction than through participation in valued adult roles in the community?"



Chapter 3:

Managing Risk in Community Integration: Promoting the Dignity of Risk and Supporting Individual Choice

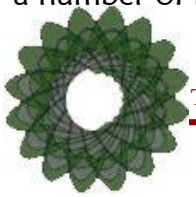
Overview

Each of us makes choices everyday. With those choices often comes some kind of risk. Some risks are generally benign; others may have consequences, both positive and negative, that can be either seen or unforeseen. The bigger the decision, or the newer the choice, the more we need to weigh the possibilities of risk before we act. That is to say, the more we need to explore both the potential positive consequences of our action (what we are hoping to gain) and the potential negative consequences of our action (as noted above, often seen or unforeseen).

> *"There is an inherent risk in most everything we do in our lives, this should not exclude us from participating, but rather ensure that we properly plan to mitigate harm that can be associated with the various domains and life activities."*
>
> John Rose

For example, I am at my favorite Italian restaurant and decide on the pasta with red crab sauce. I have had it before and have always enjoyed it. As I recall that enjoyment, I make an easy choice (a fairly benign choice) between that and the eggplant parmesan. On this particular night, however, it appears that the crab was "tainted" and shortly after I return home from dinner, the stomach cramps, brought on by food poisoning, begin. There really was not anything that I could have done to foresee that outcome. After all, I have made that decision and had the same dish many times before without such a consequence. In the grand scheme of things, I experienced no real enduring harm. In the short-term I had an uncomfortable evening to be sure, but in the long-term I will return to that restaurant and more than likely, at some point, order the pasta with red crab sauce again.

On the other hand, many years ago I decided to drop out of undergraduate school. I was young, not really interested in school, and was motivated by other extra curricular activities that often did not allow time for adequate study. Way beyond the "drop/add" period for the semester; I decided to just stop going to class. At the time, I did not explore the potential consequences of my decision. I saw only the immediate gratification of more free time as a result of my decision. As it turns out, there were quite a number of negative consequences associated with that decision that could have been



mitigated or even eliminated if I had taken the time to explore that choice. In the short-term, I failed all my courses, my GPA plummeted, and my mother lost disability income that she had been receiving for me based on my father's untimely death years earlier (because I was no longer a full-time college student). In the long-term, I had difficulty transferring to another college because of my academic record; and I had difficulty finding work other than part-time, entry-level, low wage work without more schooling than my high school diploma demonstrated.

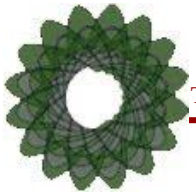
The process of making decisions, especially important and meaningful decisions about our lives is, whether we are aware of it or not, a process of managing risk. Generally, living our every-day lives and actively participating in our community involves taking many risks. As individuals begin to embrace recovery and reintegrate into and actively participate in the communities of their choice, they too will experience risk. We must point out, however, that with each of those choices and associated risks, come incredible possibilities for happiness, better quality of life, increased recovery and well-being, and healthy feelings of self-worth.

The role of the service provider in this process is to collaborate with individuals in recovery to develop meaningful goals based on actively participating in valued roles in the community integration domains of their choice. Once a goal is decided upon, the potential consequences (risks), both positive and negative, are identified and explored. This process helps individuals make informed decisions about their choices and identify the necessary supports and resources needed to be successful. Organizations and their staff should provide the opportunity for individuals to choose, from a variety of options, how they may want to achieve a particular goal. The point is to actively identify and assess the possible risks associated with a given choice, and implement a plan involving suitable supports, resources, and practices to reduce the risk (be they to the individual, the agency, or the community at large) and maximize success in pursuit of a goal.

Supporting Individual Choice

Managing risk is a discipline for dealing with uncertainty and supporting individual choice. It "involves developing flexible strategies aimed at preventing any negative event from occurring or, if this is not possible, minimizing the harm caused" (Dept. of Health, 2007, p. 5). As noted above, most, if not all of the choices we make are accompanied by uncertainty. The model we will delineate below to assess the potential positive and negative consequences related to the desired goal is based on a process of identification, evaluation, construction, implementation, monitoring and review (adapted from Rose, 2006).

The individualized support plan designed to achieve the identified goal(s) in the community integration domains should be developed collaboratively between the provider, person in recovery and his or her supporters (Rose, 2006). It should focus on recovery and draw upon individual strengths (Dept. of Health, 2007). The process of



developing, executing, and subsequently reviewing a support plan should respect an individual's rights and desires, as well as respond to concerns of his or her capacity to make informed choices. The process of managing risk must promote an environment of safety and support for individuals while advocating independence and self-direction (Rose, 2006).

Managing Risk: The Assessment Process

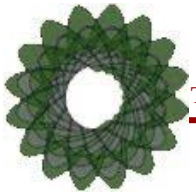
To begin, an individual chooses a goal in one or more of the community integration domains such as going to work or taking classes at a community college. The goal is specific to the person. For example, Selena's goal is to work at a Dunkin Donuts; or Patrick wants to take a photography class at the local community college. After choosing a goal, the managing risk and support planning process can begin with the first step - identification.

1. Identification

First, collaboratively **IDENTIFY** and recognize the person's skills, strengths, and the resources/supports that will help in achieving the goal. Next, identify all possible risks associated with an individual's particular interest and activity. Use the first two rows of our Managing Individual Risk Assessment Tool (included in the appendix) to guide you through the risk identification process.

Let's look at the example of Selena choosing to go to work at Dunkin Donuts.

> First, now that Selena has identified a goal in the employment domain, we work with her to identify the strengths, skills, knowledge, and supports that she currently has to help her be successful in achieving the identified goal. Selena's skills include timeliness, a pleasant personality, a willingness to work hard, past experience in a fast food environment, and the ability to make change. An additional support that she has is that her parents are encouraging her to seek employment.
>
> Next, we brainstorm with Selena (and perhaps her parents) to make a list of the risks that may come with this job (or with employment in general). First of all, even though Dunkin Donuts is currently hiring, she might not get the job. A potential risk might be increased feelings of rejection and or depression as a result. Other risks may include changes in the way that her social security entitlements/benefits are received, gaining excessive weight due to eating too many readily available sugary and carbohydrate filled foods, lapses in refilling prescription medications secondary to missing doctor and case management appointments due to her work schedule, getting fired because of making mistakes giving change and/or responding



rudely to difficult customers, and getting lost travelling to and from work as she is commuting to an unfamiliar neighborhood.

