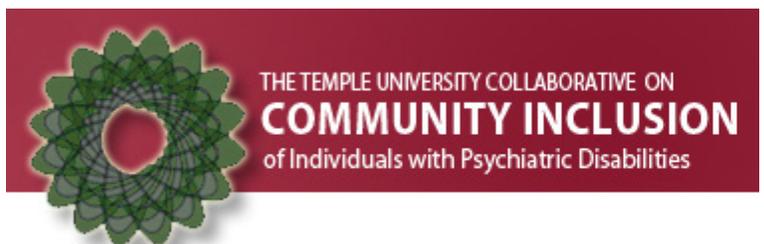


COMMUNITY INCLUSION

FROM THE PERSPECTIVE OF CAREGIVERS OF
PEOPLE WITH PSYCHIATRIC DISABILITIES



November 2016



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Requests for training, technical assistance, or other inquiries related to this monograph should be directed to The Temple University Collaborative on Community Inclusion for Individuals with Psychiatric Disabilities (TU Collaborative) at tucollab@temple.edu.

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Who We Are

[Mental Health America](#) (MHA) is the nation's oldest mental health advocacy organization, with more than 200 affiliates in 40 states. MHA has represented the perspective of and amplified the voices of people who have lived experience with mental health conditions since 1909. The work of MHA is driven by its commitment to promote mental health as a critical part of overall wellness, including prevention for all, early identification and intervention for those at risk, integrated care and treatment for those who need it, with recovery as the goal. For over a century MHA's advocacy and public education has been strong force for systems, policy and culture change. Many MHA affiliates also provide a wide variety of community-based mental health services and supports for individuals that are affected by behavioral health conditions and their families.

The [Temple University Collaborative on Community Inclusion for Individuals with Psychiatric Disabilities](#) (TU Collaborative) is a Rehabilitation and Training Center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Research at the TU Collaborative focuses on targeting obstacles that prevent people with psychiatric disabilities from fully participating in their communities; developing the service and supports consumers and communities need to promote full integration into all aspects of community life; and expanding the range of opportunities for people who have psychiatric disabilities to participate in their communities as active, equal members. Eloquenty stated by Principle Researcher and Center Director [Dr. Mark Salzer](#), the purpose of the TU Collaborative is to help people with psychiatric disabilities have "the opportunity to live in the community and to be valued for one's uniqueness and abilities like everybody else."ⁱ

Executive Summary

This monograph highlights and expounds upon the views expressed in a 2016 survey of almost 500 caregivers of people with mental health conditions. The intended purpose of the survey was to assess the caregivers' perceptions about participation in community life of the people for whom they provide care. The underlying intention of this project was to use what caregivers identified as working well and the advice they offered to remediate barriers in order to create tools to further foster community inclusion for individuals with psychiatric disabilities. Instead, the survey uncovered a trove of caregiver insight that will inform forthcoming studies and projects, and will help to influence public policy and perceptions.

Caregivers were asked questions related to the domains of community inclusion. In the survey, the domains were explained as competitive employment; recreational activities; religion of choice; friendships unrelated to psychiatric services; community events; housing of choice; educational supports and opportunities; health and wellness; family supports; and meaningful intimate relationships. Caregivers were asked to answer 10 questions using a rating scale to describe involvement and impacts, which ranged from not at all, to minimally, to somewhat, to very/highly.

In addition to the scaled ratings, most of the questions also invited comments. Thousands of comments were received. This monograph explores the themes found in these comments. The comments often went beyond the community inclusion domains to issues related to poverty or lack of funds, transportation issues, trauma, stigma, and common but erroneous beliefs held by schools and employers about the intellectual capabilities of people with mental illnesses. Many also expressed their own beliefs that their loved ones' low levels of involvement were attributable to the person's illness, the effects of treatment, reflected the person's internalized shame/stigma, or were because the person was difficult or hard to get along with.

Caregiver comments reflected their frustration with systems issues (e.g. schools, employers, benefits) and worry about their loved ones' lack of finances and opportunity, as well as what they perceived as lack of motivation. Caregiver comments reflected that they understood and appreciated the value of community inclusion for their loved ones, for themselves, and how more inclusion would also benefit the community. They also demonstrated understanding of the many barriers that impinge on community inclusion. Some of the caregiver sentiments bordered on despair; some showed hope, and all reflected love.

Here is a brief summary of caregiver views expressed by domain:

- **Housing:** Only one-third of caregivers reported that their loved ones were involved or very involved in housing choice. Many respondents conveyed that the person being cared for was living with the caregiver, described as "living at home." For those living in the community, caregivers noted it was more likely than not in economically depressed or high crime areas.
- **Employment:** Caregivers reported that 80% of their loved ones were uninvolved or minimally involved in competitive employment. When caregivers reported that the person cared for did have a job, only 18% indicated that these people were involved or very involved in a competitive employment situation.
- **Friendships and Intimate Relationships:** Caregivers stated that their loved ones had extremely low involvement with friends, and slightly lower still when it came to intimate relationships (only 25% and 26% respectively said that their loved ones were involved or very involved).

- **Educational Supports:** Education was an area with very low reported involvement. Less than one-quarter of caregivers responding to the survey (23%) reported that their family member was involved or very involved with school supports.
- **Health and Wellness:** Caregivers overwhelmingly recounted that they want their loved ones to participate in health and wellness programs and activities in the community, but stated that they felt that it was very difficult for their loved ones to do so. Less than one-third of caregivers felt that their loved one was involved (22%) or very involved (9%) with their health and wellness.
- **Religion of Choice:** There were a number of caregiver comments that showed that the person's religious organization was sometimes the only community institution that was inclusive, yet more than three-quarters (77%) of the people they were reporting about were uninvolved or minimally involved with a religion of choice.
- **Recreation and Community Events:** Caregiver comments about recreation often called for "more inclusion" and "acceptance" in recreational activities, but caregivers reported that less than one-fifth (19%) of their loved ones were involved or very involved in community recreational activities, and a mere 11% had anything but a minimal degree of involvement in community events.

Respondents had a great deal to say about barriers that they and their loved one's face. Surprisingly, they reported that barriers occurred in almost equal measure with respect to transportation and physical location, financial issues, access to services, stigma/discrimination and physical limitations their loved ones faced. Caregivers also reported that caregiving negatively affects their own lives, especially in the domains of friendships, recreation, religious activities, and with respect to their participation with family activities and gatherings.

Finally, caregivers called for help and understanding for themselves and their loved ones. They called on providers and provider agencies to be more helpful in fostering community inclusion. They called on policy makers and legislators to address structural issues, such as poverty, lack of transportation infrastructure, and discrimination. Caregivers implored educators, employers, and the general public to become more educated about mental health issues, and to be more supportive and understanding.

Community Inclusion from the Perspective of Caregivers: Why It Matters

[The National Alliance on Caregiving](#) (NAC) estimates that “as many as 8.4 million Americans are providing unpaid care to adults with emotional or mental health issues.”ⁱⁱ For many people with psychiatric disabilities, their strongest supports come by way of close family members. A recent national study entitled [On Pins and Needles: Caregiving for Adults with Mental Illness](#) (Pins and Needles), completed in early 2016 by NAC in collaboration with MHA and the National Alliance on Mental Illness (NAMI), found that caregivers of adults with mental illness are overwhelmingly family members (88%), and that most are parents (45%), but also often include adult children caring for a parent (14%) and spouses (11%).ⁱⁱⁱ The Pins and Needles study showed striking differences among caregivers of people with mental illness as compared to those providing care for people with other conditions, including that the length of time care was provided is more than twice as long (9 years as opposed to 4 years), and that a high percentage of those for whom care was provided live in the home of the caregiver (45%). This study also found that there were significant effects on caregivers’ wellbeing.^{iv}

Among the eight [policy recommendations](#) in the Pins and Needles study is one that explicitly refers to the community inclusion and a number of its domains:

Provide access to a full array of high-quality behavioral and mental health services across the continuum of care, as well as access to community inclusion, vocational, educational, and peer supports.^v

An eloquent explanation of why community inclusion matters comes from the TU Collaborative:

Community Inclusion is what recovery is for.^{vi}

Community inclusion encompasses eight domains: housing, employment, friends, education, health and wellness, religion and spirituality, family, and intimacy. It is increasingly being recognized as one of the most important concepts for fostering the recovery of people with psychiatric disabilities, and for assessing recovery progress.^{vii} In order to learn more about the role of caregivers in the community inclusion of people with psychiatric disabilities, Mental Health America and the Temple Collaborative, with technical assistance from the [Caregiver Action Network](#) (CAN), undertook a national survey of caregivers in the summer of 2016, explicitly focused on community inclusion.

