



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

The Guthrie Legacy Project on Community Inclusion: An Initial Progress Report

August 2015

for the Pioneer Center for Human Services

McHenry, Illinois

from the Temple University Collaborative
on Community Inclusion

Philadelphia, Pennsylvania



Temple University

Collaborative on Community Inclusion

In 2013, the Pioneer Center contacted the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities to discuss community inclusion, strategies to promote community participation, and input on what they, as an agency, could do to promote independent engagement in the community. From this initial conversation, the TU Collaborative provided technical assistance that was funded through the National Institutes on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number #90RT5021-02-00). With ongoing consultation from the TU Collaborative, the Pioneer Center began to deliver services with a clear focus on community inclusion.

The community inclusion services at the Pioneer Center were partially funded through a generous donation that allowed for the establishment of the Guthrie Legacy Project of Community Inclusion. This evaluation report and related products (video) were funded through a contract from the Pioneer Center with Temple University. The content of this report was developed by Temple University and reviewed prior to publication by the Pioneer Center.

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This report was created in August of 2015 for the **Pioneer Center for Human Services**.



“when we developed the community inclusion program, we really looked at helping people to participate in the community rather than re-creating under our own roof things that were already in the community”

“community inclusion gives us all the tools we need to be able to say to program recipients, ‘if you really want to pursue these goals, that’s great, and here’s how we can do it and here’s how I can help’”

“it’s been amazing to see how this group of people change so quickly”

“I’m serious: since I got involved in community inclusion I’ve got a smile on my face”

Introduction

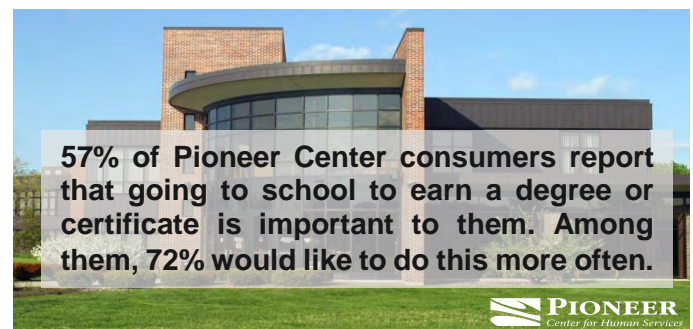
An Innovation. In early 2013, the Pioneer Center for Human Services was challenged to re-invent itself. Pioneer Center is an established social services agency providing a wide range of services and supports for individuals with mental health conditions and/or intellectual/developmental disabilities in McHenry County, an hour north of Chicago. A combination of staff questions, parent concerns, and consumer ambitions suggested that Pioneer’s traditional model of focusing on assuring the stability and safety of service recipients needed to be supplemented by a new emphasis on helping individuals to re-connect to mainstream activities throughout McHenry County – to regular educational and employment opportunities, to civic activity and membership in religious congregations, to recreational programs and independent housing, etc. New goals – ending the pattern of so many of Pioneer Center’s service recipients of building their lives around the Center’s services – would require new programs that helped people participate in and contribute to community life.

Over the past two years, the Pioneer Center has indeed re-invented itself, working more closely than ever with individual service recipients to help them set and meet new goals focused on community participation. The Center has retrained staff, hired new ‘community inclusion specialists,’ identified public and philanthropic funds to support its new initiative, and begun to revise its mission. Although this emphasis on what is now referred to as ‘community inclusion’ had begun as a special initiative, community inclusion is now the framework for a broader and deeper re-orientation of Pioneer Center’s fundamental goals. This report provides an early look at and assessment of Pioneer Center’s progress in that regard. (with quotes from service recipients, staff, and Pioneer Center executive leadership).

Community Inclusion. For over a century, individuals with significant mental health conditions and/or intellectual/developmental disabilities have lived at the fringes of everyday life. At the end of the Second World War, the vast majority of those with significant mental health (MH) or intellectual and/or developmental disabilities (I/DD) issues lived in large, impersonal, and often

inadequate state hospitals, separated – often for their entire adult lives - from the mainstream of community life. In the 1970s, driven by court recognition of the legal rights of those with disabilities, shifts in public financing for care, and changes in social service philosophies, institutional care rapidly began to decline and the presence of those with disabilities in community settings rapidly increased. However, even while those with MH or I/DD conditions now lived in neighborhood rather than hospital settings, they often continued to live ‘apart’ – sometimes in group homes and boarding houses and specialized residential programs solely for people with disabilities, and consistently unconnected to the broader life of the community.