This part of the process and the outcome will be different for each individual. Each individual's perception of the risks associated with pursuing similar goals will be different based on their past experiences, their strengths and resources, and the strength of their beliefs that they can be successful achieving the goal. Take a look below at the Managing Individual Risk Assessment Tool example using Selena's identified strengths and risks.

Managing Individual Risk Assessment Tool

Name: _____Selena_____ Date: _____

Community Integration Domain - Activity or Goal: Employment – "I want to work at Dunkin' Donuts."

IDENTIFICATION	Skills & Strengths Resources/Supports	Always on time for work	A pleasant personality, good with customers	Past experience in a fast food environment	Ability to use a cash register and to make change	Strong work ethic, hard worker	Parents support decision to go to work
	Identified Risks	Not getting the job – Increased feelings of depression and/or rejection	Changes in entitlements/ benefits	Eating readily available sugary and carbohydrate filled foods and gaining weight	Missing doctor appointments due to work schedule – lapses in refilling medications	Rude customers, making a mistake giving change or wrong order and getting fired	Getting lost traveling to and from work
EVALUATION	Likelihood & Frequency of the Risk						
	Severity of Risk						
	Is the Risk worth taking (positive consequences)?						

2. Evaluation

Second, collaboratively EVALUATE the likelihood or frequency and the potential severity of each identified risk. Will the risk be daily, weekly, monthly, rarely, etc? Will the risk be an inconvenience, have an impact on maintaining employment, or staying healthy, or negatively affect the person's health? Is the risk reasonable or unreasonable? Is this a risk that can be eliminated or mitigated? Next, answer the question, "Is the risk worth taking?" Is the risk worth the reward in terms of safety? Identify the positive consequences of the pursuit and achievement of the goal and weigh them against the risks. Use the Managing Risk Assessment Tool's three evaluation rows to answer these questions.

"We all have value despite where we are on our journey and what challenges we are facing. Employment is worth struggling for and worth the risk."
George Brice, Jr., MSW

Let's continue with our example of Selena going to work.

> It is important that we work with Selena to identify and evaluate the level of risk presented above. In evaluating the risks, we must weigh the negatives against the skills, knowledge, and supports that Selena possesses as well as the other positive outcomes identified. When we delineate the risks and skills, we can clearly see how Selena's skills and knowledge (her positives) will help to mitigate some of the potential negative risks. For example, it is likely that from time to time Selena will be confronted by a rude customer. How severe is this risk for Selena? The severity is likely to be effected by whether or not she is working alone at the time of the confrontation and the skill set that she has to deal with the experience. In this case, the severity is most likely very low as Selena will not be alone while working behind the counter and when confronted by a rude customer, she can draw on her pleasant personality and the customer service skills she has developed from her previous employment in a fast food restaurant to manage the situation.

Below, our assessment tool example with Selena continues.

Managing Individual Risk Assessment Tool

Name: _____Selena_____ Date: _____

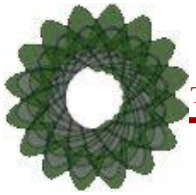
Community Inclusion Domain - Activity or Goal: Employment – "I want to work at Dunkin' Donuts."

IDENTIFICATION / EVALUATION

Skills & Strengths Resources/Supports	Always on time for work	A pleasant personality, good with customers	Past experience in a fast food environment	Ability to use a cash register and to make change	Strong work ethic, hard worker	Parents support decision to go to work
Identified Risks	Not getting the job – Increased feelings of depression and/or rejection	Changes in entitlements/ benefits	Eating readily available sugary and carbohydrate filled foods and gaining weight	Missing doctor appointments due to work schedule – lapses in refilling medications	Rude customers, making a mistake giving change or wrong order and getting fired	Getting lost traveling to and from work
Likelihood & Frequency of the Risk	High – economy is struggling and many others could be applying	Likely as earnings will impact benefits on a monthly basis	The risk will be there daily when she is scheduled to work	Limited –sees doctor every 3 months for meds	Somewhat likely, potentially on a daily basis	Low – Selena will learn the travel route back and forth to home.
Severity of Risk	Low – she has not gotten jobs in the past and knows it may take some time	Low –will be provided benefits counseling	High – Selena has diabetes and has to strictly regulate her diet	Low – agency has flexible appointment hours	Low to Moderate – has good skills and support when working	Low – Selena successfully navigates public transportation
Is the Risk worth taking (positive consequences)?	Yes – She recognizes the benefits of work and wants to work	Yes – because overall Selena's monthly income will increase	Yes – she has been successful in the past and will develop a new support plan	Yes – there is little risk involved	Yes – positive experiences in the past; will increase her customer relations skills	Yes – this will allow her to work and learn about other sections of town

3. Construction

The third step is to collaboratively **CONSTRUCT** an individual support plan to reduce risk and achieve the stated goal. Use the Community Integration Support Plan – Part 1 (included in the appendix) in this document to discuss, develop, and write a detailed

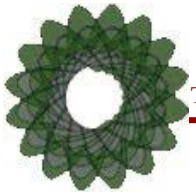


step-by-step plan with the individual. Use the first three columns to review the identified risk(s), list the current strengths, resources, and supports the individual has, and then, identify the additional support hat is needed (if any). Next, develop a series of Action-Steps that will lead to reaching the goal. Help the individual to decide which action-steps will be taken based on reasonable risk. Remember, all goals can be worked on in the form of action steps and each action step met is an achievement on its own, whether or not the goal is eventually fully actualized. A key component to help keep the momentum moving forward toward the achievement of the goal is to identify the time frames in which each action step will take place. This allows both the individual and his or her supporters to evaluate and monitor progress. It is a way to measure progress toward the goal. Finally, be sure to include a review date to evaluate progress toward the goal.

The goal of the support plan is to mitigate or eliminate the risks identified. You can see that steps one and two in this process (identification and evaluation of the risks) are critical to the development of a comprehensive support plan. The more time and effort dedicated to this process, the greater the likelihood of success in effectively managing the potential risks.
Let's get back to our example with Selena.

