



Agency Transformation



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Each year, the TASH Conference strengthens the disability field by connecting attendees to innovative information and resources, facilitating connections between stakeholders within the disability movement, and helping attendees reignite their passion for an inclusive world. The 2017 TASH Conference will focus on transformation in all aspects of life and throughout the lifespan.

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Letter from our President and Executive Director

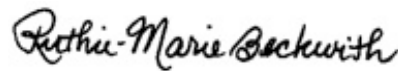
Dear TASH members,

This issue of Connections is devoted to transformation – transformation of programs that support individuals with disabilities from a variety of perspectives. The journeys these programs undertook say a lot about the people who engaged in the work and how they embraced the values that TASH has always sought to promote. Ultimately the transformations resulted in expanded opportunities and enriched lives for the persons these programs supported. Even more so, the outcomes of these efforts demonstrated that the willingness to embrace change, when undertaken with care and attention to true person-centered practices, is a critical component of the work we do.

In 2014, the Centers for Medicare and Medicaid Services (CMS) issued a new rule that all states are required to implement in their programs that are funded by Medicaid. The Home and Community Based Settings Rule is based on the principle that all services and supports funded by CMS should be provided in the most integrated setting. Since then, states across the country have been engaged in the development of state plans that assess all of the settings that serve individuals with disabilities for compliance with this rule. The planning process requires the participation of providers, stakeholders in the system, and the individuals being served. Further, states must also include plans on how settings that are viewed as segregated will be transitioned to those that are community based. More information about this rule can be found at <https://hcbsadvocacy.org/learn-about-the-new-rules/>.

TASH's values and mission to assure that individuals with the most significant needs lead lives where they experience equity, opportunity, and inclusion. So, as systems across the country implement their plans to provide services and supports in the most integrated setting, the stories in this issue of Connections provide important examples of how best to proceed. Finally, the stories shared in this issue also demonstrate the responsibility of transformation must be equally shared. We should all be about the business of transformation--for the people we are committed to serve, for ourselves, for our families, and for our communities as a whole.

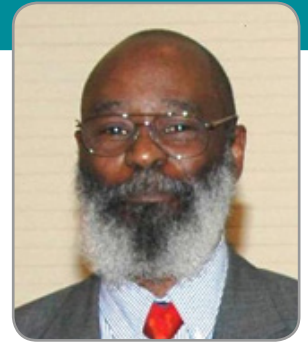
Sincerely,



Ruthie-Marie Beckwith, Ph.D.
Executive Director



Ralph Edwards
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Ralph Edwards,
President



Ruthie-Marie Beckwith,
Ph.D., Executive
Director

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The Role of Agency and Systems Transformation in Supporting “One Person at A Time” Lifestyles and Supports

By Guest Editor Michael Kendrick

Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.

-- Helen Keller

There is agreement internationally that individualized services for people with disabilities is the best way to promote positive outcomes for people with disabilities. Indeed, at this point in time, most of our human service agencies and systems state such person centered aims of full participation in the community quite routinely, yet, in far too many instances, we often seem unable to create systems of agency support that turn such ideals into practical and beneficial outcomes. Undoubtedly, much of this persistent gap between intentions and actual results in people’s lives is due to a largely unacknowledged failure to master what is involved in generating results that make a difference in people’s lives. Fortunately, this observation does not apply to at least some systems and agencies that have transformed themselves such that the people they support are demonstrably having much

more individualized lifestyles and supports. These organizations have created outcomes that clearly better conform to the ideals of a socially inclusive, self-directed life in the community.

This issue of *TASH Connections* presents 7 examples of adult service agencies that are at different stages of transforming themselves based on the ideal that individuals with disabilities have the same opportunities to be a part of their communities as individuals without disabilities. Some of these organizations started their journeys 30 years ago, while others are just beginning this transformational work. Each article provides an example of the work being done “on the ground” and throughout this issue are a range of lessons learned, suggestions for support, and honest conversations around the difficulties of transforming organizations, both on a small and large scale. Some of the organizations, such as the Spectrum Society for Community Living in Vancouver, Canada, started with this vision. Susan Stanfield shares how they work to help people have “authentic choice and control over important life decisions, like where to live and with whom to live”. Other organizations, such as the Arc of Rensselaer County, New York, are still working to change historical and institutional barriers that were in place when they began. Dennis Harkins with Monica Bear and Dan Rossiter share

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how Dane County Centers for Medicare & Medicaid Services in Wisconsin have been operating with the idea of individualized services for 30 years. Their snapshot of supports and programs provide excellent examples of thinking about the whole person.

