

The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

AccessAbility

Winter 2014-2015
Number 117

KNOWING WHAT WE DON'T KNOW

By Ken Dibble



I am the first to admit that we at STIC don't always have all the answers. When it comes to serving people with mental illness, we are not alone.

We have served people with mental health disabilities, "serious and persistent mental illness," "emotional disturbance," or whatever you want to call it, since we opened our doors in 1983. In fact, people with those types of disabilities were among the first people we served, because nobody else wanted to deal with them.

STIC doesn't seem to be on the local mental health "radar" among service providers, perhaps because we don't get any money from the state Office of Mental Health or any county mental health departments to provide these services. We manage in other ways though; conservatively estimated (these disability categories can overlap), we served about 250 people with mental health disabilities in the fiscal year that ended this past September 30. We provide psychotherapy, peer counseling, independent living skills training, and advocacy (which amounts, in some cases, to informal, but at times rather intense, service coordination) to them.

All of which goes to say that we have a great deal of experience with this disability category. So while we are not fully informed on the topic, we do know a lot.

We know that the Broome County Mental Health Commissioner's claim that other service providers are rapidly expanding to cover services lost in the steep downsizing of the county mental health clinic is false. There are some initiatives to expand community mental health services. Lourdes, for example, is trying to do so. However, these initiatives were, at press time near the end of November, still largely on paper, with no certainty that real services will appear. Meanwhile, if you are having a mental health crisis in this county, you can go to CPEP (the mental health "emergency room" at General Hospital), where you will wait for several hours, and may or may not get anything beyond a list of phone numbers to call. When you call those numbers, you may be able to get an initial appointment for evaluation within a few weeks, but you will wait at least 6 months for your next appointment.

We know that CPEP's response to the people it sees is wildly inconsistent, depending on who is on duty at the time, and the

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program is under intense pressure because it is far too small to meet the community's needs. This is why some people can go there and have a good experience, while at other times, a person with both developmental and mental health disabilities who is highly agitated, aggressive, and hearing voices telling him to kill his parents can be turned away and told to call the developmental disabilities Article 16 clinic for an appointment.

We also know that the county jail is being expanded in part in order to accommodate people with mental illness, because the availability of actual community mental health services in this county is totally inadequate.

We aren't knocking the jail; the jail actually has the best track record in the county

AccessAbility

December 2014

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AccessAbility is published seasonally (Spring, Summer, Fall, Winter) by Southern Tier Independence Center. Letters, information, articles and ads are always welcome. Deadlines are February 15, May 15, August 15 and November 15.

Our address is:

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135 E. Frederick Street
Binghamton, NY 13904

Subscriptions

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Authorship

All articles appearing in this newsletter are written by Ken Dibble unless otherwise noted. Generally, I get tired of seeing my name on every page, and I'd rather use the space for something more interesting. I do put my name on controversial stuff, though, so you'll know who to blame.

for being an effective mental health crisis management service. They are pretty good at ensuring that people get appropriate follow-along support after they are released.

Although we deplore the loss of services at the county mental health clinic, we're not arguing that it should stay open. We aren't big fans of government-operated direct services for people with disabilities. We think several other local providers could do what the clinic used to do, and do it well. What we are saying is, that's not happening now, and that needs to change.

Unfortunately, it seems that the political leadership around here would rather pay for mental health services in jails than in the community. Sadly, this is probably due to simple bigotry about mental illness. We keep citing the facts: people with mental illness are far more likely to be the victims of crimes than to commit them. And the decision-makers keep treating them like criminals anyway.

But as I said, we don't know everything about this. Still, one of the things Centers for Independent Living are supposed to do is learn about these issues and then figure out ways to fix the problems. That's systems advocacy; that's our bread and butter. So a group of us has been focusing on this and trying to learn and troubleshoot.

One consistent theme we've noticed, as we've traveled the highways and byways of social service systems over the past 30 years, is that service providers of all kinds tend to be isolated in their own corners of the system. They only know their own piece of it, and rarely are aware of the other pieces, how they work, and how to

access them. Over and over, we hear from the people we serve that such-and-such service provider didn't know about this or that other service, or gave them wrong information about it. This is endemic to all social services: people come and go; staff turnover is especially high in the more stressful positions—and this means that hard-won knowledge keeps getting lost. Staff training budgets are among the first things to be cut when money gets tight, so that knowledge isn't always regained.

Unlike most service providers, Centers for Independent Living like STIC serve people with all types of disabilities of all ages. We are generalists, not specialists.

That gives us an advantage; we *have to*

know more about everything in the social services sphere than specialists do. We are definitely not bragging here; we don't know everything, and when it comes to mental health services, we have a lot to learn. But it is our job to find out,

improve our knowledge, and spread that knowledge through the community.

Already, we do clearly know two things: We have a severe shortage of community-based mental health services, and a significant training problem among service providers, including a lack of knowledge about cross-disability services, in this county. The training problem makes it impossible, for all of us, to use the limited services we do have efficiently and effectively.

So in the coming months we will reach out to providers in an effort to learn more ourselves and create a permanent resource for training and troubleshooting that will share what we've learned. When you hear from us, we hope you'll respond. Together, we can face this and make it better.

We know two things: We have a severe shortage of community-based mental health services, and a significant training problem among service providers.



If the weather is bad, call 724-2111 (voice/TTY) to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

Employment—or Self-Serving PR—First?

In September, Governor Cuomo issued an Executive Order establishing an “Employment First Commission.” The commission consists of state agency heads; they will review existing policies and services related to employment for people with disabilities and make recommendations to increase “competitive integrated employment” by March 1, 2015.

The Order’s definition of “integrated setting” is potentially important: “a work situation where each employed individual with a disability has equal opportunity to interact with co-workers without disabilities. Individuals who are paid to provide services to support the work of individuals with disabilities are not included when evaluating integration.” This is the best definition of integrated non-residential settings to ever come out of NY State government. The commission is supposed to evaluate regulations to “remove barriers.” If they enshrine this definition in state regulations that govern payments to employment programs, it could be big.

Right off, it blows the NYS Commission for the Blind’s cozy relationships with sheltered workshops out of the water. That agency claims that workshops are “integrated settings” because they are full of nondisabled employment services staff.

We’re still awaiting guidance from the federal Centers for Medicare and Medicaid Services (CMS) on how the new Medicaid Home and Community Based Services (HCBS) regulations, which took effect in March 2014, apply to employment services. Old guidance (from September 2011), allows “small group” supported employment models such as enclaves and mobile work groups, as long as they operate “in a manner that promotes integration into the workplace and interaction between participants and people without disabilities in those workplaces.”

There is no such thing as an enclave or mobile work group that does that. Indeed,

the entire purpose of these models is to set up special, separate locations in ordinary workplaces where only people with disabilities work, and the only nondisabled people who get anywhere near them are the supported employment staff who are paid to serve them.

In a recent response to comment on this issue, OPWDD tried to claim that the 2011 CMS guidance is consistent with the new regulations, and stated that the agency “will allow” use of HCBS funds for these options.

OPWDD likes to say that it has enlightened regulations already on the books that support highly-integrated services. We have shown that agency, and CMS, several examples of how it doesn’t enforce its own regulations. One of them is the fact that OPWDD lets these segregated-by-definition employment programs operate unmolested. Perhaps Cuomo’s commission can educate OPWDD on this topic; the agency’s Commissioner should be right there at the table.