> Selena is now ready to construct her plan and outline the action steps that will help her to reach her goal. After a review of the risks and supports, Selena's action steps include applying for the job at Dunkin Donuts, talking to someone at the state-wide benefits planning organization funded by the Social Security Administration so she can get a better understanding as to how her new employment will impact her existing benefits. Additionally, the benefits planner can work with Selena to develop a strategy to report her earnings to SSA on a monthly basis. With the assistance of her case manager, Selena will take the time to learn how to use a calendar/planner. This tool will help her to schedule her work hours, other activities, and her doctor's appointments. Realistic time frames for when Selena will complete these tasks need to be identified, discussed, and agreed upon. Again, other identified risks can be addressed through the development of her individual support plan.

Now let's take a look at what Selena's Community Integration Support Plan – Part 1 might look like.



Community Inclusion Support Plan – Part 1

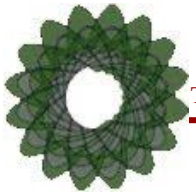
Name: SELENA Goal: "I want to work at Dunkin Donuts." Date: _____

Identified Risk(s)	Strengths/Resources and Supports	Additional Support Needed	Action Steps & Time Frames	Review Date
Not getting the job – Increased feelings of depression and/or rejection	Parents, case manager, she knows what to expect	None identified at present	1. Apply for the job 2. Receive support from parents and case manager when needed	Monthly
Changes in entitlements/benefits	Has some idea how work will impact benefits based on past experience	Connection to SSA benefits planner for review	2. Selena will contact benefits planner 2a. She will meet with planner 2b. Follow process for reporting earnings	Monthly with case manager and/or parents
Eating readily available sugary/carbohydrate filled foods and gaining weight	Has managed to keep diabetes in check while working in the past	New plan to maintain diet and diabetes management	3. Meet with MD to evaluate current status 3a. Develop plan with MD	Monthly
Missing doctor appointments due to work schedule – lapses in refilling medications and case management appointments	Managed these in the past while working; parents; case manager	Needs tools to better organize her schedule	6. Purchase calendar 6a. Meet with case manager, log all appointments, work days, etc.	Within first week of employment
Rude customers, making a mistakes on the job and getting fired	Experience using a cash register; experience in customer service	Understand policies & procedures for correcting mistakes at work	5. Inquire at interview about orientation period 5a. Learn procedures for correcting mistakes & know who shift supervisor is when working	Within first month of employment
Getting lost traveling to and from work	Has traveled successfully on public transportation in the past/ parents will help.	Parents agree to teach Selena the public transportation route and travel with her on her first day of work	4. When job is secured, will travel with parents at least 3 times to learn route 4a. Practice at least one time on her own before start date	Week before job starts

But what if …?

But what if things do not go as planned? What if the individual has done all that he or she can do to anticipate untoward events and/or consequences, has developed a comprehensive support plan, and still something negative, seen or unforeseen, happens? This too is a contingency for which we need to prepare. Looking at our example with Selena, what might happen if she was unable to maintain her balanced diet because she began to eat too many sweets while at work?

> Despite her best planning and attempt to maintain her diet, Selena begins to be tempted by the constant availability of fresh donuts while working and on breaks. She also begins to bring donuts home from work with her as an unanticipated perk of the job is a generous discount on purchasing donuts. Over the course of a number of weeks Selena starts to gain weight, stops her strict adherence to monitoring her blood sugar, misses a doctor appointment, and begins to feel the negative physical effects of these changes. Selena feels too ill on several occasions to attend work and when she does manage to go to work, the quality of her performance suffers. Selena's supervisor notices her increased absences, the frustration of co-



workers who have to pick up the slack for Selena, and meets with her to discuss the negative impact this is having with the other employees and business in general. Her supervisor states that if her performance and absenteeism continue in this way he will have to fire her. Selena is embarrassed by all of this and storms out of the store telling her supervisor that she quits.

Unfortunately, for all of us - just like Selena - despite our best efforts and planning, we can still manage to lose control of things. Again, we cannot always anticipate and plan for all potential risks, but we can take the additional step in the support planning process and answer the "but what if" questions that could arise. If we take the identified risks individually we can develop potential crisis plans to address the "but what if" scenario if indeed it does happen. Use the Community Integration Support Plan – Part 2 (Contingency Plan) to develop this crisis plan (included in the appendix).

In Selena's example it is somewhat reasonable to think that we could have laid the groundwork for a crisis plan in the event of the scenario above happening even if we did not specifically see it unfolding in quite this way. The key components of Selena's crisis plan would include identifying the supports she can reach out to if things do not go as planned. This might include friends, family members, and staff members at the provider agency. The plan might look something like this:

Community Inclusion Support Plan - Part 2
(Contingency Plan)

Name: SELENA Goal: "I want to work at Dunkin Donuts." Date: _____

Identified Risk(s)	"But What If" Scenario	Identified Supports and Resources	Crisis Plan and Action Steps
Eating readily available sugary/carbohydrate filled foods and gaining weight	Negative physical effects due to poor diet and monitoring of diabetes	Friends, family members, provider agency staff Medical doctor Other diabetes support group in the community	1. Reach out to supports for assistance 2. Schedule medical appointment 3. Attend support group
	Poor work performance leading to being fired or quitting	Friends, family members, provider agency staff SE job coach if she is connected to SE program	1. If still interested in job at DD, either alone or with support make contact with employer to talk about what happened. 2. If job still available, negotiate restart date and work schedule
	Minimal or no connection to supports for period of one month	Friends, family members, provider agency staff	1. Supporters make effort to check-in with Selena 2. Supporters check-in with each other

As you can see the plan also includes the steps that Selena can take to address the crisis, steps that her supporters can implement if they have no contact with her for a set time

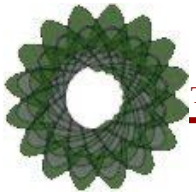
period, and strategies that address both the issues of diabetes and the loss of her job. It is likely that some of these crisis plans will need to be developed during the initial stages of the crisis itself and may need to be adjusted as new and/or unforeseen circumstances arise. The point is, however, that if we assist individuals to plan ahead through the development of support and crisis plans, we can help mitigate potential risks and minimize the negative consequences if a crisis does occur. There are also a number of recovery-oriented self-help and wellness tools that are available to compliment the process of managing risk described in this document. Below, we briefly present two: the Wellness Recovery Action Plan (WRAP), developed by Mary Ellen Copeland (2001) and the Psychiatric Advance Directive.