This monograph examines the responses of the 457 caregivers as they answered eight multipart, multiple choice questions, half of which invited additional written comments. Thousands of detailed comments were received. These comments express the perceptions and personal opinions of the caregivers about themselves and about the people for whom they provide care, who are referred to in this document as “loved ones.”

The survey questions may be found in the Appendix.

For nearly every question, most respondents offered written comments in addition to answering the questions along the scale provided (uninvolved, minimally involved, somewhat involved, or very involved). The comments offer insights into caregivers’ own beliefs, as well as their perceptions about the people for whom they provide care. Caregivers, as reflected by their comments, prove to be astute observers of their loved ones and articulate translators of system and policy issues that need to be remediated.

This monograph examines the survey responses and highlights the voice of caregivers, as it puts forth a wealth of information contained in the profusion of heartfelt and sometimes heartbreaking comments. Caregivers generously shared their hopes, disappointments, pleas, and recommendations for policy, systems, and culture change. To maintain the integrity of the respondents' voices, their comments are left largely unedited.

Who Responded to This Survey and What Were the Major Themes?

With great candor, caregivers provided a significant amount of information about themselves and their loved ones. Caregivers demonstrated an unquestionably biased, but remarkably honest perspective, based on deep connection with their loved one. The comments reflected love, hope, more than a little frustration, and sometimes a bit of despair. Some comments illustrated very positive outcomes. The comments showed that caregivers do understand a great deal about community inclusion and how it could benefit their loved ones. They also clearly understand that caregiving impacts their own community inclusion. Caregivers were expert in identifying barriers. In spite of expressed frustration, and what at times seemed like hopelessness, caregivers also had some excellent concrete suggestions.

While the survey respondents were not asked to provide demographic information or even to identify the relationship between themselves and the person for whom they provide care, many chose to disclose. This survey found that the caregivers were mostly parents, as indicated with comments that began with "my son" or "my daughter." Other close family relationships include an adult child caring for a parent ("my mother," or "my father"), a spouse ("my husband," or "my wife"), or sibling ("my sister," or "my brother"). Some respondents additionally identified themselves as mental health professionals, or as working in the mental health field. There were also a small number of people who indicated that they were speaking about their own personal experiences as well, such as the respondent that wrote:

I am a caregiver and a consumer of mental health services.

Although the survey explicitly asked for respondents to be caregivers of individuals who were eighteen years old or older, we did not exclude the responses or comments from caregivers of older teens, mostly still in high school. These caregiver comments were prescient, and illustrative of the fact that mental health conditions often begin at an early age; and that people with serious mental health conditions face many structural issues during their school years that impinge on community inclusion when people are young, and foreshadow impediments that can come later.

I am the parent of a 17yo young adult. She has been on meds and in therapy since age 5...Children that have suicidal or homicidal thoughts, are engaging in self-injurious behaviors (i.e. cutting), have eating disorders, have trauma history, have true depression or anxiety, have gender identity issues, are hallucinating (and not due to substance use) or a myriad of other MH symptoms are often either seen as having behavior issues or when emotional, are dismissed, singled out, embarrassed in front of peers, etc...Unfortunately, teachers, school personnel, school nurses or guidance counselors are under-educated/undertrained on how to manage these children. As a result, children are not getting the supports needed, are alienated from peers and possibly referred to other programs (i.e. day programs that again are equipped to address behaviors more so than MH issues) and drop out of school. This can lead to a downward spiral of environmental stressors, minimal supports, and issues in a

number of the above areas. (As an employee in the MH field, the latter is all too often seen with our adult population and addressing issues as an adult that were not addressed during adolescence, is an uphill battle.)

Caregiver comments also provide some examples of good community inclusion. Older adults, teens, and younger people had the greatest reported opportunities for community inclusion. Many caregivers said that their loved ones were involved in the community and were connected to services, although in many instances those services were not necessarily directed to people with psychiatric needs.

She enjoys grey bears [older adult group] and her church groups. She's good about taking the bus to grange hall for [monthly] senior breakfast and occasionally lunch at senior center. Likes to ride the bus, and "people watch," Attends day program "Elder Day, 2- 3x's weekly, though that program is more for memory / dementia type disabilities so she seems to keep to herself there, have lunch, do crafts, but not the best match for her because mentally, she's clear as a bell. No hearing or vision or ambulatory deficits', just her mental illness.

Parents of younger people offered the most positive community inclusion rankings for their sons and daughters in all domains. There were some parents who detailed how when intensive services and supports were provided when their loved one was young, it yielded positive outcomes in adulthood:

My son was welcomed as a child chorister in a large, community based church that provided structure, peer support, and inclusion. The program helped him to be an accomplished musician and taught him karate, swimming, and following instruction. He attended a very structured middle and high school environment where he focused on academics and band. In college, he was mentored by the director of student disability services who gave him a student mentor, and the opportunity to become a student mentor himself. In college, he learned how to effectively search for work, and his church taught him how to confidently network and seek employment.

Judging from the comments, it seems that the largest number of respondents were caregivers of adults in their twenties through their middle years. Overall, caregivers reported low levels of involvement for their loved ones in each of the community domains we asked about. There were examples of people living in the community, who had some type of income, and family support, but who were still very isolated:

Once the person has paid rent and bills, there is no money to be able to go out and enjoy a movie or play a game of pool, it's all they can do to buy cigarettes!
Transportation can be a problem; not being able to have a car means relying on the bus system, but bus passes take a big chunk of money out of your monthly SSI.

Sadly, some caregivers reported that their loved one was deceased:

At this time, I cannot help further as my family member is deceased.

Some caregivers disclosed that their loved ones are incarcerated, including a parent who reported their loved one was "currently in jail due to being a victim of criminalizing mental illness."

The common situation in which people with mental illnesses cycle between inadequate mental health services and jails and prisons^{viii} was also represented:

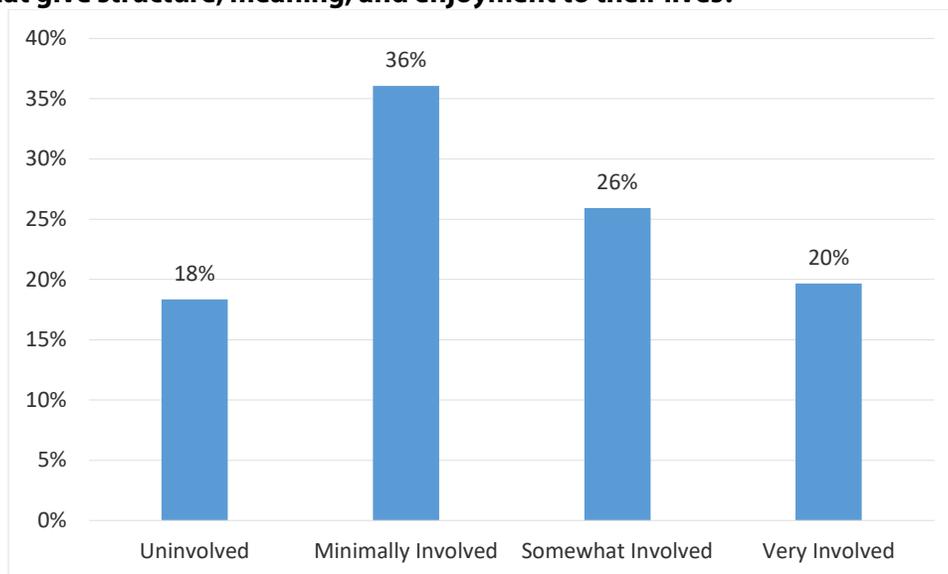
She is, after 20 years with a mental health diagnosis, in denial about most things in her life. She rotates from rehabs, jail, psych wards, and now prison. We have found it impossible to get her the help she needs and will adhere to.

How Caregivers Rated Their Loved Ones' Community Inclusion

The first question on the survey asked the caregivers to rate overall the degree of their loved one's community involvement. The answers to this general question at first seemed equivocal. The bar chart that follows shows that 54% of the caregivers reported that their loved ones are generally uninvolved or minimally involved in the community. But it also shows that 46% of the caregivers reported that their loved ones are somewhat or very involved. Given that these are relatively close ratings; it didn't tell us very much until we compared domains.