Even today, several decades after the ‘deinstitutionalization’ movement, few people have found jobs in the competitive labor market or are enrolled in community college or job training programs, and many remained estranged from family members and unconnected to the social, civic or religious groups that might have lead to new interests and new friendships. Living ‘in’ but not being part ‘of’ community life was a common condition. Mental health and intellectual/developmental disability provider agencies - like Pioneer Center - gradually developed an array of social settings, recreational programs, vocational workshops, and other group activities that compensated for their service recipients’ distance from everyday community life.



Over the past decade, however, there has been a growing recognition that individuals with MH and/or I/D disabilities ‘should, would, and could’ live more satisfying lives participating as part of mainstream community life , particularly if they had the consistent encouragement and support needed to reconnect with the individuals and organizations around them. Today, service philosophies are shifting, providing new answers to old questions:

- **should people participate in community life?** Old assumptions that individuals with disabilities shouldn’t engage in community life - because it was too challenging for them and likely to lead to failures and behavioral crises, have given way to a broad body of research indicating that re-engaging in community life – getting a job or an apartment of one’s own, attending community college or neighborhood civic association meetings, joining a congregation or a local ice hockey league – is more likely to *improve* one’s functioning and stability.
- **would people choose to participate in community life?** Many human service professionals once believed the consumers with whom they worked were clinically unmotivated

or simply uninterested in participating in community life, and preferred the reassuring and undemanding days within the walls of service providers; however, more current surveys of service recipients clearly indicate an enduring interest in finding a decent place to live on their own, landing a good job in the competitive labor market, and a few regular friends of their own.

- **could people succeed in expanding their participation in community life?** It is reasonable to ask whether people with significant MH and/or IDD disabilities can participate successfully in community life, there is growing research evidence that, many people with disabilities – and even those with significant disabilities – who are offered initial and ongoing supports are indeed increasingly successful in returning to work and school, rebuilding family and social lives, and contributing substantially to civic, religious, and recreational life in local settings.

This changing orientation around what individuals with disabilities ‘should, would, and could’ do with their lives was part of a broader discussion of ‘recovery’ – particularly the idea that individuals with mental health conditions could indeed ‘recover’ and move toward more satisfying and engaged lives if provided with both the opportunities and supports they needed to do so. Indeed, ‘community inclusion’ is increasingly seen as what recovery is ‘for’ – the opportunity live more like everyone else.

“community inclusion supports individuals in participating in life like everyone else”

“community inclusion is what recovery is for”

Project Overview. Pioneer Center has committed itself to acting on the research evidence and begun building a community inclusion approach that focuses on supporting individuals in their broadening engagement in community life. Over the past year in particular, Pioneer Center has initially focused on community inclusion programming for service recipients with mental health conditions. The program is composed of three major elements:

1. Each individual with a mental health condition receiving adult behavioral healthcare services at Pioneer Center participates in an assessment process identifying how much they are engaged in a wide range of community activities, how much more they would like to be engaged in particular community activities, and the priority they attach to various aspects of community inclusion, so that service recipients and staff can jointly develop strategies to support their community participation.
2. Those who could benefit from additional supports to achieve their community inclusion goals are referred to one of Pioneer Center’s newly-hired ‘community inclusion specialists’ who work intensely with each individual to both define specific community inclusion goals and to offer ongoing guidance, counseling, emotional support, and encouragement – as well as sometimes initially accompanying service recipients to mainstream community activities – to help people attain their goals; and

3. Individuals who need financial support – for instance, who need help with the fees for a membership at a gym or tuition to take classes at a community college, enough funds to buy a lawnmower to start a business, or a down-payment to rent and/or furnish an independent apartment, or carfare or gas money to arrange transportation to a community event – can turn to a special ‘scholarship fund’ designed to make participation possible.

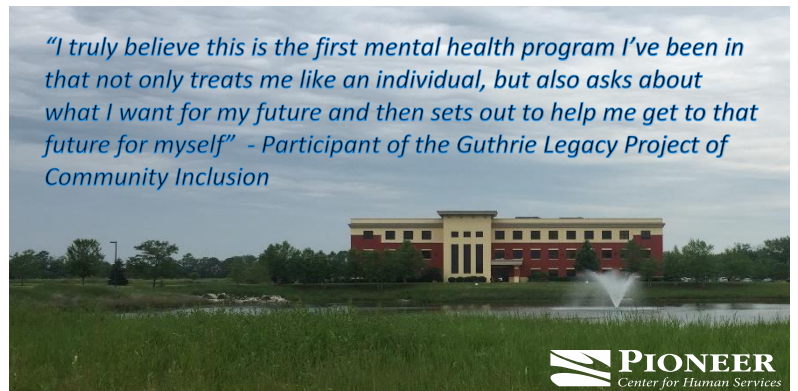
The community inclusion program has been an early and pronounced success, with consumers, staff, and the agency’s leadership increasingly committed to expansion. The next section of this brief report provides an account of how they did it.