Complementary Recovery and Wellness Tools

There is increasing evidence that utilizing self-management or self-help strategies enhance the recovery process for individuals living with psychiatric disabilities. There are many wellness and recovery supports/tools that persons in recovery can utilize in their pursuit of valued adult roles and increased participation in the community. The Wellness Recovery Action Plan, or WRAP as it is commonly known, is a structured, self-directed monitoring tool developed to promote individual empowerment and recovery. It is a self-help tool designed to help individuals living with mental illnesses identify and develop positive coping supports and responses to difficult thoughts, feelings, and behaviors that inhibit their wellness and recovery, and their ability to participate fully in community life (Copeland, 2001).

> WRAP is a "plan or a process for identifying the resources that each person has available to use for their recovery, and then using those tools to develop a guide for successful living that they feel will work for them."
> Mary Ellen Copeland, Ph.D.

Psychiatric Advance Directives (PADs) are legal documents written by the individual to ensure that their needs and treatment preferences are known during a crisis that may or may not lead to psychiatric hospitalization. During a mental health crisis, it is often difficult to think clearly and communicate important information, such as which treatments are helpful and which might cause harm, who should be notified and how to reach them, and what techniques might de-escalate an individual's crisis and hasten his or her recovery. PADs are especially important when a person needs to be hospitalized and is judged to lack the capacity to make decisions regarding his or her own mental health treatment. With specific information in hand, hospital or crisis response staff and treatment teams can minimize inappropriate, ineffective, coerced or involuntary treatment. A good example of a PAD is the Advanced Self-Advocacy Plan (ASAP), developed by the Temple University Collaborative.



These tools used individually or in tandem can help identify strategies, resources and supports in both pre and post-crisis periods. WRAP can be built around the goals that individuals are pursuing in the community integration domains and practice of the strategies identified in this plan can also help reduce the potential harm (if any) of associated risks both seen and unforeseen. Should a potential risk lead to psychiatric crisis and/or psychiatric hospitalization, the PAD will help identify how best to provide services to the individual at that time. Additional resources for developing and using WRAP and/or the PAD can be found in the reference section of this document.

4. Implementation

Next, **IMPLEMENT** the agreed upon steps of the plan. Following the time frames laid out in the action steps, the individual will pursue the achievement of his or her goal.

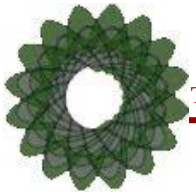
What might this mean for Selena?

> Selena and her case manager will use the support plan form as the starting point for the completion of each step – applying for the job, connecting with the Social Security benefits planners, etc. It is important to remember that when someone has a new goal, they are very excited about that goal. Sometimes that excitement can translate into a "now" mentality where the person wants to get all of the action steps accomplished immediately. Here then, it is our responsibility to talk with Selena to help her understand how and why things take a certain amount of time. If Selena understands some of the reasons why things take more time than she (or any of us) might like, she is less likely to get frustrated and lose motivation to work toward her goal. With the help of her case manager, Selena will use her new planner to schedule case management and medical appointments to correspond with the completion of action steps.

5. Monitor and Review

The fifth step is to continually **MONITOR and REVIEW** progress to assess the effectiveness of each implemented Action-Step. Use the Community Integration Support Plan Review form (included in the appendix) to assess the action steps taken. Collaboratively review each step and note the progress made or the obstacles that prevented progress. When obstacles have prevented progress, explore what happened and make the necessary modifications for continued progress toward the goal and safety. Revise or add Action-Steps as necessary. Also, monitor to ensure that individual's rights are being protected. This is a process that will be ongoing as the person reaches the goal and moves on to other goals.

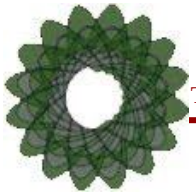
Let's take one more look at our example with Selena.



At the designated review dates, all of the actions steps will be reviewed and discussed. If completed, Selena will be congratulated and that step will be crossed off of the list. If she was unable to complete a task, then the obstacles will be discussed and additional steps can be added or other means of accomplishing the steps can be listed. Remember, support plan is a living document. That is to say, as progress is either made or delayed, it will grow, shrink and change. This is to be expected. We want Selena to keep moving toward her goal and should support her in the ups and downs of the action plan.

Throughout the risk management process, it is important to remember that you are there to help the individual achieve his or her goal as safely as possible (Rose, 2006).

"It is not 'choice' that one should fear, but the failure to offer 'informed choice' to those you support..."
John Rose



Chapter 4:

Community Integration and Managing Risk for the Agency or Organization

As noted above, an agency or program can never have absolute control over a situation, and cannot guarantee success in every endeavor. It can however, thoughtfully and thoroughly anticipate possible risks, plan ahead, and promote a safe environment while increasing opportunities for people with mental illnesses to participate more fully in the community. The adoption of a community integration framework and the promotion of opportunities for increased presence and participation in the community is not business as usual in the mental health system. Strong agency-wide and/or organizational leadership and support will be necessary for the successful implementation of a community integration framework.

"While experience is the best teacher, it is usually from bad experience that we learn. The role of the provider and the individual's team is to identify those potentially 'bad experiences' as far as reasonable and to implement an individualized risk management plan."
John Rose

There are also advantages to provider agencies and organizations that should drive the comprehensive implementation of a community integration framework in our mental health service delivery system today.

1. We know that first and foremost provider agencies/organizations are committed to the recovery, quality of life, safety, and welfare of the individuals to whom they provide service. The adoption and implementation of a community integration framework and its associated risk management processes clearly demonstrates that commitment to individuals served.

2. We know that some individuals in recovery and their family members alike verbalize legitimate concerns for the safety and wellbeing of themselves and their loved ones in response to the promotion of greater community presence and participation. The adoption and implementation of a community integration framework and its associated risk management processes clearly demonstrates that we understand and respect these fears and concerns and that we are willing to do all that we can to minimize these fears (risks) and increase the likelihood of success.