We expect CMS to forbid these models in its new guidance. They clearly conflict with the new regulations for residential services, which are required to support “full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings ... to the same degree of access as individuals not receiving Medicaid HCBS.” “Same degree of access” in employment would mean that the person works alongside, and interacts with, people without disabilities just as much as a nondisabled worker in the same job would do. Presumably, this is also what “equal opportunity to interact with co-workers without disabilities” means in the Governor’s new definition. That is simply impossible in an enclave or mobile work group.

We’ll watch the Commission and let you know if it actually has any teeth.

Sciarrillo v Christie: Close ‘em Down!

As we reported last time, a federal district court judge in this case ruled against the guardians of a group of people with developmental disabilities who wanted to stop New Jersey from closing two developmental centers (DCs). Since then, the federal Department of Justice (DOJ) website recovered from its temporary malfunction and we were able to review the judge’s decision.

Our original article (see *AccessAbility* Winter 13-14) described several arguments made by the guardians, all of which, we noted, were indefensible as matters of law or even of common sense. However, the judge only focused on the three most obviously false claims.

The first concerns remarks made in passing by the author of the US Supreme Court’s *Olmstead v L.C.* decision, that “nothing in the ADA or its implementing regulations condones” forcing people with disabilities into community settings if they are “unable to handle or benefit” from them, and that there is no “federal requirement that community-based treatment be imposed on patients who do not desire it.” In legal terms, these statements are “dicta”, that is, remarks, not rulings. The Court was asked, “Does the ADA prohibit states from segregating people with disabilities unnecessarily?” The Court responded, “Yes, it does,” and that’s the only ruling it made. The rest of the decision is mostly suggestions, but not orders, for what state governments can do to comply with the ruling.

The Court was not asked, “Does the ADA prohibit states from integrating people with disabilities under any circumstances?” But, the Supremes said, “[w]e do not in this opinion hold that the ADA imposes on the States a ‘standard of care’ for whatever medical services they render, or that the ADA requires States to provide a certain level of benefits to individuals with disabilities.”

The point is that the *Olmstead* decision describes the right of people with disabilities not to be segregated unnecessarily. It does not create any “reverse” right to be segregated if somebody thinks it *is* necessary. That would be stating a “standard of care,” which

is not part of the ADA or the *Olmstead* ruling. States can close any or all institutions for people with developmental disabilities if they choose (and several already have), and they can tell people they can accept integrated supports and services, or no services at all, without violating the ADA or *Olmstead*.

The second issue concerns federal Medicaid law, which does establish standards of care. If a state chooses to provide or pay for Intermediate Care Facilities for people with developmental disabilities (“ICFs”, which is what developmental centers are), then the state must provide or pay for specific types of services in those ICFs. But Medicaid law does not require states to have any ICFs, at all.

In any case, the district judge said that NJ wasn’t refusing to provide ICF services to anyone; it was just trying to close two large ICFs. The people living in them were offered the option of receiving integrated community based services, or being transferred to an ICF that the state plans to keep open—more generous terms than the ADA or Medicaid law require. The guardians weren’t satisfied with that. They wanted the court to force NJ to keep two ICFs open that they happen to like.

The judge also briefly considered the claims that closing DCs and putting people into community settings will endanger them, and that downsizing the institutional staff as people moved out has harmed the remaining residents. He said (as judges often do), that people can’t sue based on a future prediction of theoretical harm, but only after evidence of actual harm has been produced. Then he said that the complaint provided no specific evidence of any harm coming to anyone at either DC as a result of staff reductions. The complaint told one story of how one ICF resident had injured another one, but, as the judge pointed out, it didn’t demonstrate that this happened due to a staff shortage. In fact, it happens in DCs everywhere, no matter how many staff are on duty. It happens because grouping a lot of people who have behavior problems together in the same place is a bad idea.

The plaintiffs have appealed to the Third Circuit Court of Appeals, and DOJ has filed a “friend of the court” brief supporting the judge’s position. Several other district courts have made rulings similar to this judge’s, and we are not aware of any that have ruled the other way. It seems unlikely that the appeals court will overturn this decision, but stay tuned.

More COLA for You

The federal Social Security Administration has announced that people who receive SSI will get a cost-of-living increase of 1.7% beginning in January 2015. That’s not exactly super-sizing, but it’s something, in this time of low inflation.

SSI is Supplemental Security Income, a federal stipend for people with certain types of disabilities who have never been employed or are very under-employed. According to the Social Security Administration:

“Social Security and Supplemental Security Income (SSI) benefits are adjusted to reflect the increase, if any, in the cost of living as measured by the Consumer Price Index for Urban Wage Earners and Clerical Workers (CPI-W) prepared by the Bureau of Labor Statistics (BLS). ...

For purposes of determining the COLA, the average CPI-W for the third calendar quarter of the last year a COLA was determined is compared to the average CPI-W for the third calendar quarter of the current year. The resulting percentage increase, if any, represents the percentage that will be used to increase Social Security benefits beginning for December of the current year. SSI benefits increase by the same percentage the following month (January). If the increase in the CPI-W is at least one-tenth of one percent (0.1 percent), there will be a COLA. However, if the CPI-W increases by less than 0.05 percent, or if the CPI-W decreases, there will not be a COLA.”

Try *that* with yer Pop Rocks.

Follow the Money

Some time ago, the federal government got sued by disability advocates for failing to make paper money accessible to people with visual disabilities. The feds lost.

So over the next few years the Bureau of Engraving and Printing (BEP) will be redesigning the currency (again) to include more features for people with limited or no vision, including higher-contrast color variations, larger numerals, and even some sort of “tactile enhancement”—something blind people can feel.

In the short term, the government is also working with the National Library Service for the Blind and Physically Handicapped (NLS) to provide free smart-phone curren-

cy-reading apps, and free hardware currency readers, to any person who can produce a doctor’s statement to the effect that they are blind or visually impaired.

The currency reader was tested with focus groups over the summer, and the application process was opened to the public on November 14. Currency readers will begin shipping in January 2015. To apply, go to the BEP website at www.bep.gov. If you already have an NLS account due to a visual disability, you don’t need the doctor’s note, you can call 1-888-NLS-READ and get a reader mailed to you.

Here are some Frequently Asked Questions from BEP about the program:

1. Who is eligible to receive a currency reader?

US citizens or persons legally residing in the US and its territories who are blind or visually impaired will be able to obtain a currency reader device at no cost.

2. How do I get a reader?

Complete an application form (available to download at www.bep.gov), and have it signed by a competent authority such as a doctor who can certify your eligibility. Mail the signed application to the NLS at the address listed on the application. NLS patrons are not required to complete an application, just call NLS at 1-888-NLS-READ; your account will be noted and a currency reader will be delivered to the address on file.

3. How long will it take to receive my reader?

After January 2015, the average time to process and ship a reader is expected to be approximately six-to-eight weeks.

4. Can I get a reader for my child, parent, or friend?

Parents or legal guardians of a child under 18, caregivers, legal guardians, or those with power of attorney may act as a proxy on behalf of a blind or visually impaired person, but a certified application must be submitted for that individual.