The table that follows it shows that the only category that caregivers ranked as having a high degree of involvement is family. This may mean that caregivers define family as being synonymous with community. We also can't discount the fact that overwhelmingly the survey respondents are family caregivers.

Q1: In general, how would you describe the degree to which the person you care for is actively involved in everyday community activities—e.g. working, school, family, friends, religion, sports—that give structure, meaning, and enjoyment to their lives?



Looking at the relative degree of involvement by domain provides much more clarity.

Q2: For these 10 questions, please tell us the degree to which the person for whom you provide care is involved with the following activities:

	Uninvolved	Minimally Involved	Involved	Very Involved
Competitive Employment	62%	18%	11%	8%
Recreational Activities	42%	41%	13%	4%
Religion of Choice	52%	25%	15%	8%
Friendships Unrelated to Services	28%	45%	21%	6%
Community Events	49%	39%	8%	3%
Housing of Choice	45%	22%	21%	12%
Educational Supports and Opportunities	48%	29%	15%	8%
Health and Wellness	26%	44%	22%	9%
Family Supports	13%	33%	29%	25%
Healthy, Meaningful Intimate Relationships	45%	31%	17%	8%
Overall (Answer to Q1)	18%	36%	26%	20%

The chart above shows low levels of involvement in employment, friendships, and intimate relationships. Involvement in other domains was quite low too. These findings were clarified by caregiver comments, described in the section below.

Psychiatric disabilities are closely associated with social and health status changes—and not for the better.^{ix} No matter what income level, or socioeconomic class that a person may have been born into or previously occupied, having a psychiatric disability almost always made it harder, and limited opportunities in all community inclusion domains, especially in the areas of intimate relationships and employment. Caregiver comments strongly reflected this.

Caregiver Responses by Domain

Housing

By the numbers, one-third of caregivers reported that their loved ones were involved/very involved in housing choice. Many of the caregivers conveyed that the person being cared for was living with the caregiver, most often one or both parents, which was often described as “living at home.”

In a few case caregivers report that their loved one’s only supports (in addition to the mental health systems), are parents, spouses, or other close family members. The comments excerpted below from two sets of family caregivers of people in their forties were not atypical. Both of whom wondered what would happen after they were gone:

My adult son 47, has always lived with us, his parents. He is quite isolated... We are in our early 70’s and worry about housing for him in that his only sibling lives [abroad].

My daughter...is 41 years old. She has lived with me most of her life. She does not fit into society. She can’t take a job because she can’t get along with people for very long. ... Family seems to have to bear all things... and this is tough... I am worried about what will happen to her after I am gone.

When the loved one was reported to reside elsewhere than the family home, usually in an independent community-based setting, their neighborhoods were frequently described as impoverished, or dangerous. Caregivers were clear that such locations, coupled with limited financial resources, severely limited social engagement.

Caregivers were quite cognizant of the common reality that often put their loved one between the proverbial rock and hard-place when it came to choosing housing:

Sometimes the only choices are within a segregated mental health setting or an unsafe community setting.

Employment

As has been widely reported elsewhere, caregivers responding to this survey also offered bleak picture regarding employment.^x Caregivers reported that 80% of their loved ones were uninvolved or minimally involved in competitive employment. A few caregivers reported that the person that they cared for did have a job, but only 11% of caregivers indicated that their loved ones were involved and only 8% indicated that their loved ones were very involved in a competitive situation.

Caregiver comments seemed to reflect what research shows about employment being not only a measure of recovery, but a path to it.^{xi} Their comments show that not only do caregivers want those they care for to have meaningful work, but their loved ones also want to work. The results of this survey are in line with what other national studies have found, which is that two-thirds of people report they want to work, but that only approximately one in ten have full time employment.^{xii}

Caregivers offered a myriad of reasons why they believed that their loved ones, wouldn't, couldn't, or didn't want to work. They attributed their loved ones' lack of employment to employers, to systemic issues, and to their loved ones' illnesses. Caregivers lamented a lack of accommodation from employers. They reported that employers and co-workers often equated mental health conditions with low IQ and/or intellectual disabilities. (This was reported to be true of school personnel as well.) Caregivers stated that often the only jobs that were offered were ones without "growth potential."

Respondents also cited systemic and policy issues. A number of caregivers are under the erroneous impression that their loved ones were only able to work a limited number of hours, or were afraid to work, because of risks to disability benefits and health insurance.

If she were allowed to be semi-employed and earn some money not lose her Medicaid that would be a good thing for her and for our society. Unfortunately, the rules make it impossible for her to work and earn money.

Caregivers described their loved ones as "lacking skills training," "not having a high school diploma or GED," and as having "no job training or experience." They also cited uneven job history, and criminal records, as well as job applications themselves as impediments.

There are gaps in employment...especially with online applications, there is simply no response.

Although it is not true to what we know, many caregivers attributed their loved ones' lack of involvement in competitive employment to their loved ones' illness. Common statements included "the person refuses to participate," or "he has difficulties finding and keeping a job." Caregivers were explicit about what they perceive as performance issues, or the manifestation of symptoms, such as "impulsiveness" or "inconstant performance and attendance." Some caregivers shared that their loved ones were fired due to symptoms they identified as "paranoia," "anxiety," "depression," "anger," "outbursts," and "mood swings." They cited lack of motivation and energy, which they attributed to "the illness," and/or to "medication side effects." Caregivers also cited interpersonal issues, saying that

“the person is difficult to get along with,” or that there is “coworker discomfort,” and conversely that the “person feels uncomfortable around co-workers.” Caregivers said appearance was also an issue: “the person is not neat or well-groomed.”

Quite a few caregivers reported that they wanted more vocational training programs. But there were also many comments about programs not being helpful, such as these:

He tried them, but it didn't work

He tried using vocational rehab, but found a job on his own.

For people who did find competitive employment, caregivers warned that “disclosure is a ‘double-edged sword.’” Even for a person with high degree of employment achievement, a symptomatic display, such as a panic attack, could result in being fired, as relayed by a respondent:

After a diagnostic disclosure the person faced demotion, reduction in pay, lost company car privileges, and was eventually encouraged to retire.

Even though it is contrary to the principles of community inclusion, many caregiver comments nonetheless called for more social activities (structured or otherwise) being offered by mental health agencies or providers. But sometimes when caregivers spoke about organizations that specifically provide employment services to people with disabilities, such as Goodwill and Easter Seals, they also noted that the jobs through such programs had no career potential.

But while caregiver comments belied frustration about the perceived dearth of offerings from mental health provider agencies and complaints about what mental health systems do offer, some caregivers ultimately conceded that their loved ones don't want to participate in vocational programming, or that they, or their loved ones don't find what's available very helpful.

She doesn't want to do anything.

The only mental health clinic near us, they are not helpful, and are hard to deal with.

Friendships and Intimate Relationships

Caregivers reported that their loved ones had extremely low involvement with friends, and slightly lower still when it came to intimate relationships (only 25% and 26% respectively reported that their loved ones were involved or very involved). A number of caregivers, such as those quoted below, attributed this lack to their loved one's behaviors and perceived appearance.

My son finds it impossible to make friends. Often his behavior is "odd" and it put a strain on his social skills.

...He has never had an intimate relationship. Few women can tolerate his "weirdness."

...and has NO intimate relationships because he is awkward.

Many comments showed that for people with mental health needs it is commonly the case that their friends and social interactions come primarily from inside of programs. While these programs may be

based in the community, they are not inclusive of people who do not receive mental health services. A number of survey comments described the situation like this:

My daughter...attends day treatment three days a week. She does not have money for recreation to go to civic activities... She sees people in the day treatment program, but has no friends outside of the program, but seems to get along well with those in the program.

Caregivers also said that their loved ones find it difficult to be around others, explicitly stating that isolation was the person's choice, which again caregivers attributed to the person's illness:

He has lost all his friends due to his mental instability and his unwillingness to admit he has an illness. He is paranoid of people and because of that he is isolated.

Still other caregivers simply made remarks such as: "he isolates himself," or simply "it is his choice." A caregiver who self-identified as a psychotherapist pointed out the importance of a trauma informed^{xiii} perspective. This caregiver made the point that a history of trauma may underlie or add to a person's reluctance to engage:

They feel different, and that big "T" and little "t" traumas have a lasting impact on people.