3. We know that there are fears and concerns on the part of provider agencies, their staff members, and even the community at large (real or imagined) in response to the promotion of greater community presence and participation for individuals living with psychiatric disabilities. The adoption and implementation of a community integration framework and its associated risk management processes clearly demonstrates our willingness to stand up for the rights of individuals living with psychiatric disabilities, and again, demonstrates that we are willing to do all that we can to support individuals in the pursuit of their goals and increase the likelihood of their success.

Below we outline four broad steps that can be taken at the agency/organizational level to increase the likelihood of success for persons in recovery as they pursue valued adult roles in the community integration domains of their choice, while also identifying, minimizing, and/or responding to the risks associated with increased participation, real or imagined, by individuals in recovery themselves, the agency, and the community at large.

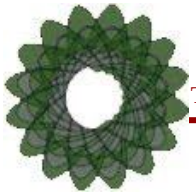
1. Adoption and Implementation

The first step is full **adoption** and **implementation** of a community integration framework, including the managing risk strategies described above, across the entire agency/organization – from the board room to direct service staff. Commitment at this level is critical if we are to really address the many institutional barriers that inhibit full access and participation in the community for individuals living with psychiatric disabilities. Community integration outcomes are everyone's responsibility. Agency and organizational mission statements, policies and procedures must reflect a real commitment to community integration and recovery. Staff must acknowledge and accept the principle that community integration demands that persons in recovery have every right to expect nothing less than that which individuals living without disabilities look forward to in their lives.

Success can only be assured if the entire agency is committed to following through on the processes and strategies described in this manuscript and the clear and ongoing documentation of what it is doing to demonstrate that you have thought critically and thoroughly about the issues and risks involved, collaboratively developed and implemented a support plan to mitigate and/or eliminate problems, and were prepared to act responsibly if things went awry.

Remember that the *Roadmap for Recovery* that we presented above can be used to help foster the adoption of a community integration framework. A quick review reminds us that the Roadmap can be used to:

1. Identify barriers that people face in each of the domains and develop strategies to address these barriers in the community;



2. Review the supports program's offer in each of the domains and consider how to fill some gaps in supporting people in areas where programs are not currently providing support;

3. Ensure that programs are offering the full range of supports, or utilizing already existing community supports, to increase the community integration of the persons in recovery that they support; and

4. Identify barriers that a specific person in recovery experiences and develop strategies to address these barriers.

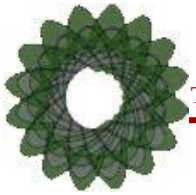
> "At the heart of this document is the belief not only that disappointment is relatively rare, but also that effective planning – recognizing the risks involved and taking steps to better insure success and respond to the occasional failure – can make integration a reasonable and responsible goal."

2. Training

Training will be an important component to the adoption and implementation of a community integration framework. Training needs to be broad-based, across the entire spectrum of the agency/organization, including persons in recovery, and their family members, receiving services. Training should encompass the principles and practices of community integration, implementation of community integration strategies, and the use of tools designed specifically to promote increased participation. Training should focus on the new expectations of staff and persons in recovery receiving services. This will include adopting a recovery-oriented approach, belief in recovery and the value of participating in adult roles in the community, understanding and supporting the dignity of risk, the utilization of strategies and tools to identify potential risks, and the ability to develop comprehensive support plans to address and respond to these risks when necessary.

3. Education, Outreach, and Advocacy

In recovery-oriented systems of care service providers are called upon to wear many hats. Given the continued societal stigma and discrimination experienced by individuals living with mental illnesses, community education and outreach, as well as individual advocacy are also integral to the successful implementation of a community integration framework. Education to combat stigma, i.e., anti-stigma campaigns directed to community and religious leaders and organizations can be an important strategy to help mobilize increased support in the community. Outreach to community and religious groups will be necessary to promote integration and recruit volunteer mentors to help individuals needing one-to-one support to participate more fully in the community



activities/groups and/or religious communities of their choice. And of course, continued advocacy at the national, state, local, and individual level to eliminate stigma and discrimination and to honor and support the rights of all individuals living with disabilities must not be forgotten.

4. Monitoring Outcomes and Record Keeping

Another important component in the adoption of a community integration framework is **monitoring outcomes** and **record keeping**. Program outcomes should move from more generic measures, e.g., days in the community, number of hospitalizations or crisis service contacts, compliance with medication regimens, etc., to measures that are developed collaboratively and reflect the positive subjective experience of growth and recovery of the individual. These might include measures of recovery, physical health and wellbeing, measures of increased presence and participation in the community (e.g., working, going to school, joining a gym, etc.), and satisfaction in numerous community integration domains.

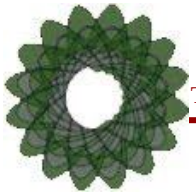
Additionally, the agency/organization should keep track of the protocols utilized to identify and manage any risks associated with promoting opportunities for increased presence and participation in the community. Use the Community Integration Monitoring Tool (included in the appendix) to keep track of the process of managing risk described above. This will help you develop a record keeping system to document:

1. The identified risks thought to be possible;
2. The action steps planned and taken to minimize those risks;
3. What was planned if something did happen; and
4. If something did happen, what was done and what was the outcome.

We recommend that the agency/organization include this record keeping process in its training plan and that there is a periodic review of these records to see if there are adjustments that need to be made.

Conclusion

The mental health system has long held to the belief that serious mental illnesses are deteriorative diseases associated with poor prognosis and little hope for living a fulfilling life in the community. But today, we are in a new era of systems transformation; we have a new vision of recovery and participation in valued adult roles in the community for individuals living with psychiatric disabilities.



"The community integration approach recognizes that many people with psychiatric disabilities have not participated in community life simply because of their disability: either the community has closed its doors or mental health systems have gone too far in providing alternative opportunities within the psychiatric milieu."

Recovery-oriented mental health systems, policies, practices and programs must be built on the principles, values and relational processes that promote and support individual recovery and community integration. This is the new cornerstone of our work and our relationships with each other. We are all human beings, here to witness our humanity in each other, and here to support each other to reach our fullest potential. For all of us, life is a journey of healing and transformation where we seek to live a meaningful life in community with each other while all the time striving to achieve our potential. This is the transformation that we seek.