5. I just bought a currency reader. Can I get reimbursed?

The US government cannot reimburse individuals for currency reader devices they purchased.

6. Am I responsible for repairs to my device?

Currency readers will be shipped with a AAA battery. Replacement batteries will be the owner's expense. If your reader fails to perform, you may call (844) 815-9388 toll-free for assistance.

Text to 911

Well over a hundred million Americans have cell phones that transmit text messages, and more and more often people would rather text than talk. Texting isn't just a fad, but for some people it is considerably more than just convenient. It has opened up communication in ways that were not dreamed of just a decade ago.

People with hearing disabilities have found many communication barriers removed with the advent of texting. A lightweight cell phone lets them communicate with retailers and employers as well as with friends and family, in a way that now seems natural to almost everyone. Typing rather than talking no longer identifies you as disabled. It's what everybody does.

But emergency services have been slow to respond to this development. In most places you can only contact 911 by voice phone—and if you're deaf that usually means you must spend precious time hooking up to a relay service, time whose loss may kill you.

The Federal Communications Commission (FCC) has recognized this problem, and in

August 2014 it issued rules that will require every wireless carrier, and many so-called "SMS" messaging services (typically internet messaging software such as Yahoo! Messenger, ICQ or Skype), to support text-to-911 by the end of 2014. At that point, any 911 call center that requests text service from any of these carriers must be able to get it within 6 months.

As the FCC said, "More than one hundred 911 call centers serving portions of 16 states and two entire states (Vermont and Maine) are now accepting emergency texts, and there are already reports of lives saved." So we are looking forward to early roll-out across New York (it's already available in Rochester, Utica, Syracuse, and Elmira).



Support for Disabled Veterans

by Maria Dibble

STIC is pleased to announce that we have received a three-year grant through the NY State Education Department and ACCESSVR to provide peer support services and other assistance to disabled veterans in Broome, Chenango, and Tioga Counties.

The part-time (20 hours per week) Veteran Peer Advocate will provide peer support, information & referral, advocacy, assistance securing housing, and life skills development, as well as collaboration with local veterans groups. S/he will rotate between our Broome, Norwich, and Owego offices, to reach the maximum number of people who need services. We will outreach to and work with the Veterans Administration, Disabled American Veterans, Broome County Veterans Service Agency, and other organizations in our three-

county service area to find ways to enhance and expand available services.

At press time we were recruiting to fill this position. The most important qualification is that the peer must be a veteran with a disability, so s/he can be a role model of independence and community integration for other veterans, and share an understanding of issues they face.

Money Follows the Person: Taking a Different Path

by Maria Dibble

The New York Association on Independent Living (NYAIL) has been awarded a grant to establish a coordinated statewide program for the NY State Department of Health Money Follows the Person (MFP) Demonstration Transition Centers Project.

As one of nine Centers for Independent Living (CILs) around the state, STIC will work with NYAIL to assist people with disabilities to leave nursing homes and other institutions and get services either through the NHTD, TBI or OPWDD Waiver.

NYAIL will be the hub for the project, communicating with CILs, receiving referrals, providing oversight, and developing training for CILs across the state. Nine CILs will serve as Regional Leads: Albany North (Southern Adirondack Independent Living in Queensbury); Albany South (Independent Living Center of the Hudson Valley, Troy); Binghamton (STIC); Buffalo (Western New York Independent Living); Long Island (Suffolk Independent Living Organization, Ronkonkoma); Lower Hudson Valley (Westchester Independent Living Center, White Plains); Rochester (Center for Disability Rights); Syracuse (ARISE Child and Family Services); and New York City (Center for Independence of the Disabled in New York, Manhattan). NYAIL will also subcontract with other CILs that have expertise and capacity to staff Transition Specialists familiar with local services and supports located near individuals who wish to transition.

Dacia Legge will be STIC's MFP Coordinator, as we bid a sad farewell to Robin Carroll. The new project will begin right after the first of the year.

This is an exciting initiative and we're proud to be a part of it.

STIC Goes

BACK 2 SCHOOL

By Maria Dibble

STIC has been awarded a grant from the NY State Education Department called the “Regional Vocational Rehabilitation–Community Employment Specialists (RVR-CES) Project”. (We didn’t make up this name, we promise, and we would rather you not pronounce it as “River-Cess”).

The project will provide consultative and technical assistance to inform school districts and educational agencies in our region regarding student eligibility requirements for, and availability of, vocational rehabilitation services, and of community supports to connect students to vocational rehabilitation and independent living services and other area providers, to improve post-secondary outcomes.

STIC will base one staff person at AIM independent living center in Corning, serving school districts in the Greater Southern Tier BOCES region covering Schuyler, Steuben, Chemung, Tioga, and Allegany counties. STIC will also have staff based at our Binghamton and Norwich locations to serve school districts in Broome-Tioga-Delaware and DCMO BOCES in Broome, Chenango, Delaware, Madison, Otsego, and Tioga Counties.

RVR-CES will work directly with school districts to develop procedures for appropriate and timely identification of youth for referral who are in their last two years of high school, and those up to age 25 who may be eligible for VR services through ACCES-VR or the NYS Commission for the Blind. We will provide

information about services available through independent living centers, the NYS Office of Persons with Developmental Disabilities (OPWDD), the NYS Office of Mental Health (OMH), the federal Social Security Administration (SSA), county Departments of Social Services (DSS), local housing programs, and other community support services. We will inform districts of VR-approved community work and employment experiences that may be provided as activities to help students with disabilities meet their post-school employment goals.

Our efforts will seek to improve post-secondary outcomes for youth up to age 25 with disabilities by helping school personnel expand their knowledge of the connection between the student’s IEP, referral, and preparation for adult services. We will build upon school personnel’s experience with the roles and responsibilities of adult state VR services, community agency providers, independent living centers, and other community support systems that may be beneficial in attaining successful post-secondary outcomes such as jobs or higher education.

We thank Corning AIM for providing space for our staff person, and for their continued partnership with STIC on a variety of projects. We do not yet have a start date for this project, but we hope to begin recruiting for positions soon. Watch our web and Facebook pages for all job openings at STIC.

The Haunted Halls of Horror 2014 Review

by Bill Bartlow

The leather-face butcher lunges forward, slamming his roaring chainsaw on the table strewn with body parts. The natural startled reaction is the fight/flight adrenaline rush and its accompanying scream and recoil. Losing balance and impacting the wall opposite this violent confrontation is an almost universal response. No chance to recover, no reprieve, as one of the many severed heads sitting on the shelves starts hollering at you. The panic increases. Some begin running; all are making some descriptive “bodily function” expression or appealing to a deity and their friends for protection. AAHH, yes, the thrill has returned again, for the scared and for the volunteer scare-actors who celebrate the reactions they have elicited from the many visitors at the 5th annual Haunted Halls of Horror. We’ve done it again.

Binghamton’s premier haunted attraction hosted almost 3000 visitors and our balance sheet yielded record revenues of approximately \$40,000 to support STIC’s mission. Sixty volunteers generously contributed a total of 1542 hours during our ten performances and over 1400 hours in construction and setting of the scenes. Outstanding cast members created remarkable characters, by far surpassing previous years’ levels of excellence in make-up, wardrobe, and acting. Congratulations and our deep thanks for their selfless participation in putting HHH on a par with professionally-staffed haunts. Bravo!