Educational Supports

Less than one-quarter of caregivers responding to the survey (23%) reported that their family member was involved or very involved with school supports. Several parents of young people recounted that not only were their children not supported but that they were hindered or hurt by school personnel and policies. Comments like these from parents of high school age youth with mental health needs were not uncommon:

Asking for supports to be put in place during high school was not supported by school staff because her IQ and test scores were "too high" yet she clearly needed additional support in some subjects, and with managing her mental illness. My child was bullied at school, not so much by other children -- but by staff and teachers. She has been victim to some dreadful verbal abuse by teachers.

I am responding as I am the caregiver for my sixteen-year-old son, who lives with mental illness. He has no friends, and is very fearful about employment. He has been expelled from school twice, and was recently kicked out of dual disorder treatment. He mostly isolates in his room.

A few caregivers found a continuum of supportive school environments, such as reported by this caregiver:

(1) Tutor through school home bound program invited my son to events. (2) Community college has been very accommodating enabling my son to begin working on GED. (3) U of Michigan Transitions in care program has helped my son exercise. (4) NAMI and U of Michigan support groups provide socialization and resources. (5) Social skills group in area combines exercise with education.

Health and Wellness

Caregivers overwhelmingly reported that they want their loved ones to participate in health and wellness programs and activities in the community, but stated that it was very difficult for their loved one to do so. By far the largest number of comments concerned what kept loved ones from participating, as opposed to engaging in community-based health and wellness programs. Overwhelmingly this was for two reasons—the person’s unwillingness to engage, and a lack of monetary resources:

... Hard to focus on physical wellness when so much energy needs to go into the management of the mental illness.

Participating in health and wellness beyond doing home exercise also requires interaction with others.

There are many wellness activities/groups and programs that are simply unaffordable and out of reach to her.

Some caregivers mentioned community resources that support health and wellness which are open to all, such as the YMCA/YWCA. But often this was to relate that their loved one cannot afford to take to participate. Other caregivers indicated that they considered support groups such as Alcoholics Anonymous as a community health and wellness resource.

Religion of Choice

There were a number of caregiver comments that showed that the person’s religious organization was sometimes the only community institution that was inclusive:

Our Unitarian church is small and has been a life saver of being welcoming, supportive and loving to my son. I have yet to find a good job support program or appropriate recreation program in the city of Houston for my son. The education supports really don't support a transition to life after school.

She has been welcomed by the Methodist Church and she has enjoyed being part of the church and bible study.

Caregivers had many comments that identified a wide variety of religious perspectives, often naming specific denominations, such as Roman Catholic, Buddhist, Mormon, Methodist, and Unitarian. Mostly caregivers just spoke of “church” or “congregation.” There were many comments that stated the congregation was “being very supportive”, or saying “church is welcoming,” or that their loved one was the beneficiary of “church member visits,” or a member of a “church group.”

There were also expressions of disappointment, and even exasperation from caregivers, and individuals with mental health conditions, about how they were perceived (even when included) in the religious community of their choosing:

We have attended Church and heard from pastors that there is no such thing as mental illness, and people should not be taking pills and expecting to get better, they just need a better relationship with the Lord; (explain that to your mentally ill young person).

The church thinks if I had more faith I'd be "healed".

...I have been particularly disappointed by the lack of outreach from her church - she attends fairly regularly but I have seen no effort on the part of the ministers or lay volunteers from the congregation in the nearly 10 years I have been the caregiver make any effort to come visit her in her home or otherwise involve her in church activities.

Caregivers also reported matters into their own hands in order to facilitate inclusion of a loved one into their religious organization:

I started a ministry at our church to hopefully get him to be more welcomed at our church.

Recreation and Community Events

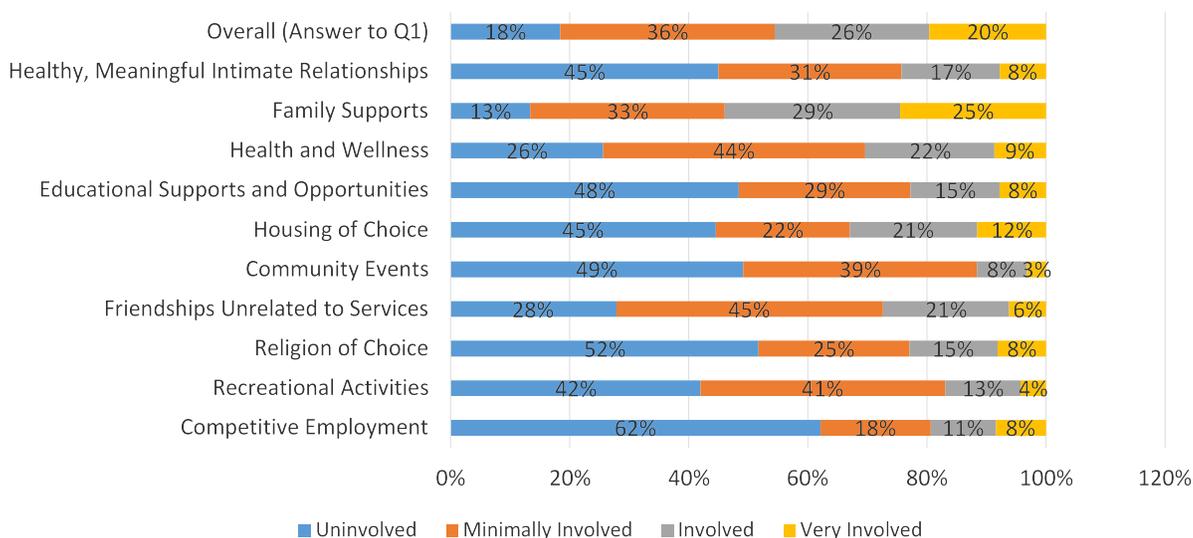
Caregiver comments about recreation often called for "more inclusion" and "acceptance" in recreational activities. Frequently, caregivers remarked on the cost of recreational activities:

Provide more low cost activities at the local recreational centers by reducing the price for disabled people. Cost is a big factor in this town.

A few respondents indicated that their loved ones were participating in community recreational activities like going to a community park, but still had difficulties in other domains, as in the comment below:

Inclusion is a softball league, welcome at current church, has been able to make friends with those who share a common interest in history and gaming. Place of employment seems to be where the struggle currently is and hopefully that will improve.

Q2: For these 10 questions, please tell us the degree to which the person for whom you provide care is involved with the following activities:



In most domains, the majority of caregivers reported that their loved one was uninvolved or minimally involved.

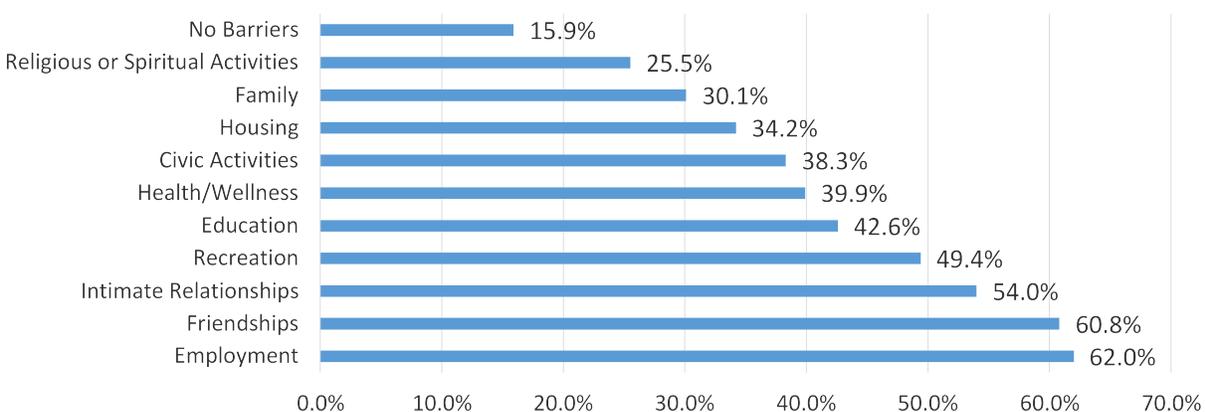
Barriers, Barriers and More Barriers

Above all else, this survey demonstrates that in spite of considerable effort on the part of mental health providers and caregivers to help increase inclusion in community life for those they care for, structural, psychological, cultural, and financial barriers are omnipresent. Caregiver comments described in this section emphasize the variety and pervasiveness of these barriers.

Included in this section are visual representations of the frequency and types of barriers that were identified. The graphics compare caregivers' categorical response to their comments. Other graphs represent a textual analysis of the open-ended responses received. (Note that the open-ended option asked respondents: "If you checked "Yes" to any of the above, please describe the barriers to greater connections.) Also visually represented are comparisons of numeric responses and textual analyses.