The Guthrie Legacy Project of Community Inclusion at Pioneer Center

In 2013, Pioneer Center established The Guthrie Legacy Project of Community Inclusion. The project started as series of conversations between Pioneer Center leadership and the parent of an individual with a disability who had been receiving service for over 28 years.

This parent had much admiration and gratitude for the work Pioneer Center did; believing that the safe environment provided had undoubtedly contributed to their son’s, and many other clients, stability. Over the course of many conversations, a single vision emerged that more could be done; that support services could be refocused to a service delivery model that would promote broader opportunity for community engagement. With a shared passion to “empower individuals to achieve their full potential” this mother’s insight provided the impetus for Pioneer Center to look outside its four walls to the community for unique ways to broaden services. Out of these conversations The Guthrie Legacy Project of Community Inclusion was born.

“I truly believe this is the first mental health program I’ve been in that not only treats me like an individual, but also asks about what I want for my future and then sets out to help me get to that future for myself” - Participant of the Guthrie Legacy Project of Community Inclusion



The program design included six key elements:

1. **agency-wide training:** Pioneer Center determined that a series of agency-wide training programs on the importance of community inclusion would create a more consistent atmosphere supporting these new directions, and contacted one of the leading proponents of community inclusion – the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities, funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) – both to provide agency-wide training and to facilitate Pioneer Center’s workgroup of *community inclusion champions* to drive this new approach;
2. **community inclusion specialists:** Pioneer Center then hired a full-time community inclusion program director and two part-time community inclusion specialists to meet and work with individuals who had been referred from the Pioneer Center’s MH case management and psychosocial rehabilitation program staff for specialized community inclusion support, including assessment, planning, accompaniment, and more, and over the past year the number of community inclusion specialists has expanded to eight half-time individuals with unique job descriptions that focus entirely on community inclusion goal setting and support services;
3. **scholarship awards:** The Center used some of the philanthropic funds provided to establish The Guthrie Legacy Scholarship Fund, which makes relatively small grant funds available to enable individuals to achieve what might otherwise be unattainable goals offering support for transportation costs, community college tuition, gym memberships, independent apartment first month rental fees, employment-related equipment, etc.): community leaders from a variety of local agencies review and approve/deny applications that individual consumers and community inclusion specialists have worked on together to make community inclusion actions more feasible;
4. **sustainable funding:** the philanthropic support from the Guthrie Legacy Fund also supported initial staff costs for the community inclusion manager and the first two half-time community inclusion specialists, but Pioneer Center quickly found they could bill Medicaid under one of its ‘case management’ categories for the services of the community inclusion specialists, permitting both a much-sought-after expansion of the program and a recognition that the community inclusion program is likely to be sustainable over the long-term;
5. **assessment:** Pioneer Center has recently decided to use the Temple Collaborative consultants’ Community Participation Measure (TUCPM) to provide an initial assessment on all of its service recipients with mental health conditions who are participating in its case management and psychiatric rehabilitation programs, both heightening the focus on community inclusion and providing a rich set of data for both initial service development and program evaluation; and

6. **a focus on outcomes:** as noted above, the widespread use of the TUCPM permits Pioneer Center to structure ongoing evaluations of program outcomes: initial use of the TUCPM establishes early measures of both community participation and future community participation goals, while repeat use of the TUCPM – at six month intervals – will permit outcome assessments with regard not only to individual goal attainment but also broader agency-wide progress.

Since the program's first efforts in December 2013:

- 186 individuals have completed the Temple University Community Inclusion Participation Measure and have been working with staff to both establish and move toward community inclusion goals;
- 56 service recipients have been referred to the services of the community inclusion specialists and have received intensive counseling, goal setting, scholarship application assistance, and support;
- 8 part-time community inclusion specialists are employed, have received both orientation training and ongoing supervision, with approximately 8 individuals on each caseload
- 78 scholarship applications have been approved, for a total \$20,063.17, across a wide range of life 'domains' (e.g, work, school, independent housing, recreation, etc.).