2014’s new features began with “Christine the Cadaver Coach,” a 1993 Cadillac hearse in pristine shape, complete with coffin, welcoming you at the entrance. You’ll recognize her out on the town by her distinctive hood ornament and the HHH logo across her hood. The addition of “The Catacombs,” containing the osseous remains of the predeceased, displayed an alternative interment option for long term planners. The occupants’ vacuously blank stares were similar to that of the patient found in the brain salad surgery suite. “I Survived” T-shirts and hooded sweatshirts with the HHH logo were the badges of courage taken home by some of the devotees whom we expect to greet again in 2015.

We encourage our fans to patronize the many advertisers featured in our 80-page event booklet and support our generous community partners, whose contributions are the under-

pinning that makes this event possible. Their philanthropy brings this holiday celebration to life while supporting a great cause that benefits many individuals and families in our region.

Thankful recognition is extended to:

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Wegmans Food & Pharmacy

Our thanks to the thousands of attendees for your continuing support of our attraction. We have, in our five years, now surpassed ten thousand HHH visitors.

Follow us at our website: www.hhh-stic.com.

Like us on Facebook.

Join us for 2015. We're already working on next year.

STIC Christmas Trees at Roberson Museum "Home for the Holidays" Display

by Sue Lozinak

Looking for a fun, local holiday activity for the family? Visit the Roberson Museum and Science Center and see their Home for the Holidays Christmas tree display, open from November 19 through January 4. They have an International Forest, community tree display, model train room, and a mansion all decked out for Christmas!

This year, one of STIC's trees is decorated in a red, gold, and green color scheme with white doves and holiday teddy bears displayed in a children's theme.

STIC's other tree represents our Haunted Halls of Horror fundraising event. This spooky tree has skeletons, bats, and black crows in a purple, black, and silver color scheme with a Halloween theme.

Both trees were decorated by Sue Lozinak, the Director of the Parent Technical Assistance Center at STIC.

The museum is located at 30 Front Street in Binghamton. They are open 7 days a week with extended hours of operation for the event. Check their website, roberson.org, for more information.



HOCKEY FANS!!

The Binghamton Senators are on the ice again!

By getting your tickets through the Haunted Halls of Horror and STIC, a portion of your purchase price will be donated back to STIC for the HHH fundraiser. We are sponsoring the following home games:

January 16

February 13

March 18



We are trying to sell 50 tickets per game, so please share with your Facebook friends and help us reach our goal. Look for our display on the promenade on the above dates, and meet some of our HHH Scare-Actors in action.

To get tickets:

call (607) 724-2111 (voice/TTY)

Ask for Todd or Bill

We appreciate the support. Happy Haunting!

Glossary of Abbreviations

We try to define every abbreviation the first time it appears in every article. Sometimes there isn't space to do that, so here's a list of some of the most common ones.

ACA – Affordable Care Act, also known as “Obamacare.”

ACCES-VR - NY State Adult Career and Continuing Education Services – Vocational Rehabilitation; formerly “VESID.”

ADA – Americans with Disabilities Act, federal civil rights legislation.

ADAPT – A national grass-roots disability rights organization with many local chapters, including one in our region.

BHO – Behavioral Health Organization; a form of Medicaid managed care for people with mental health disabilities.

CDPA – Consumer Directed Personal Assistance program; “self-directed” personal attendant services where the consumer hires, trains, schedules, supervises, and fires his/her attendants, with paperwork and billing help from an agency; available in NY under ordinary and managed-care Medicaid, and some OFA programs.

CIL – Center for Independent Living; a not-for-profit local consumer-controlled cross-disability service and advocacy agency like STIC.

CMS – Centers for Medicare and Medicaid Services; the federal agency that oversees those programs.

DC – Developmental Center; one type of large institution for people with developmental disabilities.

DD – Developmental disability

DISCO – Developmental Disabilities Individual Support and Care Coordination Organization; OPWDD's proposed new managed care organization.

DOCCS - NY State Department of Corrections and Community Services, which administers state prisons.

DOH – NY State Department of Health

FIDA – Fully Integrated Duals Advantage program; a federal managed care demonstration grant program to offer a broad array of HCBS services to people who have both Medicaid and Medicare.

FPL – Federal Poverty Level; an amount of income, adjusted for family size, below which people are considered to be impoverished.

HCBS – Home and Community-Based Services, a category of Medicaid-funded services for people with disabilities defined by CMS, intended to support people in settings other than nursing facilities, DCs, ICFs, and psychiatric hospitals.

ICF – Intermediate Care Facility (sometimes called “ICF/ID” or “ICF/DD”); a segregated congregate residential setting of any size for people with developmental disabilities which meets certain CMS regulations to provide intensive medically-oriented supports and services; all DCs are ICFs, but not all ICFs are DCs.

ID – Intellectual disability, a type of developmental disability, formerly known as “mental retardation” or “MR.”

IDEA – Individuals with Disabilities Education Act; a federal law that requires school authorities to provide public-school-age children with disabilities a free, appropriate public education in the least restrictive environment.

IEP – Individual Education Plan; a plan to ensure that a child with disabilities gets a free, appropriate public education, as required by IDEA.

IRA – Individual Residential Alternative, a residential program for New Yorkers with developmental disabilities; it can range in size from one resident to 12 or more and can be provided in any type of residence; it is supposed to be designed and staffed to meet the specific needs of the individuals who live in it; almost all IRAs are group “homes” with 6 or more beds and owned and operated by OPWDD or not-for-profit agencies.

LTHHCP – Long Term Home Health Care Program (also called the “Lombardi” program), a Medicaid HCBS waiver used by some elderly New Yorkers with relatively limited support needs.

MFP – Money Follows the Person; a federal systems change grant program that gives NY

extra Medicaid money to help get people out of nursing facilities and other institutions.

MISCC – Most Integrated Setting Coordinating Council; a committee of NY State agency heads and interested others charged in 2002 with creating an “Olmstead Plan” for the state, it now apparently only exists to allow disability activists to mau-mau the flak-catchers (see Tom Wolfe's 1970 essay, “Mau-Mauing the Flak Catchers”).

MLTC – Managed Medicaid Long-Term Care; a form of mandatory managed care for people with significant permanent disabilities; already in use in New York City and slowly being expanded to the rest of the state.

MMC – “Mainstream” Medicaid Managed Care; currently available to and required for all nondisabled and many disabled New Yorkers.

MRT – Medicaid Redesign Team; a group established by the Cuomo Administration to devise its Medicaid “reform” plan.

NHTD Waiver – Nursing Home Transition and Diversion waiver program; a federal HCBS Medicaid waiver intended to enable people with physical or cognitive disabilities not served by other waivers to leave, or avoid entering, nursing facilities.

OASAS – NY State Office of Alcoholism and Substance Abuse Services

OFA – NY State Office for Aging

OMH – NY State Office of Mental Health

OPWDD – NY State Office of People with Developmental Disabilities

SHU – Special (or Secure) Housing Unit; a name given to “solitary confinement” cells in prisons.