The purpose of this guide has been two-fold:

1. To assist mental health providers in supporting individuals living with psychiatric disabilities to pursue valued adult roles in the community, that is to say, to adopt a community integration framework to guide service provision; and

2. To provide a strategy or template for use in identifying and managing the potential risk persons in recovery may experience as a result of their increased presence and participation in the community.

This might seem like tedious practice; but it is competent and comprehensive practice that all mental health provider organizations should be striving towards in this recovery-oriented service delivery era. To address and reverse decades of mental health practice that separated individuals from their families and communities and inhibited individuals from participating fully (if at all) in the communities of their choice, requires competent and comprehensive practice. There is a moral and legal imperative compelling us forward in this pursuit - righting these wrongs is an issue of justice. Risk and integration are opposite sides of the same coin; and as demonstrated in this guide, both can be respected, nurtured, and fused together to welcome home to community those who have been excluded for so many years.

"We don't have to lose another generation to a life outside of the mainstream, if we act now – in our practice, programs, and policies - to promote community integration."
Richard Baron

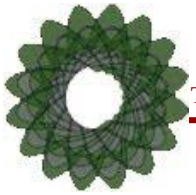
Chapter 5:
Examples of Community Integration in Practice

In this section we take a look at examples of community integration in real world practice settings throughout a sampling of the community integration domains identified in this manuscript. For each example presented, we first describe the domain involved and the individual's chosen goal in that domain. Second, we review the strengths and resources the individual has to support the pursuit of the goal. Third, we identify the potential risks involved in pursuing the goal as well as evaluate the frequency and severity that the risks pose. Fourth, we develop a brief support plan to mitigate or eliminate the risks identified, and finally, we explore a potential "but what if scenario" detailing a plan to intervene in the potential crisis.

These examples are presented in brief narrative form without the use of the individual and organizational risk assessment/management tools provided in the appendices. We do suggest, however, that as you read through the scenarios below, that you utilize the assessment/management tools by filling in the information provided in the narrative (and perhaps adding additional information as you see fit). This exercise will provide you with the opportunity to become familiar with the assessment/management tools and increase the likelihood of your effective use of the tools as you begin to incorporate them into your daily practice with the individuals to whom you provide service. Finally, we also recommend that you choose two additional community integration domains not explored in this section and complete the same exercise, walking through the process of using the assessment/management tools based on someone with whom you currently work. Do this with a colleague and have a robust discussion of all the issues involved, as again, this exercise will help you to become more familiar with and comfortable using the instruments in your daily practice.

An Important Note:

As detailed above in chapter three, the goal of the support plan is to mitigate or eliminate the risks identified. We know that the first two steps in the process - identification and evaluation of the risks - are critical to the development of a comprehensive support plan. The more time and effort dedicated to this process, the greater the likelihood of success in the chosen endeavor. We cannot emphasize this point enough. So why, then, do we suggest exploring a "but what if scenario?" We certainly do not believe that an adverse consequence will be the prominent outcome for individuals as they move to more actively participate in the community. We know that with the right supports and resources people can and will be successful. But we know too that some individuals will struggle, there will be some miss-steps - and in those limited instances where things do go poorly, we want to be sure that we have a plan to intervene swiftly to support individuals and to minimize any potential harm.



Example 1

Community Integration Domain: Civic Involvement

Community Integration Goal: Ricardo wants to volunteer with a local political campaign canvassing nearby neighborhoods about local political issues.

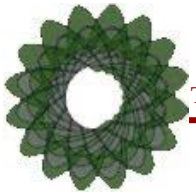
Skills/Strengths/Resources/Supports: Ricardo holds a Bachelor's Degree in Political Science; he is articulate about and keeps up with local politics; he has a positive therapeutic relationship with the members of the ACT (assertive community treatment) team who provide services to him; he shares an apartment with two peers with whom he gets along with well; he has recently been participating in a Wellness Recovery Action Plan (WRAP) group and is in the process of developing his own WRAP.

Identified Risks: **Rejection** – Ricardo is afraid that if others find out that he is living with a psychiatric disability they may reject him or be fearful of him; **Withdrawal and isolation** – in the past when Ricardo has experienced rejection/discrimination in the community he has tended to withdraw to himself and isolate in his room; **Increase in depression and/or other symptoms related to his psychiatric disability often leading to hospitalization** - withdrawal and isolation from his daily routines and supports in the past has tended to lead to an increase in distressing symptoms with which he has had difficulty.

Likelihood/Frequency and Severity of the Risks: The frequency and severity of the risk of rejection is potentially low as it is somewhat predicated on Ricardo's disclosure of his psychiatric disability. He has had both positive and negative experiences in the past disclosing his psychiatric disability to individuals he has met in the community and he has worked with staff members on the ACT team to develop stronger boundaries for himself when it comes to self-disclosure. The severity of the risk then seems to be dependent on his ability to maintain those boundaries and his assessment of the situation he finds himself in should he choose to disclose.

Support Plan: Ricardo's support plan could include action steps that he could take after each day of volunteer work to check in with a supporter and process the experience. Of particular importance may be to talk about the interpersonal relationships that he is developing (if any) and the topics of conversation, including a discussion of the potential disclosure of his psychiatric disability. He can also use the strategies (action plans) that he has developed in his WRAP to deal with his withdrawal and isolation should he experience some type of rejection.

But What If … Ricardo has been volunteering on Saturdays now for a few weeks and has been paired as a volunteer with Joanne, a student at a local community college. On this particular week, while waiting to be picked up by the volunteer coordinator after a couple hours of canvassing, he and Joanne begin to talk a bit more about their personal lives. Feeling comfortable with Joanne, Ricardo shares that he has been in the hospital on



a number of occasions as he is living with a mental illness. Seeming genuinely interested, Joanne asks what his diagnosis is. He discloses that he lives with a diagnosis of schizophrenia and that presently he is not working but receiving mental health services from an assertive community treatment team. Joanne is noticeably quiet after that and soon their ride appears to take them back to the campaign headquarters.