Scholarship Requests. The scholarship requests have been quite varied, and roughly evenly distributed across several domains:

employment and education – 20%. It should be noted that approximately 20% of all scholarship awards have been related to participant interest in returning to competitive employment - interview clothing, business cards, fees to request copies of birth certificates, alarm clocks, nursing assistant program fees, computer classes, GED prep courses, etc. - indicating how strongly service recipients feel about returning to the labor market;

"I did something I never thought I'd do – I went back to school, with enthusiasm, and the scholarship fund helped me with the tuition costs"

health and wellness – 25%. Service recipients also indicated a desire to take the measures necessary to improve their physical health and wellbeing. Nearly a quarter of awards for scholarships were designed to help improve the applicants' health, including a strong focus on gym memberships, weight watchers classes, personal trainers, etc. - highlighting concerns within the mental health community about the startlingly high mortality rates of individuals with serious mental health conditions and their vulnerability to metabolic health-related problems;

transportation – 15%. Scholarships to support program participant transportation needs were also significant, and include costs associated with driver education classes, driver's license fees,

repair costs for a scooter, car registration fees, car repairs, bus fair, etc. – all designed to assist individuals in moving about the McHenry community in order to participate in its programs;

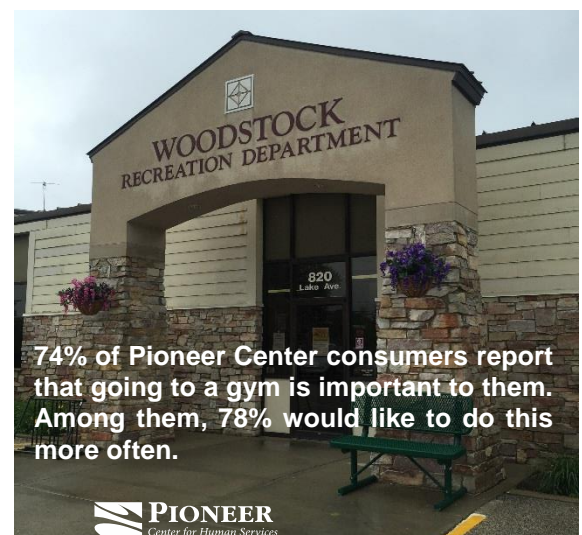
recreational programs and supplies – 20%. Approximately 15% of scholarship awards targeted recreational programs and supplies – art supplies and art classes, song writing classes, a cake decorating class, a song writing class, frames and supplies for displaying art at a local arts fair, etc., which provides evidence of service recipient interest in and willingness to participate in the community's social and recreational life; and

residential and other costs – 20%. Modest scholarships were awarded to support individuals who were either moving into their own 'first apartment' or were seeking to improve their living circumstances, and went toward home rental deposits, furnishings, initial rental assistance – making it possible for individuals to achieve a level of independent functioning otherwise not considered possible.

“when I got an apartment, the scholarship money helped me to buy furniture, and when I got the chance to be part of an art exhibit, the scholarship fund helped me to print up business cards, and when I wanted to learn to join a local knitting class, the fund paid the fees”

An Evaluation. After only 18 months of operation, Pioneer Center turned to the Temple University Collaborative for an early qualitative evaluation, with several broad questions to be answered: How has the program been doing? What do service recipients, staff, and community members think of the program? What impact has the community inclusion initiative – assessments, community inclusion specialist services, and scholarships – had on service recipients, staff, and the community?

In June of 2015, Temple University Collaborative staff spent two days interviewing service recipients, community inclusion specialists and case managers involved in the program, Pioneer Center's administrative staff, the program's initial philanthropic donor, and community members of the Guthrie Legacy Scholarship program's review committee. Temple's staff reviewed available data, asked follow-up questions, and analyzed the data that emerged from this process, yielding both a set of findings that spoke to the popularity and effectiveness of the program and to the substantial challenges ahead as the program seeks to expand to all of Pioneer Center's service recipients and to serve as a model for replication for other human services programs in Illinois and other states.



Key Findings

Overview. Pioneer Center’s community inclusion initiative, in its first eighteen months of operation, has been very popular, with high marks for its effectiveness coming from service recipients, community inclusion specialists, the case managers and psychosocial program staff who refer service recipients to the program, and key administrative personnel. In addition, the Guthrie Legacy donor, who both encouraged Pioneer Center to rethink its services and provided initial staff and scholarship funding, believes the program has far exceeded her expectations. There were six key findings from the interviews, highlighted below.