SSI - Supplemental Security Income; a federal stipend for people with certain disabilities who have never been employed or are very under-employed.

STIC – Southern Tier Independence Center; hey, that's us!

TBI – Traumatic Brain Injury; a type of brain injury caused by a blow to the head or other sudden cause (not by a disease process).

SELF HELP

😊 Better Attitudes 😊 Breed Better Behavior

The claim that dangerous behavior in people with developmental disabilities can't be "reformed" is one of the biggest falsehoods ever perpetrated by public officials. Improving behavior depends on attitude—the attitude of the staff. New York State has a long history of surrounding people with bad behaviors by staff who have bad attitudes. When we get people with the right attitudes involved, behavior "miraculously" improves, and we've got the stories to prove it.

Story 1: Effective Rehabilitation

Well over a decade ago, Maureen was mandated by a judge to live in a secure "Intensive Treatment Unit" in one of NY's developmental centers. Over the years she was transferred to other similar facilities in the state. Finally, around three years ago, she wrote to the appropriate county court judge and asked to be released. She said she knew she had accomplished everything she could in the program where she was living, and was no longer benefited by living there.

The judge agreed and Maureen was given 72 hours before she would be released to provide time for a social worker to obtain information verifying that she would be stable enough to leave. A psychological evaluation was completed that deemed her ready to leave the institution. Maureen went to live with her mother, with whom she still lives today. She is helpful at home and an active member of the community. She is independent and motivated to learn new skills. She successfully held a community job for nine months, and is currently seeking other employment opportunities. Maureen has a strong religious faith and participates in faith-based activities at her local church. She spends time with friends and has even traveled out of state to attend music festivals. She is pleased with her accomplishments as well as with her independent life.

Story 2: Responsible Community Participation Despite Severe Hardships

JA fought long and hard for his rights and was eventually released from one of New York State's developmental centers about three years ago. He went to live with his mother and stepfather. A few weeks later, his home was completely destroyed by the September 2011 flood, adding more stress to this newly reunited family.

The family lost the ability to own their own home, in part because JA's mother had been forced to cut her working hours in order to meet JA's needs for support and supervision. The family found an apartment to rent and has had to move three more times since.

JA was safe under these circumstances but was not able to participate in real community life or learn skills to support himself so his mother could return to full-time work. Eventually JA was approved for OPWDD-funded support services and began to receive some assistance.

JA began to learn important independent living skills, including money management, appropriate socialization, maintaining health, and volunteering in the community. He has coped well with frequent turnover in the staff who work with him, and continues to strive toward his valued outcomes.

JA has been volunteering at an animal care shelter for 18 months and takes great pride in his duties there. He has gotten to know the staff and has developed many relationships. JA enjoys going to a health club, dining out, shopping, and to a variety of community activities. He looks forward to obtaining more-targeted pre-vocational services with a goal of having a paying job.

Story 3: Serious Behavior Issues Eliminated by Community Immersion

Antoinette had been in and out of foster care homes, psychiatric centers, and developmen-

tal centers since she was a child. She had anger outbursts, was physically and verbally abusive to staff and other people with disabilities, and also showed other aggressive and self-mutilating behaviors. She never had much in the way of real community interaction. Due to her behaviors she was placed in a secure OPWDD Local Intensive Treatment (LIT) unit.

However, the LIT had little success in improving her behavior, nor did she receive any significant survival skills training from that facility. When the staff of a Center for Independent Living (CIL) began working with her, they agreed that a team approach was the best way to assist Antoinette to reach her goal of independence. What was the major difference between the CIL approach and the LIT approach? First, the CIL let Antoinette know that she was in charge of her services, and was also responsible for them. Second, the CIL provided one-on-one training in real community settings, not artificial sheltered environments.

With intensive peer counseling and independent living skills training provided in real community settings instead of the LIT, Antoinette learned the responsibilities of money management, including paying bills on time and how to grocery-shop on a budget, as well as how to keep her home clean, care for her possessions, and other essential skills. The CIL worked with her on how to find an apartment and what questions to ask a potential landlord. The CIL also helped her establish community supports, including learning how to make friends and to distinguish between paid staff and real friends. After many hours of training, and many more of advocacy, from the CIL, the LIT granted her release.

With the CIL's assistance, Antoinette was able to move into her own home. Antoinette is an active member of her church and volunteers in several community opportunities, most of which she found on her own. She has lived on her own for years now and is doing very well. Currently she is taking the steps needed to become a nurse.

Story 4: Triumph over Abuse and Mistreatment

Hillary was dually-diagnosed with both mild intellectual disabilities and psychiatric disabilities. She was a danger to herself and others; it could take up to four staff to restrain her when she was having a violent outburst. She was housed in one of OPWDD's Local Intensive Treatment (LIT) units. She was young and full of energy, and had a difficult time adjusting to institutional living. While in that facility she was raped by a staff member, which seriously worsened her behavior issues. Advocates recommended that she receive rape victim counseling but the LIT refused.

Eventually, after considerable advocacy, OPWDD agreed to move her to a group home—but not to the environment she requested and preferred. She was moved to a “secure” (locked-down) group home in a rural setting with no access to community activities or to people she knew and trusted. Hillary wasn't even allowed to sit out in the back yard unless all of the other residents wanted to go out. Due to the behaviors of the other residents, this was not allowed very often. The group home she was placed in was not the “real home” the staff described or promised her.

The group home also did not provide the specific individualized services that Hillary needed to improve her life. She was very angry and was often in “fight or flight” mode. Sometimes other residents would attack her and she felt staff weren't protecting her. She punched out a window, and rather than appropriately addressing the legitimate causes of her anger, the staff had her arrested.

However, she was able to maintain contact with a local Center for Independent Living (CIL). With intensive peer counseling, independent living skills training, and advocacy from the CIL, Hillary was able to move out of that group home. Due to her youth and the exhilaration of finally tasting real freedom, she “sowed her wild oats,” as many young nondisabled adults do.

Eventually, just like most nondisabled people who are free to make their own mistakes, and learn from them, she settled down. Hillary met a nice young man (not a person with a disability). They had a baby together and later, another. Hillary has taken very good care of herself and her family for several years now.

Real Jobs, Real Issues

After decades of advocacy by people with disabilities, New York State has finally begun to take concrete steps to put an end to sheltered workshops. Although disability rights advocates have hailed these changes, for some people they are disturbing.

We at STIC are in favor of closing all workshops and maximizing supported employment. But we are realists, and we want to be straight with you. When it comes to having jobs and getting paid, and the social benefits that go with that, the vast majority of people with disabilities of all kinds can do better in supported employment than they can in a workshop. However, there is also a downside: Workshops provide supervision for those who need it, in ways that it is difficult for integrated support services to duplicate.

Wherever sheltered workshops have been closed, the results have been the same: people with disabilities—including significant intellectual, physical, and behavioral issues—went from making pittance salaries to minimum wage or better. They also developed good relationships with nondisabled co-workers. Many of them, and their families, were initially reluctant, or even militantly and vocally opposed, to making the change. But once the change was made, just about everyone said they were happier with real jobs.

It is natural to fear change. Sometimes change isn't good. But beneficial change is part of all of our lives, and most of the time we have to accept it—and we eventually realize it was a change for the better.