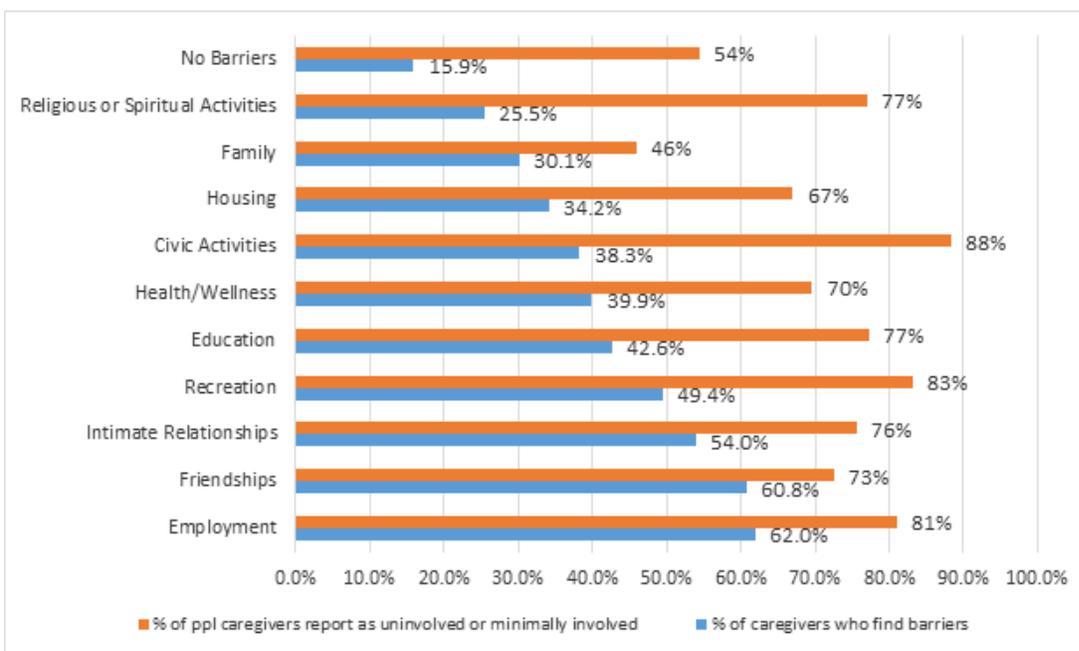
The chart below shows scaled "ranking," lowest barriers to highest barriers, in response to the question:

Q3: Does the person encounter barriers to inclusion in the following areas?



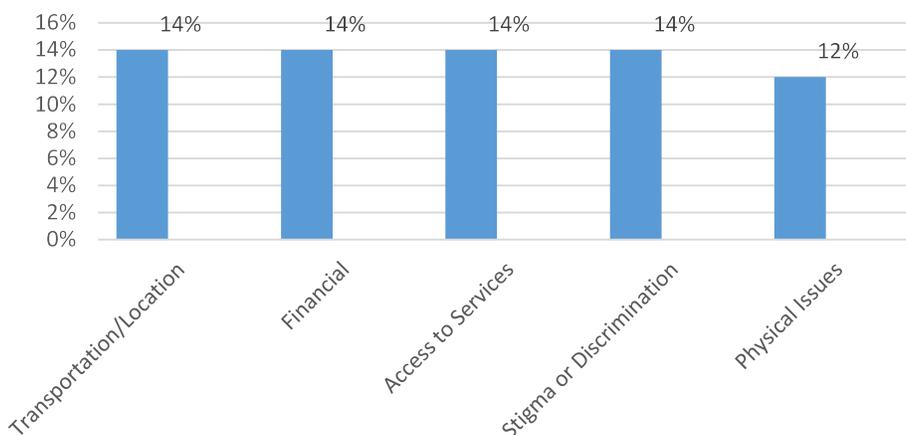
Respondents reported the highest number of barriers in the domains of employment, friendships, intimate relationships, and education, which corresponded to domains where the lowest levels of participation were reported. In some cases, caregivers indicated that there were few barriers, but at the same time indicated low levels of involvement. For example, respondents reported few barriers to participation in religion or spiritual activity, though only 23% of respondents indicated that their loved ones were involved in religious activities. The chart that follows on the next page illustrates this further:

Percentage of Caregivers Reporting Their Loved One as Being Uninvolved or Minimally Involved Compared to Caregivers Who Find Barriers



When asked explicitly to rank the degree to which their loved one’s experienced barriers to community inclusion, caregivers reported a lower degree of barriers than they described in their open-ended comments. In domains such as civic activities, 88% of respondents indicated that their loved one was uninvolved or minimally involved, but only 38% reported barriers. This discrepancy might be attributable to the fact that approximately one in seven respondents listed one or more barriers outside of the listed domains. Textual analysis of the comments showed that several themes regarding barriers were discussed even though such categories were not explicitly asked about in the survey. The following barriers were mentioned at nearly the same rate: transportation/location, financial barriers, access to services, stigma or discrimination, and physical issues.

Barriers Discussed by Respondents in Survey Comments



Poverty/lack of financial resources was commonly cited as a barrier, and was often attributed to low income from unemployment, underemployment, or the relationship between disability income and poverty. Lack of confidence, expressly attributed to the person's illness, to experiences within the mental health system were also given as reasons for insufficient employment and income.

Another common barrier outside of the listed domains was lack of access to transportation. Transportation issues included having no money for gas or bus fare, lost drivers' licenses, and difficulties related to living in rural locations. Comments such as the one below touched upon many barriers:

My sister encounters barriers in all these areas...She has barriers in healthcare. She is simply treated differently by medical professionals and is often not taken seriously. She has barriers in maintaining employment and community engagement. She has been unable to maintain steady employment. Financially, due to her fixed income, she regularly faced with difficult choices related to meeting her basic needs. There is little left to allow her to engage in community activities. Even money for gasoline or public transit to get her to free events is cost prohibitive. Her mental health takes a toll on her relationships with family and friends when she is unwell.

Caregivers also cited what they believe to be endogenous or "internal" barriers, which they articulated in terms of positive symptoms like delusions, voices, and paranoia. They described how these symptoms outwardly present as weirdness or seeming odd or awkward, and shared that individuals themselves feel that they are different, don't fit into society, and are treated differently. These types of issues were sometimes connected to damaged relationships within the family, with friends and employers. These types of barriers were explicitly placed within, if not upon, the person with a mental health condition:

Primarily the barriers seem to be within the person, due to a lack of energy from the depression and/or a lack of confidence.

Our son can't find housing because he can't get a job, therefore, he can't afford housing. He has lost all his friends due to his mental instability and his unwillingness to admit he has an illness. He is paranoid of people and because of that he is isolated.

Many barriers are self-imposed barriers as unwillingness to seek help or take advantage of services. Some barriers are the result of the mental illness itself.

Financial barriers included fiscal issues in mental health systems, such as budget cuts to programs or being cut off from services. Common complaints included cuts to case management services, and the termination of supports when someone was no longer in immediate crisis without regard to progress towards recovery.

With services, counseling, meds, my son was able to complete his degree and obtain employment—then he was completely dropped from programming because he was "all better," "stable," unfortunately the dropped programming means he is slipping away again. Services are impossible to obtain unless "you are a danger."

Both caregivers and individuals speaking for themselves referenced “stigmas,” and other things outside of their control:

There are barriers to all of the above which we, the family, cannot control. The focus is always on disabilities, not abilities. Stigmas are strong. Supports are often inadequate and pulled too soon.

Stigma! Small town, people hear bipolar and want NOTHING to do with me!