1. **Service Recipient Satisfaction.** Program satisfaction on the part of service recipients has been very strong. Service recipients emphasized four specific aspects of the community inclusion program that worked particularly well for them, and which they felt would continue to work well with new program recipients:
 - **Listening Closely:** first, many of those working with Pioneer Center’s community inclusion specialists went out of their way to note that they felt this was the first time - often over a long course of illness, treatment, and rehabilitation programming in a variety of other agencies - that someone had taken the time to listen to the hopes and dreams they had for their own futures;
 - **Encouraging Inclusion:** second, service recipients were impressed that the community inclusion specialists had encouraged them to identify ‘community inclusion’ goals that went beyond clinical stability and helped recipients return to long since abandoned hopes for participating in community life, as well as consider new options for themselves as part of their recovery journey;
 - **Scholarship Opportunities:** third, the additional opportunity for pragmatic financial assistance, although generally at a relatively modest scale, reinforced their ambitions to move toward an apartment on their own, a vocational training program with a promise of economic self-sufficiency, or engagement in artistic, social and recreational activities as part of the community; and
 - **Ongoing Encouragement and Support:** fourth, the availability of the community inclusion specialists – to help them dream and plan, to help them prepare scholarship applications, to accompany them into what service recipients experiences as quite challenging community settings, and to process their reactions to these new ventures, proved a powerful new service modality.

“my community inclusion specialist is full of enthusiasm – it makes me want to succeed in this program: they are so sincere, and you wind up

believing there's nothing you can't do with their support. I feel like I'm alive again"

2. **Individualized Planning.** Several recipients made the point that services in many of the other mental health agencies they used in the past had been far less individualized. Service recipients reported that the programs they had been offered had been prescribed on the basis of current program structures at the agency in question and /or staff perceptions of consumers' needs, and that these services often had little in common with the service recipient's own sense of their priority goals. Service recipients were very pleased that they could work with community inclusion specialists on a one-to-one basis, rather than participating in group activities, to both identify long dormant goals and develop a plan – and scholarship application – that spoke directly to their individual priorities.

There was a sense that the program – in its focus on individual priorities and re-awakened ambitions – provided service recipients with a new and more encouraging notion of themselves and what they could accomplish in the future, that it had changed the direction of their lives and enhanced their estimation of their own capabilities. Although the scholarship funds were important to this process, many felt that the community inclusion program's broader goal of re-connecting them to the community activities *of their choice* was the central element of the program's success. There was almost no discussion in these interviews of 'group' activities, but rather a consistent focus on a more individualized relationship.

"the program convinced me that getting out in the community was better for me than sitting at home and looking at the walls, so I joined a yoga class – I've always been interested in yoga – and having the confidence that comes when another person is with you to support you in doing the things you want to do – well, that is just incredible"

3. **Staff Responses.** Staff members were also quite articulate about their support for the program, for two reasons. On the one hand, both the community inclusion specialists interviewed and the case management and psychiatric rehabilitation program staff who referred clients to them were very enthusiastic about the impact the program had on service recipients, particularly in light of the service recipients' excitement about the program and their consistent follow-through in their responsibilities for meeting these new goals.

On the other hand, staff were also very pleased about their own new roles. Community inclusion specialists were particularly pleased to be able to individualize programming to be able to work with service recipients around their community inclusion activities, and to feel their work with service recipients was effective. Case managers and psychiatric rehabilitation program staff felt very good about both their ability to refer service recipients to the community inclusion specialists *and* to begin talking with the other consumers they served about community inclusion goals. It was clear that early and ongoing training – particularly for the

eight part-time community inclusion specialists – had been effective in generating enthusiasm for the program, and that the actual operation of the program had re-energized staff commitment to their roles and to Pioneer Center.

“when you talk to the community inclusion staff you find that they are incredibly grateful and appreciative that this is the program they are involved in, that it allows treatment providers to be more effective and opens up new opportunities for service recipients: everybody has a chance to be a creative thinker now”

“all of us had some initial concerns with regard to the risks that people might be taking when they got involved in the community, so we’ve done a lot of training about that – managing risks – and staff are now really comfortable with promoting community engagement”

“the philosophy of community inclusion fits very well with our own case management approach, and so we’re a major user of the program”

4. **Community Inclusion as an Agency Priority.** Both service recipients and staff spoke often about the degree to which the community inclusion program had helped Pioneer Center to redefine its mission, and that community inclusion was becoming a new way for service recipients to explore what they wanted from the program. The fact that Pioneer Center was completing the Temple University Community Participation Measure (TUCPM) with a broader array of service recipients in their mental health programs was an indication that this new emphasis was an important new programmatic focus.

Staff were aware of the wide range of requests – for gym memberships, community college fees, work-related equipment purchases and training fees or to expand individual artistic horizons, or simply to make socialization possible – and noted that this was a clear indication that Pioneer Center was prepared to work with individuals around re-engaging in community life. The focus of scholarship requests had surprised many as well, revealing as it did stronger-than-expected service recipient interest in a return to the labor market and stronger-than-expected concerns over personal wellness.