People with Disabilities Can Do Real Work

Sheltered workshops, originally well intentioned, are based on false assumptions. The most important of these is the notion that most people with disabilities cannot do useful work that the “real” economy will pay for.

Workshops arose in a time when most jobs in urban areas were in factories. When people began thinking about letting people with disabilities do something other than sit around in “day rooms” all day, it seemed natural to create special factories for them to work in. The problem with factory work, though, is that in order to be economical, simple repetitive tasks must be done rapidly. It turns out that many people with significant disabilities aren't very good at doing repetitive physi-

cal tasks quickly. In factories that pay by the piece, they can't make much money. Over time this has led people to believe, falsely, that people with disabilities can't be as productive as nondisabled people—so therefore we can't expect them to hold real jobs.

In the past there weren't a lot of decent non-factory jobs. But that's no longer the case. We don't do much manufacturing anymore in the US, but we do a lot of other things that, we now know, people with significant developmental disabilities can do well. This includes things like janitorial work, child care, some types of clerical and healthcare jobs, and various other tasks that do not require rapid repetitive motion.

So yes, if we expect your family member, who now makes a dollar an hour packaging plastic forks in a workshop, to get a real job doing assembly work in an ordinary factory, we would be talking pie in the sky. But if we expect your family member to make at least minimum wage doing something else, such as caring for animals, shredding documents, cleaning offices, or something like that—well then we are being entirely realistic. In Vermont, for example, a woman who had been completely non-verbal in a workshop got a job in a daycare center, supervising the kids and making their lunches, and she started talking. Her communication skills continued to improve over time.

There is also plenty of evidence that some workshops are deliberately defrauding people. Sadly, some family members have been misled into believing they can trust workshop operators' good intentions. But this past June, investigative journalists in New York revealed that workshop operators are abusing the laws that allow them to pay people with disabilities less than minimum wage.

There are many cases where people whose disabilities do not actually prevent them from producing at high rates are nevertheless underpaid. For example, a workshop in Brooklyn paid a person with hearing disabilities only \$3.69 per hour to do assembly work. Federal watchdogs are supposed to review every workshop's application to pay below minimum wage and decide if it's appropriate. But most of the time they just take the workshop's word for it without investigating. As a result, the feds have allowed workshops to pay less than minimum wage to people doing assembly work because they have “lower leg pain,” depression, alcoholism, and a host of

other disabilities that do not affect productivity in any real way.

NY workshops are worse on this score than in any other state. According to the investigators, “more than \$1.3 million in pay was improperly withheld from New York workers who already earned below minimum wage between 1985 and 2013—more than twice as much as improperly withheld in any other state.” And that’s based only on data that the feds’ lax supervisors collected; it’s the tip of an iceberg that clearly runs into the tens of millions. As the investigators noted, “nation-wide, 3,315 employers pay a total of 228,693 people below minimum wage. At the US Department of Labor, which regulates the sub-minimum wage program, just five employees review and process applications to employ those workers at the lower wage.” And, shockingly, checking the actual disabilities of the workers is not part of the process.

The concern that people with disabilities can be exploited often serves as a reason for keeping them “safe” in segregated programs like sheltered workshops. But workshops themselves can be the exploiters. When a workshop operator tells you that your relative “just can’t” do real work for real money, can you really be sure that s/he is not being self-serving?

Another false assumption is that people with disabilities will be ignored, ridiculed, or perhaps even abused by nondisabled people in ordinary workplaces. In fact, everywhere it’s been tried, it has been found that nondisabled people embrace co-workers with disabilities and will usually be enthusiastic about helping them fit in, learn the job, and succeed. They even establish friendships with them and socialize with them outside of work.

People with Significant Intellectual Disabilities Need Supervision

Most supported employment jobs are part time. And it is also true that there are some people who will not succeed in supported employment. They don’t “succeed” in sheltered work either; they do virtually nothing except sit at a workbench and pass the time. This may be true for up to 20% of people who are now in workshops. There certainly are highly creative and ingenious ways to enable even people with “profound” disabilities to do useful paid work. But we can’t expect everybody’s service provider to be the Albert Einstein of supported employment.

What we have to ask ourselves is, what does a sheltered workshop really offer such a person that they can’t get from integrated activities? Not money; they didn’t make any money worth talking about in the workshop, so not getting a real job is not going to affect their income. Socialization? Well that’s a big issue for some people. But volunteering at a local organization, with individual supports, can address that. Let’s stop beating around the bush about this, folks. We can’t solve the problem until we define the problem in an honest way. It is not really about getting a ten-dollar paycheck so we can buy coffee, and it is not about being able to see our friends every day at the workshop.

The real issue is supervision. Workshops typically provide 40 hours a week of supervision for people who need it. Part-time work and part-time volunteering just do not meet the need that many families have to ensure, reliably, that they won’t have to put their own jobs in jeopardy in order to make sure that their relatives are safe.

We would like to say that there are places where workshops have been eliminated where they have solved this problem. But we can’t honestly say that. Even in Vermont, which has closed all of its sheltered workshops, some people have trouble getting alternative supervision services.

New York State’s Office of People with Developmental Disabilities (OPWDD) doesn’t have a solution for this problem either. But the agency has not made a credible effort to understand the problem, and it is not taking advantage of what other disability support programs in the state have learned. OPWDD’s only options for supervision at times when someone is not working are segregated residences or day programs, integrated habilitation services, or respite.

Respite is only available to people who have unpaid caregivers who sometimes need a break. There are thousands of New Yorkers with developmental disabilities who do not have any unpaid caregivers; they are mostly older people who have no living family, or whose family relationships were cut off due to institutionalization. So this option is not available to many.

“Habilitation” just means “learning life skills,” whereas “rehabilitation” means re-learning how to do things that one has lost the ability to do. If you never were able to do

a thing, then you get “habilitated”. Certainly lots of people with developmental disabilities need some habilitation. But habilitation is a structured activity with clearly defined goals and at least some amount of careful procedure (if it’s done right). It can’t be paid for if it doesn’t meet those criteria.

But how would you feel if, during every waking moment, you were required to either be working at a paid job or learning skills? You would have no real leisure time. Even when habilitation is intended to teach social or recreational skills, it comes with constant demands to meet somebody else’s expectations for improvement. There is no “down time,” no relaxation, at all. What kind of life is this? It certainly is not a life that most nondisabled people would tolerate being imposed on them. In fact, this kind of constant pressure can cause “behavior problems” among people with developmental disabilities. If this was your life, you would behave badly too.

Experts in other types of disabilities, including brain injury, which can produce support needs very similar to those of people with developmental disabilities, know this is a bad idea. That’s why New York’s brain injury Medicaid waiver pays for a simple supervision service, to keep people safe without imposing structure or expectations for skill development on them. (The state’s nursing facility waiver offers the same service.)

OPWDD has refused to add this service to its waiver. To be fair, the agency has never had to think about this before; it has always gotten supervision “for free” from segregated programs. They do not understand that more and more people are refusing to accept group homes or other forms of segregation, and they do not seem to realize that the new federal regulations for Medicaid waivers mean that they can no longer force people into them, no matter how many hours of service they need.