Each of the articles in this issue focuses on the importance of person-centered planning and the goal of supporting truly inclusive communities where people with disabilities are able to successfully and happily live, work, and play. Helen Brownlie provides a wonderful look at the work of Avalon (BOP) in New Zealand in her aptly sub-titled piece “Don’t look back we are not going that way.” She shares their strategic imperatives for change as well as some of the practical changes they made to make it happen. Gail Fanjoy presents a United States based case study of KFI Agency. She outlines KFI’s core values that guided their organizational change and then shares some practical and useful strategies related to staff and services to support their change process. Ann-Maree Davis writes about Amicus, an Australian based agency, that 6 years ago was largely congregate care and now has 70% of the people supported with individualized options. Her look at self-directed planning and the changes made in this agency to get rid of a “menu of services” and instead focus on the individual is a powerful and hopeful review of what is possible. Brendan Broderick provides another perspective on moving to individualized services in his article on Muiriosa Foundation in Ireland. One of the most freeing themes in this issue is the idea from Broderick that “one does not need a detailed 20/20 vision sense of where one wants to take things before making a start.”

Each of these articles addresses in different ways the programmatic and operational issues significant to bringing reality to bear when creating or changing systems into actual “one person at a time” life opportunities that had not previously existed. This has many implications. The first is that it proves that such ideals are clearly not rhetorical fantasies without any hope of coming into being, since they have in some instances been implemented for decades and continue to be wherever there is sufficient will to do so. These “on the ground” examples stand in stark contrast to the agencies and systems that are not providing person-centered, true community based structures. The spectrum of examples presented in this issue should be a wake-up call to agencies and systems about the possibility of creating and changing systems to provide opportunities for people with disabilities to realize their true potentials.

The types of examples presented in this publication offer the hope that if others take what they have learned and subsequently

implement their lessons, many other agencies and systems could meaningfully improve their performance and therefore benefit people with disabilities to a significant and possibly comparatively revolutionary degree. There is a saying from the psychologist William James that if you can find one white crow it proves that all crows are not black, since it invalidates the claims that crows can only be black. In many ways, the stories contained in this publication are examples of “white crows” since they prove that people with disabilities can obtain much richer and individualized lives in the community provided that they are supported in enlightened and proficient ways. The organizations spotlighted in this issue come from different countries, have different scope and foci of their work, and are embedded within different structural contexts, yet together they illustrate some key themes that serve as an important “white crow” for other organizations.

The first theme is that all of these organizations share a focus on values of people with disabilities as people first, who, like everyone, will have different preferences, needs, and goals in life. A caveat of importance is that none of the agencies and systems involved claimed that individualization per se was somehow transcendently superior or without its own flaws, challenges and limitations. In fact, what they have all discovered and said in their own way is that “life building” is not simply a matter of switching to individualized ways of operating. One still has to optimize the life potentials of people and this task has many inherent difficulties embedded in it (e.g., structural issues of the organizations and their contexts, meeting individual needs). Nonetheless, they are strikingly clear in their agreement that it is decidedly possible and desirable to persevere to support individualized support and many beneficial transformations are well within reach if pursued with vigilance.

A second central theme in this issue is one of systems change from a structural stand point. As mentioned above, structures such as staffing and funding are vital components of implementing individualized operations. For instance, all of the agencies and systems cited here significantly reduced group service models and replaced them with sizable and gradually increasing numbers of “one person at a time” arrangements. This change has significant implications for funding and paying staff, but also for hiring, training, and organizing staff. Davis shares the powerful example of a client who had 2 full-time staff during waking hours and an active staff member overnight. Using the service approach at Amicus, she has been introduced to more community experiences and increased her independence until she is now receiving only 5 hours of support each day. Without the individualized approach

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it is easy to envision a life of dependency for this individual. This focus on the individualized approach ultimately decreases staffing costs, which while not the goal of the work is an important effect to note.