5. **The Commitment of Leadership.** The interviews provided ample evidence that the enthusiasm of both service recipients and direct line staff was a reflection of the strong commitment to the program on the part of key administrative leadership. Early agency-wide training on community inclusion had played a key role in convincing staff that this new direction was important, but continued support for the program from Pioneer Center’s leadership played a critical role in staff and service recipient perceptions of the program’s likely effectiveness and continued viability. Interviews with key members of the leadership included agency wide personnel, programmatic leaders, and fiscal and administrative officers, and they expressed a

strong joint commitment to the program, one that was then reflected in staff and service recipient perceptions of the importance of community inclusion in their lives. The commitment of Pioneer Center's leadership was reflected in three important ways:

- **A Philosophical Shift.** First, it was clear that this was a philosophical shift in leadership's perception of the role that Pioneer Center should play in the lives of its service recipients, reflected in: initial and ongoing training; the steady expansion of the program as new staff were hired and service recipient participation increased, and the visibility of the program internally.
- **An Early Investment in Evaluation.** Second, it was clear in the interviews that Pioneer Center had committed the agency to both initial and ongoing evaluation of the community inclusion program's success, and that the TUCPM was valued both for its effectiveness in helping service recipients and community inclusion specialists to select priority 'domains' and for its potential for effectively tracking both individual and agency-wide outcomes.
- **Building Financial Sustainability.** Third, the leadership's financial commitment to the program was another indicator of enthusiasm, particularly with regard to the decision to use Medicaid billing codes to support the work of the expanding community inclusion staff members, with the implications this has for the long-term sustainability of the program beyond the limits of the initial Guthrie Legacy grant.

"Pioneer Center has been very fortunate in having the Guthrie Legacy Project to jumpstart our work and fund the scholarship program, but we've also discovered that much of what our community inclusion staff does within the program on a day-to-day basis is billable through Medicaid"

"having the program be something that's coming from the leadership team and the executive staff has really been a huge component in what has driven this project from a dream to a reality"

6. **A Permanent Change in Direction.** Finally, it was clear that what had initially been an interest in a new program offering had led to a more permanent change in direction. The early framing of a discreet 'community inclusion program,' the initial staff training and the hiring of two part-time community inclusion specialists, and the development of the Guthrie Legacy Scholarship program had grown into a fundamental commitment on the part of Pioneer Center to shift from more traditional clinical and rehabilitation in-house activities to a more profound challenge – to staff and service recipients alike – to set their goals on community inclusion, with the hope that early success in Pioneer Center's mental health programs would be replicated in its intellectual/development disabilities program in the not-too-distant future. Everyone interviewed felt that the community inclusion program was now not just a 'program' of Pioneer Center but a permanent and significant shift in the Center's overall service delivery philosophy.

“I think the biggest success that we’ve seen is when we have clients who are talking about community inclusion, saying this is something I want to do, because finally someone is looking at me as a whole person – as more than my illness – and trying to figure out with me what I want to do when I leave Pioneer Center behind me”

Challenges

While interviews with service recipients, staff, and administrative leadership at Pioneer Center offers a very positive perspective on the program’s progress in its first eighteen months, the interviews also yielded information on a number of challenges that the community inclusion program will need to face in the years ahead. Six particular challenges stood out, some of which are related to immediate challenges and others of which will need to be faced in the not-too-distance future.

1. Sustaining the Commitment to the Core Values of Community

Inclusion. The human services field has a long history of initiating innovative and exciting changes that over time fall back into older patterns of care, and Pioneer Center will need to be vigilant with regard to insuring that the day-to-day operation of the community inclusion program doesn’t wear down the energy needed to sustain a commitment to community inclusion’s core values of individual choice, pragmatic assistance, and genuine community participation. There may be a few areas that already may require attention:

- **group vs. individual activities** – as the number of service recipients in the program grows, there may be requests for group activities (there already are some) when several people have similar interests; while it will be tempting to work with a group – around a time to go to the gym or visit the movie theater – this can gradually come to dominate program activities and detract from the program’s commitment to meeting individual needs within the context of the community
- **establishing patterns** – already some comfortable patterns are being established in the scholarship awards, with requests for gym memberships and community college classes among these, and the program will need to guard against consistency if it is to insure that the community inclusion specialists and the service recipients with whom they work are genuinely exploring individual priorities and developing individualized approaches to addressing those priorities
- **reinforcing staff commitment** – there was some sense in the interviews that the impact of the initial agency-wide training around community inclusion may begin to fade over time, naturally enough, and Pioneer Center will need to develop a longer-term plan for both ongoing training, particularly of incoming staff, and opportunities – awards programs and success stories and public presentations – of the importance of community inclusion approaches