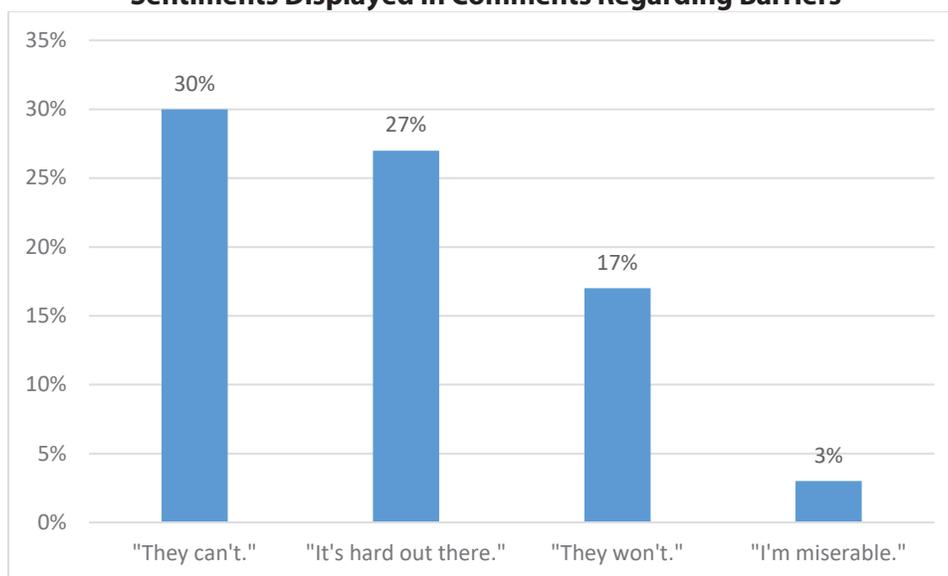
Physical limitations were also frequently mentioned. Co-morbidities, age, history of physical restraint (especially in prison or jail) and pain were cited as barriers, as seen in the comments below:

Beset of constant pain which causes such pain and anxiety and depression he cannot work, do any activities, socialize or even go to church because he is unable to sit or stand for long periods at a time.

She cannot work without great pain.

Below is a textual analysis of philosophy/attitude behind the barriers that quickly became apparent when caregiver comments regarding barriers were examined.

**Q3: Does the person encounter barriers to inclusion in the following areas?
Sentiments Displayed in Comments Regarding Barriers**



These sentiments were bucketed according to the tone implied in respondents' comments:

They can't: Person A can't hold a job. Person B can't make friends. Unable to. Keeps them from...x, y, z. Some of these attitudes were sympathetic, and others were condescending. But there was a consistent theme of, "This illness is so bad that the person **cannot** function." Even though we know that there are other opportunities.

It's hard out there: This category reflects systemic or external factors that created limitations that were not impossible to overcome by the individual, but were unfortunate realities.

They won't: Person C doesn't want to. They are uninvolved. Again this ranged from sympathetic "depression is hard so obviously they don't want to do anything" to caregivers who used the term "anosognosia," which is some people use to denote denial about having an illness.^{xv}

I'm miserable: A few caregivers complained about the total burden that the barriers made on their family. Most were sanguine:

Limited support-most support comes from family.

It was not uncommon for caregiver comments to hit upon many of these attitudes at once:

He has been on numerous job interviews, but was never hired. His recreation is dependent on his family accompanying him. He has internet friends only. Anxiety & very low self-esteem appears to prevent him from participating in outside activities without a parent(s). He completed an audio engineering certificate a couple of years ago, but doesn't have a clue how to use it. He has had "internet connections" with women, but it never lasts long. His lack of social skills, low self-esteem, anxiety (or paranoia?) & dependence on family for survival are all contributing to a very isolated & uninvolved life for our son and his parents who are nearing retirement. We feel like undesirables by some and pitied by others. We would be considered upper middle class & very well educated.

Overall this shows that there is still a long way to go in educating caregivers about the *potential* that exists when the appropriate supports are in place.

Impacts on Caregivers

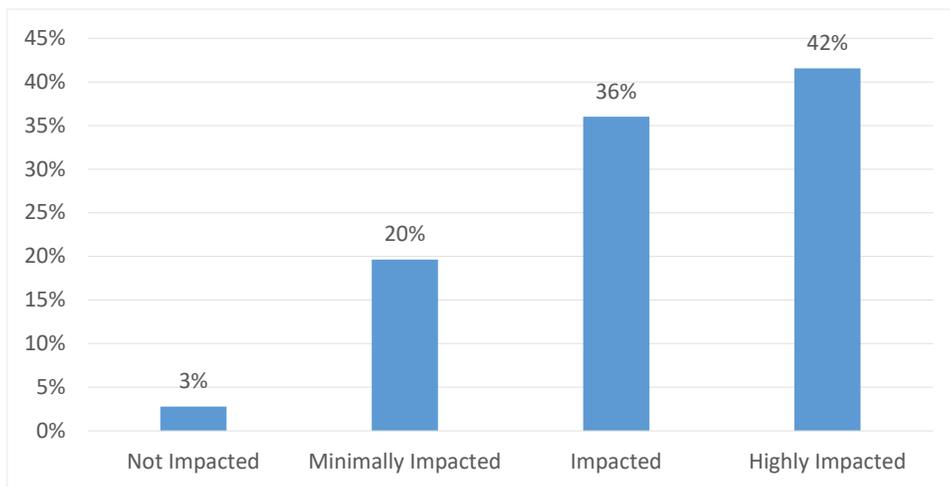
The survey posed two questions asking caregivers if, and in what areas, their own community inclusion was impacted by being a caregiver. Comments were not asked for in this section, but sometimes appeared in other areas of the survey, showing the high impact that caregiving has on caregivers' own community inclusion:

She's fine ... I have no socialization!

...It exhausts me and burns me out as it is now. I'm out of work because of the stress of this situation

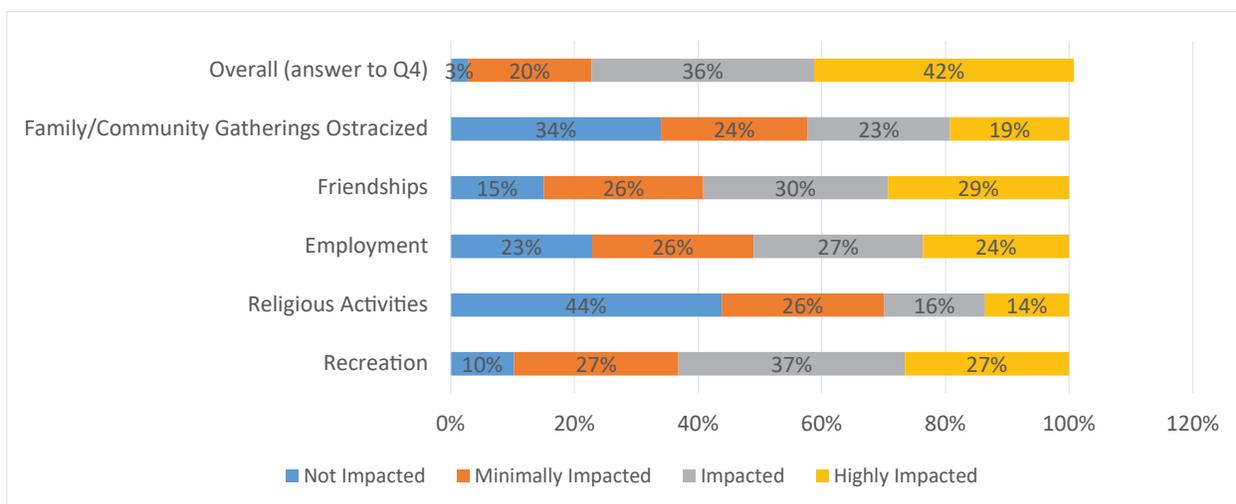
The charts and graphs that follow are also quite telling:

Q4: In general, how would you describe the degree to which being a caregiver has impacted your involvement in everyday community activities—e.g. working, school, family, friends, religion, sports—that give structure, meaning, and enjoyment to your life?



Q5: For these 5 questions, please tell us the degree to which caregiving has impacted your involvement in the following activities.

	Not Impacted	Minimally Impacted	Impacted	Highly Impacted
Recreation	10%	27%	37%	27%
Religious Activities	44%	26%	16%	14%
Employment	23%	26%	27%	24%
Friendships	15%	26%	30%	29%
Family/Community Gatherings Ostracized	34%	24%	23%	19%
Overall (answer to Q4)	3%	20%	36%	42%



While people said they were really impacted, the using the colors allows visualization of which areas were impacted most. The most impacted areas are friendships and recreation, and the area reported to be impacted least was religious activities. One conclusion that can be drawn from this data is that caregiving burdens the free time, leisure, and caregivers' other relationships.

Caregiver Perception of Community Inclusion Supports

Caregivers were asked if their loved ones received supports that were helpful in increasing community inclusion. While some caregivers did report that their loved one received services that increased community inclusion, just about as many of caregivers' rankings and comments focused on the lack of support. Many comments, like the ones below, explicitly stated that their loved one had only one source of support:

All supports are provided by family.

Family helped support social activities.