The following week when he arrives to volunteer, he is met by the volunteer coordinator. It seems that Joanne has called to say that she would not be available to volunteer today because she is extremely uncomfortable now being alone with Ricardo. Additionally, other volunteers have indicated their unwillingness to canvass with him due to his mental illness. Ricardo doesn't understand how all the volunteers now know about his psychiatric disability. The volunteer coordinator apologizes to Ricardo as he informs him that he will no longer be able to volunteer on the campaign. Ricardo leaves feeling rejected and depressed. He heads home not knowing what he is going to do. Once at home Ricardo continues to feel worse and isolates in his room for several days. He is unresponsive to his roommates' attempts to check in with him.

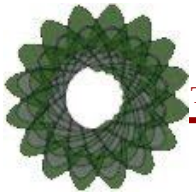
Contingency Plan: If the above described scenario were to occur the contingency plan could include Ricardo's roommates contacting the ACT team after three days of Ricardo isolating in his room. Ricardo has identified that in situations like this he would like John, a team member with whom Ricardo feels a close relationship, to be the one to make a home visit. Once at the house, John will attempt to engage Ricardo in a conversation about how he's feeling and what steps he could take to reach out to others to begin to decrease his isolation and depression. John will also encourage Ricardo to attend his WRAP group and offer support by offering to provide transportation or companionship to the group. Ricardo and John will negotiate a plan to meet in the community within the next two days. Additionally, Ricardo will identify steps that he will take with in the next couple of days to decrease his isolation and connect with his support system.

Example 2

Community Integration Domain: Housing/Independent Living

Community Integration Goal: Anna wants to move out of the boarding home where she is living and move into an apartment so she can live independently.

Skills/Strengths/Resources/Supports: Anna has been working part-time now for over a year and has saved up enough money for a deposit on her own apartment; Anna has been working with her case manager and board and care provider on taking her medication as prescribed independently as it helps her stay focused and successful at her job; Anna's sister lives in the apartment complex where Anna wants to live and they have a good relationship; Anna has developed good financial budgeting skills.



Identified Risks: **Failure** - this will be Anna's first experience living alone and she fears she may be lonely and scared at times and not be able to handle living alone; **Lapses in taking medications** - in the past under stress she has gone off her medication and this has led to periods where she experienced vast mood swings and erratic changes in her behavior.

Likelihood/Frequency and Severity of the Risks: The likelihood that Anna will feel lonely at times is high though the frequency and severity of the risk is medium as her sister also lives in the apartment complex. The likelihood that she will experience lapses in taking her medications also appears to be high and based on past experiences; the severity could be assessed as high.

Support Plan: Anna's support plan might include identifying friends at work that she could invite over to her apartment for socializing, scheduling a regular get together with her sister, and looking into social activities in the community in which she might be interested in participating. Anna can continue to use the medication monitoring tool from the boarding home that she has found helpful. She will chart her daily medication usage and review it with her sister weekly for the first three months she is living independently.

But What If … After living independently for nine months, Anna decides to stop taking her medication. After a couple of weeks she begins to act erratically. She stops showing up for work, she empties her bank account and goes on a shopping spree at the local mall. She is unable to sleep and stays up through the night playing loud music. She does not respond to her neighbors' requests to turn down her music and she is not able to pay her rent. As a result of her inability to pay rent and the numerous complaints to the apartment management by her neighbors, Anna is evicted and becomes homeless.

Contingency Plan: Despite efforts to predict potential risks of Anna's independent living, her becoming homeless was an unforeseen negative consequence of the risks that had been identified. If the above described scenario were to occur the contingency plan could include Anna's sister contacting the provider organization where Anna receives services to notify them of the eviction and subsequent homelessness. The agency could refer Anna to their homeless outreach division. The homeless outreach staff would engage Anna and discusses with her the options for available crisis housing, including the possibility of short term hospitalization to restart a medication regimen and regain a sense of control. Anna might determine that a brief hospitalization is probably the best strategy for her and asks for support to access that option. During the period of Anna's hospitalization the provider agency would work with the hospital and other community supports to identify a residential option that Anna is comfortable with upon discharge.

Example 3

Community Integration Domain: Education

Community Integration Goal: Tony wants to return to trade school to complete coursework to be an air conditioning and refrigeration (AC&R) service technician.

Skills/Strengths/Resources/Supports: Tony's brother currently works in the AC&R field and occasionally has Tony assist him on the job; Tony has been accepted in a training program at a local trade school and has been approved for financial aid through the state Vocational Rehabilitation office; he has also applied to receive supported education services from the organization where he currently attends outpatient therapy; he is highly motivated to go to school.

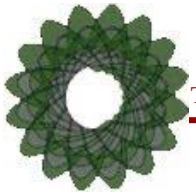
Identified Risks: **Dangerous Consequences** – Tony has a co-occurring alcohol abuse problem and when he drinks he often gets into fights; Tony has a tendency to drink more when he is experiencing higher levels of stress.

Likelihood/Frequency and Severity of the Risks: Currently the likelihood and severity for dangerous consequences is low as Tony has been participating in his program's co-occurring treatment and has been abstinent from alcohol for the past six months.

Support Plan: Tony's support plan might include attending AA meetings in the community several times a week, as well as attending his treatment's evening aftercare program. Tony will also meet with his supported education counselor to identify needed academic supports and/or accommodations. Together Tony and his counselor will work on time management and study skills in an attempt to keep Tony's stress levels low as he begins his school experience.

But What If … Tony has successfully completed the in-class portion of his training program and has begun his paid internship. Tony's school experience has been positive thus far and he has maintained his sobriety and connection with his treatment supports. Upon receiving his first paycheck Tony is invited by his fellow students to celebrate at a local bar. Tony feels confident in his ability to maintain his sobriety in this situation and decides he will go along. After declining several drinks Tony decides he will have just one drink. After the first drink Tony continues to drink more with the encouragement of his peers. Eventually Tony ends up in a heated argument with one of his classmates, a fight ensues, the police are called, and Tony is arrested for drunk and disorderly conduct. After being processed at the local police station, Tony calls his brother to bail him out of jail.

Contingency Plan: If the above described scenario were to occur the contingency plan could include that Tony and his brother contact his therapist from the co-occurring program to let him know about the situation that has occurred. Tony's therapist could invite Tony, his brother, and the supported education specialist to a meeting to develop



a plan. At the meeting they would review what happened at the bar, discuss the precipitants to Tony's drinking, and what led to the fight. Then they could identify strategies to mediate the potential negative consequences that may occur as a result of Tony's behavior. For example, the program's court liaison could contact the local police department to find out the status of Tony's case and the potential legal dispositions. Additionally, Tony's supported education counselor would contact the internship placement coordinator to discuss the ramifications of Tony's actions. Tony could continue to engage in regular AA meetings and the evening aftercare program.