- **linking program elements** – although the TUCPM and the scholarship program have a tendency to focus on individual ‘domains’ of community life – getting an apartment of one’s own, taking classes at community college, joining a congregation – it is important to remember that genuine inclusion often means a link between domains, so that the individual moving to a new apartment may also need some support in establishing relationships with new neighbors and neighborhood groups

“sometimes we use the program to get people into their own apartments, but after they move they find themselves really struggling with isolation and we have to do more to set up services and connections for them even before the move”

- **transportation** - transportation issues are a persistent problem for the community inclusion program, clearly because participating in community depends upon actually being able to ‘get there,’ and while the Guthrie scholarships have often focused on short-term fixes, longer-term solutions – ride sharing, low-cost and/or low-interest loans to support car ownership, bartering services for transportation, and identifying other local human service transportation resources, etc. - need to be explored.

Recommendation. Pioneer Center may want to ask its ‘champions’ group to review challenges to the community inclusion approach at an every-six-month or once-a-year basis, or establish a ‘fidelity review committee’ to annually assess the degree to which the community inclusion program has sustained its commitment to a set of core values, and to recommend changes or adaptations or new approaches to insure the program continues to move forward.

2. **Developing Personal Connections.** One of the implicit goals of community inclusion programming – of getting individuals into mainstream homes, jobs, classes and clubs, etc. – is that participating in community activities leads service recipients toward developing personal relationships – friendships – with other community members beyond the frame of Pioneer Center. The community inclusion specialists interviewed indicated that this was a goal that they did not feel had yet been fully attained: although participation in community activities had increased, more personal relationships either had been slow to develop or had been blocked by community members’ wariness about interacting with ‘the new guy’ because of some measure of awkwardness or shyness or inappropriateness, and that this still led to some degree of painful and disappointing personal isolation for service recipients.

“the biggest challenge our service recipients face in making those actual personal connections – doing more than just participating in a social or sports activity or a class, but not having a real connection with the teacher or other students, and I’ve seen interactions that ever very positive and a lot where you can tell the community member is aware of some problem and is ignoring or snubbing someone or being rude to

them, and it is very discouraging – and the service recipients are all very aware when this happens, because it has happened to them all their lives”

Recommendation. Pioneer Center may want to develop a joint staff/community/consumer discussion about these interpersonal barriers and what efforts Pioneer Center can take to help individuals strengthen their interpersonal ties with community members. Some in-house individual or group counseling around social skills may be useful: a prior community inclusion specialist indicated that he regularly developed role playing activities around the difficult social interactions that were likely to occur in specific community settings the service recipient had selected, both to increase the individual’s social skills and social confidence. The greater emphasis on social skills development, however, needs to be on strategies that can be implemented within the context of the community itself.

- 3. Under the Radar / Open about the Past.** Interviews with both community inclusion specialists and service recipients indicated that most service recipients participate in community activities without revealing either their history of mental health problems or their current status as Pioneer Center clients. Indeed, most consumer surveys indicate that this is often the best approach to community inclusion, allowing each individual the opportunity to reveal or not reveal their mental health issues when, to whom, and how as they choose. This does mean, however, that the community inclusion program at Pioneer Center continues to have a relatively low profile in the broader community. If Pioneer Center moves to broaden community awareness of the program – in part to generate both practical and financial support from community organizations – it does raise concern about the preference of its service recipients to ‘fly under the radar.’ This is a particularly difficult issue given the importance of respecting the decision of the individual with regard to disclosure – whether or not to disclose, when and to whom to disclose, and how to anticipate the consequences of disclosure.

“lots of people don’t disclose – when joining a group or going on a job interview – although lots of businesses and agencies have worked with us and community inclusion specialists when we have talked to them directly about our program”

“when I first came here I was very open with everyone about my history of emotional problems, but I slowly started to keep it to myself – I don’t have to tell everyone everything about me when I’m just getting to know them as neighbors or co-workers – and then I have the chance to tell people when I’m comfortable”

Recommendation. Pioneer Center’s ‘champions’ group might want to develop a multi-faceted strategy that includes:

- a public relations campaign to both the general public and community organizations about the community inclusion program and its success, to heighten awareness and support, seeking opportunities for community groups (e.g, the library, the YWCA, the community college, etc.) to work with Pioneer Center to developing ‘welcoming community’ strategies; and
- an in-depth program to help service recipients make personal decisions about disclosure – so that people are making the best choices *for themselves* about whether, when, how, and to whom to disclose, drawing on the skills of national consumer organizations to frame a training program for both service recipients and community inclusion staff. There is also the opportunity to draw upon – and offer leadership opportunities to - the community inclusion program’s service recipients who have now had the experience of making their own decisions around disclosure issues, and (in at least one instance) being more open about these issues in order to play a more meaningful role as an advocate for public understanding.