He gets no support outside the family

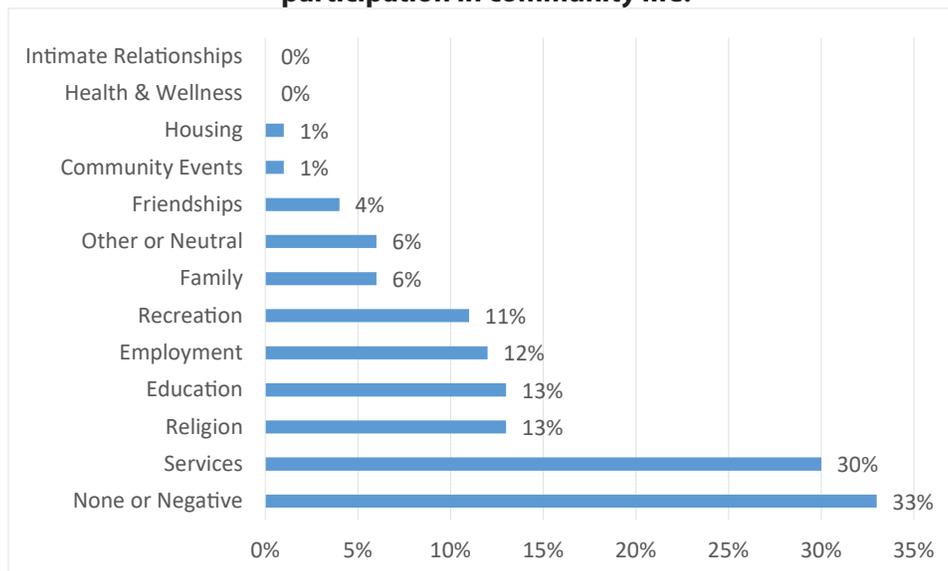
My relative lives at a room and board; therefore, I am able to engage in my customary and usual activities. I provide direct care one day per week - when we do weekly shopping and we eat out for socialization.

Why caregivers found this to be true is succinctly summed up in this caregiver's response:

Sadly, there has been no community outreach provided or offered.

When describing the support that their loved ones receive to increase their community inclusion, more respondents indicate that no services and supports were provided (33%) than those that indicated their loved one had received relevant services (30%).

Q6: Please describe the support the person you care for has received to increase their participation in community life.



Most comments regarding education were negative, such as reports of receiving “absolutely minimal education support.” But college programs (including online programs) were described more positively:

on line college; coffee shop people; me (mom)

Support from the guidance office at St. Joseph's Univ.

Has had marvelous encouragement the past couple of years at Century College---
3.96 GPA! Remarkable!

My son goes to MIT. How they handle mental illness there should be a model for every college campus. Their support is phenomenal.

Caregivers also reflected upon some services that they deemed ineffective in increasing community inclusion, those that were limited, and those that came very late in the game, and were still insufficient:

I cannot get the appropriate treatment/support for her in order to get her stable enough to participate in normal life functions.

In 25 years-the only support he has received was from mental health court--which lasted for 2 years. Had an incredible social worker, but she was booted due to funding, [and] there are no supports to help him stay on medication.

What Caregivers Would Like to See More of from Support Agencies

Caregivers had a lot to offer in response to the question that asked what more agencies might do to help increase community inclusion. Their answers included generic suggestions to help people “make connections,” and to “follow up.” But quite a few caregivers remarked that agencies provide “nothing,” though these comments were frequently modified by phrases of resignation, such as “he has to want to do it,” and “it’s his choice.”

Caregivers often offered suggestions that are antithetical to community inclusion principles, suggesting that agencies sponsor parties, provide art classes and group trips to sporting events or parks, and provide more “disabled transportation.” Even when caregivers showed that they understood the principles of community inclusion in theory, sometimes they still wanted the agencies to “find more opportunities for inclusion in employment and recreation.” Others noted that agencies should advocate more for the community inclusion for their service recipients and for caregivers. Frustration clearly showed in responses such as:

Some support would be better than ZERO.

There were other admonishments for agencies, such as this one that is telling on many levels:

Nothing until he is ready to engage again, and then be willing to approach him a valued human being.

But just as common were comments that did not put forth blame or reproach, but instead seemed resigned— “it’s just the severity of her illness.”

Quite a few respondents said they didn’t know what agencies might do or expressed feelings of hopelessness:

I’m not sure. It seems like a hopeless situation.

A few caregivers instructed agencies on how to increase community inclusion by providing supports:

Participate alongside them [people receiving services] while engaging in community activities.

Still others suggested that agencies be proactive in educating those they serve, and their families, about what is available from the agency and community resources.

Respondents recognized structural issues, such as the need for more staffing and more comprehensive services. There were calls for more agencies and practitioners, and to “hold people accountable.” One respondent requested that agencies eliminate the use of a one-size fits all approach:

Work with his interests and quit assuming he doesn’t want to do anything.

Others suggested that agencies adopt a model that includes families and/or caregivers as a component of treatment and supports.

There were repeated calls for agencies to provide follow-up, especially after psychiatric hospitalization:

Follow up care and support AFTER discharge from psychiatric hospitalization. More facilitation with engaging the family and other natural supports. She is 29 years old and there is little/nothing the family has been able to access in terms of supporting her. I’m a professional in the MH field so I’m taking it on myself personally to help my family member. Nothing was offered to us.

With respect to obtaining jobs and housing, caregivers advice to agencies was to present “fewer hoops to jump through.” Additionally, caregivers suggested that agencies help to educate the public, school personnel, and employers to gain “understanding,” and “to be more tolerant.” Caregivers were clear that they want agencies to provide resources to increase the community inclusion of the people they serve, whether they do so directly or by helping families to identify resources and opportunities.

Educating the community and making people more expecting and less scared of mental health. This way the individuals could feel more supported.

Quite a few caregivers wanted agencies to provide more resources for transportation, peer services and support to caregivers of adult children.

There were also recommendations for services spanning a more holistic range of options:

...I would like to see more alternative/natural/holistic therapies being used. These would include the full range of therapies; physical, mental, social, emotional and spiritual.

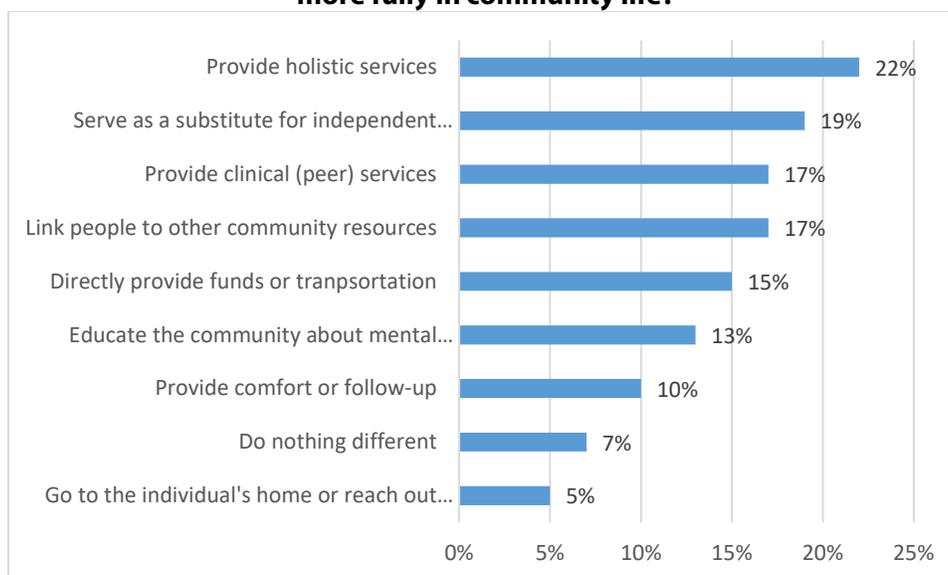
Sometimes the advice for agencies had nothing to do with increasing community inclusion, but were instead fundamental calls for more, better, and more timely services:

Increasing better psychiatric care, sooner appointments and focusing on quality time rather than quantity when in appointments.

Coordinate care and create an easy to navigate method of seeking care and reporting when appropriate care doesn't occur. agencies should be better networked, and should be more visible and accessible in educating and enforcing patient and family rights.

These requests and suggestions are depicted in the following graph:

Q7: What more could support agencies be doing to help the person you care for participate more fully in community life?