Example 4

Community Integration Domain: Spirituality/Religion

Community Integration Goal: Rebecca wants to participate in her faith community. She was raised Catholic and would like to begin attending services on Sundays at the local Catholic parish.

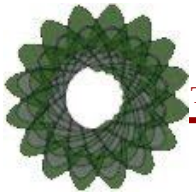
Skills/Strengths/Resources/Supports: Rebecca clearly verbalizes her desire to attend church services; she has good communication and social skills; the residential program where she lives is willing to provide her with transportation to church if needed.

Identified Risks: **Agency Embarrassment** – Rebecca's treatment program has done outreach to local faith communities to develop a mentor program in which parishioners would accompany program participants who are newly attending services; Rebecca has previously had experiences where she has believed that she was Mary, the mother of Jesus; the agency supports Rebecca's goal but has concerns that she may become religiously preoccupied and behave erratically during services, reflecting badly on the agency.

Likelihood/Frequency and Severity of the Risks: The likelihood and severity of Rebecca behaving erratically during worship services is moderate.

Support Plan: Rebecca's support plan may include the scheduling of a meeting between the church mentor, Rebecca, and her case manager. During this meeting the church mentor and Rebecca can get to know each other and discuss supports that would be helpful for Rebecca to participate fully in worship services. Rebecca will meet weekly with her case manager to discuss her experiences with worship services and monitor her thoughts related to being the mother of Jesus. Rebecca will also utilize cognitive behavioral techniques (CBT) that she and her therapist have been using to challenge religiously preoccupied thoughts.

But What If … Rebecca begins to attend worship services with her mentor on a weekly basis. She finds church very meaningful and sees it as a positive step in her recovery. After attending for a number of weeks, Rebecca decides she would like to begin attending

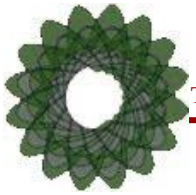


services daily on her own. Rebecca attends daily services for a couple of weeks when she begins to be preoccupied with thoughts of being the mother of Jesus. After a Sunday service Rebecca attends the coffee hour in the church basement. During the coffee hour Rebecca gets the attention of everyone in the room and announces that she has exciting news and proclaims that she is the mother of Jesus. Her church mentor approaches her and attempts to redirect the attention away from Rebecca who becomes agitated by this and feels that people don't believe her. Rebecca continues to assert her claim and finally states that if anyone doesn't believe her they can call her psychiatrist at the community mental health agency and he will tell them it's true. The following day the pastor of the church and the mentor ask to schedule a meeting with Rebecca's treatment team.

Contingency Plan: Having considered that this type of situation might occur, the treatment team welcomes the opportunity to meet with the church leaders. The treatment team is prepared to educate the church leaders about psychiatric disabilities and its associated stigma and discrimination, as well as offer to provide educational programs about mental illnesses to the parishioners. Additionally, the agency offers to develop a formal mentorship program with the church in which volunteer mentors will receive orientation, training, and ongoing support for their work.

Conclusion

We have been making the point throughout this document that community integration demands that we encourage persons in recovery to expect nothing less than that which individuals living without disabilities look forward to in their lives. We hope that these scenarios, though brief, have served to give you greater insight and understanding into the importance of the support planning process so that this integration and integration does indeed become a reality for more and more individuals living with psychiatric disabilities in the community. We hope too that they help demonstrate our belief that not only will disappointment be relatively rare, but also that effective planning – recognizing the risks involved and taking steps to better insure success and respond to the occasional disappointment – will make integration a reasonable and responsible goal.



APPENDICES

Temple University Collaborative on Community Inclusion

Managing Individual Risk Assessment Tool

Name: _____ Date: _____

Community Integration Domain - Activity or Goal: _____

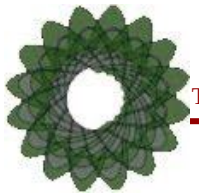
IDENTIFICATION						
Skills & Strengths Resources/Supports						
Identified Risks						
EVALUATION						
Likelihood & Frequency of the Risk						
Severity of Risk						
Is the Risk worth taking (positive consequences)?						

Temple University Collaborative on Community Inclusion

Community Integration Support Plan - Part 1

Name: _____ Goal: _____ Date: _____

Identified Risk(s)	Strengths/Resources and Supports	Additional Support Needed	Action Steps & Time Frames	Review Date
			1.	
			2.	
			3.	
			4.	
			5.	
			6.	

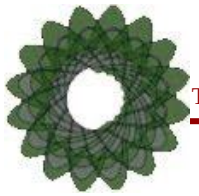


Temple University Collaborative on Community Inclusion

Community Integration Support Plan - Part 2
(Contingency Plan)

Name: _____ Goal: _____ Date: _____

Identified Risk(s)	"But What If" Scenario	Identified Supports and Resources	Crisis Plan and Action Steps



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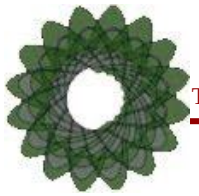
Community Integration Support Plan Review

Name: _____ Goal: _____ Date: _____

Identified Risk & Action Step	What Happened?	What Worked?	What Did Not Work?	What Was Learned?	Next Steps: Adjust Or Add Action Steps? Try Again?
1.					
2.					
3.					
4.					
5.					
6.					

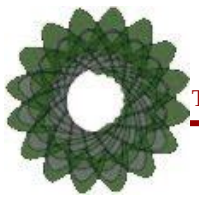


Temple University Collaborative on Community Inclusion

Community Integration Monitoring Tool

Name: _____ Date of Initial Plan: _____ Date Action Taken (if needed): _____

Community Integration Domain	Identified Risks	Plan to Minimize Risks	Action Taken If Needed	Outcome



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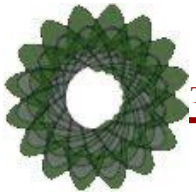

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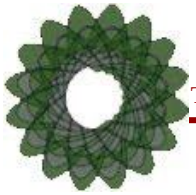

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