Backup is also an issue. Segregation sucks, but in a closed setting there are always at least some staff watching you. The reliability of individual integrated supports depends on specific workers showing up, on time, every day. If they don’t show up, there’s no “coverage” from other nearby staff. So you’d think that integrated programs would have much more fool-proof ways to handle staff absences than workshops or “day centers” do. Sadly, the opposite is true. These programs can’t pay overtime to retain somebody for an extra shift; the rates they receive from the

government don't allow it. Staff shortages are a problem, especially in smaller communities. The jobs don't pay very well, and the best workers leave as soon as they find something better. While agencies try to maintain a pool of backup workers, they can't always handle every no-show. So if Mom goes to work, and suddenly, in the middle of the day, one hab worker's shift ends and the next one doesn't show up, Mom has to go home. State bureaucrats and service agency administrators don't understand the needs of working people whose employers don't have a generous personal leave policy. For a lot of people, if you leave work for a crisis like this more than once or twice a year, you're fired. If we want people to trust integrated services and stop demanding that workshops and other segregated programs stay open, we need rock-solid backup.

So What are We Trying to Say?

Sheltered workshops are fundamentally dishonest. We don't just mean those that deliberately defraud their workers. It is dishonest, and demeaning, to tell people that they are doing useful work when they are not. It is also demeaning to claim that for "those special people" the real purpose of "working" is to spend time with friends, when the rest of us know that the real purpose of working is to make money. We need to stop deceiving ourselves and demeaning our loved ones, no matter how sterling our intentions. Closing workshops is the right thing to do, and would be even if it meant that none of their inmates would ever have a job.

The good news is that most of them can get real jobs, and make real money, and form real social relationships in the process. But it's just not all good news, and we can't be honest ourselves if we don't say as much.

That doesn't mean the news can't improve. A federal judge ordered the state of Rhode Island to close all of its sheltered workshops. It also ordered the state to **guarantee** that people coming out of those workshops will get 40 hours of integrated community support services, whether in supported employment, or in unpaid activity that **doesn't have to be** "habilitative." OPWDD refuses to make such a commitment. Rhode Island has been forced to do so; maybe we need to take further action to force our state to do the same.

For sure, OPWDD needs to hear from you about this.

But it won't work to tell them, "Don't close my workshop." Some people say this is only about saving money. It's true that supported employment services, on average, cost less than sheltered workshops. It's also true that the state has not ensured that enough of the money it now gives to workshops will be reinvested in integrated supports, including supervision, for people who won't get full-time real jobs. But sheltered workshops are wealthy and powerful; some of their CEOs make salaries in the high six- to low seven-figure range, and their trade associations are equally well-endowed. Money alone would not cause NY politicians to attack a rich sacred cow like sheltered workshops any more than it has led them to go after developmental centers in the face of the state employee unions. No, the state is under orders from the federal government to close both workshops and developmental centers, orders that the state can neither ignore nor change.

What **will** work is for you to tell the state, "I need simple supervision services, at home or in community settings, for my family member, or I'm going to have to quit my job and go on welfare so I can watch him." We need as many of you as possible to deliver that message to OPWDD and to your state legislators, as soon as you can.

The Importance of Everyone

by Pat Fratangelo, Linda Webb, Erin Edwards, Kristen Webb, Bud Buckhout

[Editor's Note: This article first appeared in iCircle's Community Connection, the newsletter of the iCircle managed long-term care organization, on whose board STIC's Executive Director sits, for September 11, 2014. It is reprinted by permission. It presents an excellent, detailed picture of what reasonably resourceful and thoughtful people have been able to accomplish right here in upstate New York when it comes to providing truly personalized, entirely integrated, supports to people with developmental disabilities. Onondaga Community Living (OCL) is in Syracuse. They used to operate group homes. They closed all but one, and turned that one over to the people who live there to operate. The article describes "real" person-centered planning—and the time it takes—very well. It can be done, with safety and quality!]

This is a story about a set of people: a fam-

ily who wanted a normal life for a daughter who was labeled with a disability, a service provider that had to listen, understand and allow life to unfold naturally, and community members that had to believe and join in, to make the circle complete.

A circle is just that, it is round. Think of a bicycle wheel. There is a hub, a center point. In this story you will find that to be Kristen. There are spokes all radiating from the hub, all equidistant and all with equal strength. You will find them to be two sets of families, community members, friends, an agency and staff supporters. You will then find the wheel, which holds the spokes intact, which is the dream and value that comes to the life of Kristen that each spoke upholds. The tire on the outside is how it runs against the world and cushions the ride when bumps are hit. Life is never perfect, and even though the ride may get harder and the tire may need to be re-inflated or replaced, as long as the spokes are equidistant and with equal strength and there is new air to replace the lost air, the journey will go on.

An Introduction

Onondaga Community Living (OCL) met Kristen when her family heard of the college service they had. Kristen's family had always felt that Kristen had a lot of potential, but they found it as a big letdown when she entered into the adult service world. Traditional day programs and grouped vocational programs were plentiful, but not at all what Kristen and her family were looking for. Wait lists for any volunteer or work programs were huge.

But, what about this college service? They had an opening. The application and information was on line. It seemed like a normal progression for their daughter. Kristen was accepted into the Access College service at OCL in August of '07. The transition from the high school setting to that of a university can be challenging for any student with a disability, but with the right supports there is success. Kristen was supported with a college mentor who works with her in a 1:1 relationship. The mentor attends class and aids in whatever area Kristen may need support in, from completing assignments to navigating through the campus. She has taken a variety of courses with the help of her mentor. Kristen has chosen now to work with the elderly, so her classes are concentrated with that in mind. Kristen meets with an advisor for the

university who discusses each class and how it best fits in with her eventual goal of employment.

In the beginning Kristen was shy and did not have adequate study skills, but as she became more comfortable with her new life and surroundings, she began to blossom. She began to be more outgoing and entered into class discussions. She began to identify with her new peers and began to enjoy some of the social aspects of going to college. Her family was amazed with the growth they saw in her as she began to expand not only her knowledge but her experiences.

Ready to Move and Nowhere to Go...Or is There?

Kristen continued to live at home with her parents as she got the support she needed to take some classes at the local university. As she became more comfortable in her student role, she began to think about what it would be like to get her own place and not live with mom and dad. But once again, mom and dad's survey of the adult service world was not what they hoped for. Kristen's mom states:

"Other agencies that we spoke to regarding a place for Kristen to live were looking at the group home model. The options discussed were either an established home that had a vacancy, or developing one with other families who were also looking for a place for their daughter(s) to live. Kristen prefers to spend time with a variety of people and we were concerned that she would be limited to spending time only with peers with disabilities and 'staff'. We had heard from other families that staff turnover rates are high, and change is difficult for Kristen. Kristen likes a schedule, but this was also a concern because she can get too dependent on a schedule and become very upset when something happens to change the schedule. We were worried that in a group home Kristen's level of ability would be compromised. She is very high functioning and if she lived with others who needed more support she would not be expected to work to her competence."