What More Can Caregivers Do to Foster Community Inclusion

The final survey question asked respondents what more they could be doing as caregivers to help their loved ones participate more in community life. Caregivers often said that they've given their all, and there was nothing more to do. Sometimes it was exhaustion (even despair) that came through; other times, resignation. But caregivers also had good advice for each other, and recognized that more much more needs to be done. They emphasized that everyone must work to change entrenched mindsets, including the ways in which their loved ones viewed themselves. Above all else, caregivers called for compassion:

People don't understand the condition and how severe the impact can be. Some days are better than others and the person is deeply embarrassed by his behavior on the bad days.

I don't know. Political forces way beyond my control work against any solution. Society has lost its compassion.

More resources so that people in service agencies can respond quickly, intelligently and with compassion.

But still, many respondents clearly showed that in spite of best efforts and successes, there still remained a dichotomy between caregiver wishes/intentions, and what their loved one was willing or able to do:

She participates when she is able, when she's unable, no supports would help anyway.

That's a really good question. If a person does not want to involve themselves in community life, I'm not really sure what a caregiver can do especially if a person is their own guardian and can make their own choices. It's pretty sad when you think about it.

Among the most frequent responses to the question of what more caregivers can do were "I don't know," and "nothing." The explanation for this type of answer was common too:

I am doing everything within my power, I take her everywhere but there are times when she just doesn't wish to leave the house.

Comments also spoke of how hard it is for caregivers:

I would rather be my mom's daughter than her caregiver.

It is a constant balancing act of providing support without being over supporting. I try to model meaningful relationships, and work to encourage the person I care for to continue to take increasing steps into the community.

Caregivers responded with encouraging words, urging self-care, caution, and compassion:

Get them out of the house and into the community when possible. Keep looking for opportunities and don't give up.

Continue to offer to take to events and encourage other friends and family to do the same.

Become informed of support services available in the community for both the person needing help and [the] caregiver.

A caregiver walks a fine line between support and encouragement. If you push too much it just sets back the trust you have worked for.

STAY CONNECTED. Make sure you are reaching out often and continuously. Show your love and willingness to listen, always.

Finally, caregivers proved themselves to be advocates, advising others to “write letters/phone calls to our state government,” and calling for systems change that captures the essence of community inclusion:

...There is a lot of opportunity in this arena for training caregivers to request support (with evidence that shows family members how they can help a person and their family to recover) and peer counseling and companionship. The latter could be a significant career field that could make change within the community happen faster and more organically. More community event that are inclusive—not just those labeled for those with mental health issues!

Heeding Caregivers’ Call

This national survey was undertaken to gather insight from caregivers in order to create a toolkit to help caregivers increase community involvement for their loved ones, and perhaps for themselves as well. Rather than provide comments outlining concrete steps or suggested activities, caregivers instead called for what they and their loved ones need, or need more of—including support, understanding compassion, and money. They also clearly identified what their loved ones need less of—discrimination, false assumptions, being marginalized, and living in poverty.

Caregivers are pleading for a continuum of care (from youth to old age) that will enable and empower their loved ones to fully participate as community members. Caregivers want services that engage their loved ones. They are asking for services that are holistic and address trauma, and that don’t end when crises abate, such as peer support and case management.

Caregivers are calling for services that not only help people with mental illnesses attain employment, but that will support them and educate employers and coworkers so they can stay employed. They are calling for understanding about how difficult symptoms and the attendant side effects of medication can be. They are asking for more for education for and compassion from teachers and other school personnel, clergy, and the general public.

They are asking for more types of supports for themselves (such as respite for people caring for adults, not just kids). They want education on how to better help their loved ones be more involved in life, including information about what community resources exist for recreation, health and engagement.

Caregivers are asking that policy makers and legislators address issues related to poverty; lack of transportation; community services that are ineffective, scarce, or hard to access; and the unavailability of housing, and unsafe housing. They are expressing anger and outrage toward policy makers about how programs that make a difference in the lives of their loved ones are cut, or ended before their loved one has made sustained progress.

Caregivers are calling for more people to step forth as “exemplars,” demonstrating recovery and showing that “people with mental illnesses are not scary.”

Individuals with mental health needs and their caregivers are the ones who are the most directly impacted by policy decisions. Rather than putting forth policy recommendations, or offering tools for caregivers based on what this sample of caregivers have said, this monograph showcases caregivers’ experiences, and perceptions. It amplifies caregivers’ voices in hope that their voices will be heard, and their pleas will be heeded.

Where Do We Go from Here?

Many of the caregivers that responded to the survey expressed a willingness to further engage with research and policy efforts. They offered their phone numbers and email addresses. Next steps will include following up with caregivers, perhaps with more detailed surveys or through focus groups. Their perspectives offer the opportunity to shape policy and practice.

Caregivers asked for more education and support from agencies. Next steps must include education to providers and provider agencies that by providing more education and support to the caregivers of those who use their services, they will further the recovery of the people they serve.

Caregivers displayed wisdom and understanding of many of the impediments they and their loved ones encounter. But they also demonstrated that sometimes they too hold on to old outmoded ideas and concepts. These include wanting their loved ones to have more—not less—social interaction with mental provider agencies, such as agency group transport and agency sponsored socials. Next steps must include more education for caregivers about ways they can help themselves and provider agencies to foster community inclusion.

Caregivers responding to the survey explicitly asked for more support for themselves. Next steps need to include more education and information about community resources that are presently available to them. Family support is available through organizations including local [Mental Health America \(MHA\)](#) affiliates, The [National Alliance for Mental Illness \(NAMI\)](#) and the [Depression and Bipolar Support Alliance \(DBSA\)](#). In regions where there are no or few groups, caregivers can start a new group or work their loved ones' provider agencies to offer support to their peers.

The caregivers responding to the survey generously provide information that will be used for policy and advocacy, and in yet unseen ways to help facilitate systems change.

For more information, and to further explore these and other opportunities for next steps, please contact:

Debbie Plotnick at Mental Health America, dplotnick@mentalhealthamerica.net

Rick Baron at the Temple Collaborative: rbaron@temple.edu

Appendix

Q1. In general, how would you describe the degree to which the person you care for is actively involved in everyday community activities—e.g. working, school, family, friends, religion, sports—that give structure, meaning, and enjoyment to their lives? (*Answer Options: Uninvolved, Minimally Involved, Somewhat Involved, Very Involved*)

Q2. For these 10 questions, please tell us the degree to which the person for whom you provide care is involved with the following activities: (*Answer Options: Uninvolved, Minimally Involved, Somewhat Involved, Very Involved*)

- How involved is the person in competitive employment up to his/her capacity?
- How involved is the person in using local recreational activities?
- How involved is the person in the life of a local religious community of his/her choosing?
- How involved is the person with friends beyond his/her connections to mental health services?
- How involved is the person in local community events?
- How involved is the person in obtaining housing of his/her choosing?
- How involved is the person with educational supports and opportunities?
- How involved is the person in health and wellness opportunities?
- How involved is the person with family supports?
- How involved is the person in healthy, meaningful intimate relationships?

Q3. Does the person encounter barriers to inclusion in the following areas?

- Employment
- Recreation
- Religious or Spiritual Activities
- Friendships
- Civic Activities
- Housing
- Education
- Health/Wellness
- Family
- Intimate Relationships
- No Barriers
- If you checked "Yes" to any of the above, please describe the barriers to greater connections.

Q4. In general, how would you describe the degree to which being a caregiver has impacted your involvement in everyday community activities—e.g. working, school, family, friends, religion, sports—that give structure, meaning, and enjoyment to your life? (*Answer Options: Not Impacted, Minimally Impacted, Somewhat Impacted, Very Impacted*)

Q5. For these 5 questions, please tell us the degree to which caregiving has impacted your involvement in the following activities. (*Answer Options: Not Impacted, Minimally Impacted, Somewhat Impacted, Very Impacted*)

- Has providing care for your loved one impacted your ability to regularly engage in recreational activities?
- Has providing care for your loved one impacted your ability to engage with a religious community of your choice?
- Has providing care for your loved one impacted your employment situation?
- Has providing care for your loved one impacted your ability to socialize with your friends?
- Has providing care for your loved one caused you to feel unwelcome or excluded from family gatherings and community events?

Q6. Please describe the support the person you care for has received to increase their participation in community life. For example, an effective job placement program, key supports for someone in school, a welcoming approach of a local congregation, an inclusive recreational program, etc.

Q7. What more could support agencies be doing to help the person you care for participate more fully in community life?

Q8. What more could caregivers like yourself be doing to help the person you care for participate more in community life?

Q9. If you are willing to participate in a follow-up telephone interview or web-based focus group to explore these topics further, please share your name and phone number below.

End Notes

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