4. Short-Term vs. Long-Term Community Inclusion Programming. Pioneer Center’s community inclusion program assigns service recipients to work with a community inclusion specialist for a short-term intervention of six months or less. This limitation clearly serves two purposes: first, it communicates to service recipients that the goal of the program is to promote community inclusion rather than a continuing long-term reliance on Pioneer Center; and, second, it allows more individuals to participate in the program by forcing relatively rapid turnover. However, there was some indication in the interviews that for some of the service recipients the short-term nature of the program was *too* short, and that individual histories of long-term disengagement from community life might require longer-term efforts to adequately address. The danger here, of course, is that the community inclusion program, in lengthening its commitment to individual service recipients, will ultimately replicate the longer-term reliance on Pioneer Center the program was designed to address, particularly given the strong bonds that have already been established between the community inclusion specialists and the individuals they serve.

Recommendation. Pioneer Center may want to establish a joint staff/recipient committee to explore the issues, examine the literature on the effectiveness of programs with established time limits, and develop guidelines for when and for whom longer-term engagement with the program is appropriate.

5. The Need for Long-Term Outcome Data. Although Pioneer Center has begun to use the TUCPM on a regular and repeated basis in order to begin to gather more quantitative data on the impact of the community inclusion program, there is little hard data thus far on impacts, answering such questions as:

- does supporting educational programs lead to course completion and job advancement?

- does helping people join a gym or community club leads to more personal health outcomes?
- does providing assistance for a new home result in greater connection to one's neighborhood?

The fundamental question is whether the Guthrie Legacy Project of Community Inclusion leads to a measurable and lasting shift in the relationship service recipients have with their communities of choice. Program continuation, replication in other sites, and the possibility of further evaluation and replication funding from state and federal, or philanthropic, sources may depend on the emergence of more quantitative data that goes beyond the satisfaction of service recipients and the development of more welcoming community organizations. Clearer data are needed.

Recommendation. Pioneer Center should both insure the continued use of the TUCPM to track longer-term outcomes, but also explore the use of other outcome measures:

- measures drawn from the recovery movement – to track both participation and self-concept measures of program impact; and
- measures that may be specific to the focus of the recipient's participation (e.g., physical health outcomes for those who join a gym, or employment status (earnings, hours, benefits, etc.) for those who use scholarship funds within the educational or employment domains, etc.).

Pioneer Center should begin to explore federal research funding opportunities and/or state pilot program assessment dollars, or philanthropic funds – to support further research development.

6. Providing Training and Technical Assistance. Pioneer Center's leadership team, in the interview process, expressed the hope that Pioneer Center would be seen as a leader in the field, providing an innovative and important shift in perspective on the mission of community-based mental health services. There are two issues for Pioneer Center to consider in this regard: first, Pioneer Center will need to develop a 'communications strategy' and commensurate resources with which to identify and communicate the essence of the community inclusion program; and, second, the Center will need to make some initial determinations about its ability to provide training and technical assistance to other community-based programs who want to learn from and replicate the Center's innovative programs.

Recommendation. We recommend that the Center's' champions' group begin discussing this new role for Pioneer Center staff, explore the costs and benefits of becoming a provider of training and technical assistance, and consult with other training and technical assistance centers for guidance on this role and the demands and rewards of establishing itself as a leader in the field. Initial steps might include a longer-term agenda for conference presentations, journal articles, and a one-day 'open house' program for individuals who want to visit and talk with Pioneer Center staff and service recipients about the operational aspects of the program.

Summary

The community inclusion project is undeniably off to a great start, with strong support from Pioneer Center's leadership, enthusiastic endorsement from staff, and very positive responses from service recipients. The growth of the program, the clarity of its commitment to community inclusion, and the initial sense of accomplishment all argue for continued growth and development. At the same time, it faces a number of challenges that should be addressed in the months ahead. At the same time, it is clear that an innovative focus on community inclusion outcomes and the development of an agency mission and staff competencies related to community inclusion all represent a significant change from services as usual. The importance of community inclusion to service recipients grows clearer every day, but the fiscal, administrative, staff training and client re-orientation barriers to change will require consistent monitoring if the program is to play the leadership role within its grasp.

"I think we've only touched the tip of the iceberg right now, and that we have many more clients to serve. Most staff have embraced the program but there is still progress to be made with other staff. But as we learned more about what the program is accomplishing – that clients are doing things in their lives that they really want to do and don't see their mental illness as a barrier and that it doesn't define who they are, and when we have better outcomes to report, we will find that we are really making a difference"