The College Coordinator knew that Kristen was looking to have her own place and thought that it might be good for Kristen and her family to begin meeting with people at OCL. A meeting was set up and slowly discussions arose about what Kristen was really looking for. As OCL has no openings or beds

to fill, the organization had the opportunity to tailor what Kristen and her family wanted. There was no hurry to fill a vacancy. There was a slow, yet targeted discussion to get to know Kristen, her wants, personal routines and desires, while also getting to know the family and the role that they currently had or wished to have in her future life. Kristen's mom states:

"Working with OCL was completely different. There were several meetings of discussions about what Kristen (and her family) thought would be the best living situation for her. These Circle Meetings were a process of getting to know Kristen as an individual rather than as 'another person with a disability.' We discussed the things that were important to her and things that made her uncomfortable. For example, she wanted a cat, so we made sure that was a priority in finding an apartment. Kristen, and her sister and I, and sometimes others, met monthly for about a year to discuss and plan for the move."

There was much to know and find out about. She had many interesting things going on in her life with her art, her studies, her community and her family life. There was much to learn about her family and Kristen's role as a daughter, a sister and an aunt. There was much to learn about how to keep her safe while also allowing her to grow.

Planning

At first it seemed logical that living in the university area might make sense as she was really identifying with the student population. She even would have a connection with her sister and her sister's family living in the neighborhood. It would probably be easy to find college housing and support her within it. Kristen at first thought that to be the best plan. But as meetings went on Kristen became more and more quiet, and eventually, thought she did not want to move. As we explored more to find what her hesitations were all about, we found that she really identified with her home community and its comfort and was worried about all she would lose if she moved from there and had a completely fresh start in another neighborhood.

As we abandoned the idea of college housing, we asked Kristen what she then wanted. *"An apartment with a cat, where I can go to see my family, have Sunday dinner with them, continue to work at the YMCA, meet with my art teacher and take my classes."* Kristen

had a life with meaning currently and did not want to lose it. As we figured out the support needs that Kristen had, we folded into the equation all that she had in her life currently, along with what could be done to enable her to grow.

Her parents were worried about security, as they felt that Kristen could be vulnerable. They also wanted good role models available for their daughter. The group met monthly for about a year to discuss and plan for the move. Time was taken to explore her needs and desires. As the support needs and weekly routine were agreed upon, goals were determined:

- Find an apartment that both the family and Kristen were comfortable with.
- Find the right person to live with Kristen that could share her new home and be a companion and support to her.
- Ensure we had the right plans in place.

As Kristen and her family knew the home town neighborhood far better than the agency, it made sense for them to do the apartment hunt. The agency gave them some parameters about rental amounts and did little else. Kristen and her mom then began talking with landlords and rental people in their neighborhood about apartments and visiting them. They eventually found a two-bedroom apartment with good space that they were both satisfied with, that also had security, accepted cats and was within the rental amount. The family passed the lease to the agency for another opinion, everything seemed to fit and Kristen then signed her first lease to her own home. As they began to think about who would live with Kristen, she wanted someone her own age going through similar life changes. So they put an advertisement together:

"Young woman with a disability, going to a local college and moving out of her parents' home for the first time, looks for someone to share her home. Free rent in return for companion and some support. Call xxx-xxxx."

Everyone in Kristen's circle was encouraged to talk with people they knew. An ad was placed in the local newspaper, the Sunday paper and on Craigslist. The majority of people who contacted us were young women going to college, looking to move out of their parents' home. The agency sorted through the applicants and did initial interviews. Af-

ter several interviews, a person was decided on: Erin. Erin stated, "the biggest thing in the ad that grabbed my attention the most is that I would be helping someone and moving in with them. My parents thought I was not responsible enough to move out and I wanted to prove them wrong."

Kristen, Erin and their families went out to a favorite restaurant of Kristen's for their first meeting. Erin and Kristen got along well from the start. Then about a week later, Kristen and her family went over to Erin's home and met with Erin's family. It was about the two families uniting on behalf of their daughters in the strong desire to have each of them have a successful life and home.

Living Life

Once the decision was made that they would live together, each woman, with their families, began gathering what they would each need to live in their new place. They both were so excited to be moving out and sharing a home together. Both sets of parents helped to move their daughters in and threw a wonderful housewarming party that brought family, friends and agency staff together in celebration of their new home and life together.

Kristen's mother states:

"Kristen now lives happily in the apartment with the roommate. She comes for a family dinner every Sunday, sometimes bringing her roommate with her. We continue to be involved in her day-to-day life, but from a distance. We meet to discuss how things are going, help to monitor her finances and help with doctor's appointments. We see tremendous growth in Kristen's independence. She now plans meals, cleans her apartment, shops and does her laundry, sometimes with minimal assistance. She balks when we act too much like parents and don't treat her as an adult."

Kristen and Erin have a great relationship and enjoy poking fun at one another. They enjoy each other's company and are very fond of one another. They do a lot together. Erin often goes with Kristen to Kristen's family gatherings or for Sunday dinner. Erin stated that Kristen's mom is a great cook! Kristen often goes with Erin to Erin's family gatherings and birthday celebrations. Erin says her mom loves Kristen and Kristen also loves her mom. Both women feel that they now have an extended family. They both love living together and say they are learning more and more from each other every day.

Life Goes On

Everyone feels that this situation went beyond what was originally expected. Kristen has fun with her staff and because she enjoys them, is better able to do the work around her home. Her mother says, "When someone other than a parent is the one offering guidance she takes it so much better." She seems to have fun while living up to her responsibilities.

It is a big step for any person to start out on their own, and when it is your child with a disability it can be very scary. Taking plenty of time to discuss all aspects of the dreams and desires of the family as well as the individual can help alleviate the worries. Having a solid circle of people around you working towards the common good makes life's harder times more bearable. And not having the answers before the planning is done is the key. It is not about residential support. It is about helping Kristen to have the life of her choice, given in a way that helps her to mature and grow over time. Kristen is very much the hub of a very solid wheel that keeps turning with relative ease because she has so many equal and strong spokes in her wheel that help to keep moving in the right direction.

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Adaptive Ski Program Begins 40th Year

by Gregg Macey

On Sunday, January 4, Greek Peak Adaptive Snowsports (GPAS) kicks off our 40th. year. As a former student and now a volunteer, I can attest that the program gets better every year. The student population has grown in recent years to about 75 people (of all ages) with disabilities both physical and cognitive. We have a very active Special Olympic component and a fleet of 8 mono and bi-skis for folks that need to sit while skiing. We also have adaptations for non-sighted or partially-sighted individuals. Any new student wishing to participate will need a doctor's signed release form, which is available on the website at www.gpadaptive.org. Also online are lots of adaptive ski videos to give you an idea of how much fun awaits you on the slopes!

Please consider joining us this coming year. We have over 100 very capable and caring volunteers who have gone through rigorous training, making GPAS one of the best adaptive ski programs in the country. We also have invaluable support from Greek Peak Mountain Resort that enables us to offer ski lessons at basically half-price. Visit our website to answer any questions you might have or give me (Gregg Macey) a call at 607-748-0174.

Personally speaking—I wish I had started adaptive skiing years before I finally did. It has not only changed my outlook on winter, but it has changed my life.



Ski **YOU** at the Peak!

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All donations are tax-deductible. Contributions ensure that STIC can continue to promote and support the needs, abilities, and concerns of people with disabilities. Your gift will be appropriately acknowledged. Please make checks payable to Southern Tier Independence Center, Inc.

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