Another aspect of staffing is discussed by Fanjoy who articulates the need to rethink how and why staff was hired to prioritize values rather than experience. Experience can be taught and supported but starting with common values moves the work forward. Harkins with Bear and Rossiter, identify some really powerful support staff that are often missing in other agencies, yet have proven to be instrumental in supporting individuals in the independence and interdependence they dream of achieving. For instance, Dane County employs a 24 hour crisis response system with staff trained in behavior intervention and they have available legal advocacy that, among other things, works to support victims and bridge criminal justice and human service systems when needed. Additionally, several of the authors discuss training staff and providing them with permission to think differently about their clients and how to implement services. This type of change in thinking helps to eradicate “community tourism” and instead help people with disabilities access and experience the community alongside their peers without disabilities.

Taken together, these articles illustrate that values or structural changes alone are insufficient to achieving a goal of people enjoying a fully inclusive and self-determined life. Yet, these clearly demonstrate that values and constructions of disability must work together with structural changes to achieve this goal. Peoples’ lives do not change for the better until the agencies set and pursue “better” as their aim. While the different organizations here may have had different impetuses for breaking away from “life wasting” structures to a more individualized set of goals and supports, each author recognizes that regardless of the initial impetus for wanting to create inclusive communities, structural and leadership changes are vital to making this change. As Liuzzo puts it, “life wasting is a stubborn and pervasive enemy” that requires good leadership to break that mold. As the stories reveal, many of the people they served could not achieve “better” until real opportunities were created, ones that had not existed up to that point, that made this more likely.

Like the “white crow,” these cases prove that meaningful agency and systems transformations can and do occur. Though it is not directly addressed in the accounts provided, it needs to be pointed out that these examples are just that, a small sample of what has both been accomplished more broadly in many countries and

over many decades and has continued into the present. In other words, it indicates that we are not properly capturing the breadth and depth of what has already been demonstrated to be feasible in transforming systems in ways that are more person centered. If we were to do a better job of letting people know what has already been achieved and why, we could most certainly begin to accelerate to the unfolding and sustaining of yet more examples of beneficial individual, agency and systems transformations.

In fact, a case can be made that we are morally bound to share our stories, since nothing would be gained by such accomplishments being kept hidden and much would be lost by way of vision, practice, and evidence of what is truly possible in the lives of people with disabilities and the lives of others in the community who cross their paths. So, we can certainly draw heart and insight from these accounts because they emphasize the importance of the contributions of people who believe you can create opportunities where they are not currently present, change lives in beneficial ways, and develop the state of the art in terms of what agencies, systems, and communities can do when they are energized by a life giving vision of what can be accomplished when we make up our mind to make a difference.

*Your beliefs become your thoughts,
Your thoughts become your words,
Your words become your actions,
Your actions become your habits,
Your habits become your values,
Your values become your destiny.*
— Mahatma Gandhi

About the Author

Michael Kendrick is currently an independent international consultant in human services and community work. He focuses on leadership, service quality, the creation of safeguards for vulnerable persons, social integration, change, innovation, values, advocacy, the role of individual persons and small groups in creating advances, evaluation, alternatives to bureaucracy, personalized approaches to supporting people, and reform in the human service field.



The Transformation of Amicus: Our Story

by Ann-Maree Davis, Chief Executive Officer, Amicus

Amicus is a not for profit organisation based in the city of Bendigo in central Victoria, Australia. We have made some significant inroads in our agency's transformation as a provider of traditional day services for adults with a disability. Six years ago it was largely a facility based congregate care model, today it is moving to a fully community based model with 70% of the people supported now receiving fully individualised options.

When we started our transformation we noted that there were few documented examples of the journey of similar organisations transitioning. The available examples largely focussed on one person at a time organisational change, often driven by the person with a disability's and/or their family's dissatisfaction of the traditional model of support. Our organisational transformation has to a large extent been agency driven and we are keen to share our story with others who may be interested in undertaking similar work.

Evidence shows that design and delivery of support for people with a disability on a "one person at a time" basis is by far the most effective approach to ensure that people live a good life, through pursuing normative pathways, active participation in their community and valued social roles. But for organisations like Amicus, that used to support many people in facility based congregate care arrangements, it takes a very long time to transform the agency to a "one person at a time" approach.

Although Amicus was very keen to work one person at a time, as an organisation we felt that we needed to compliment this work with a reorientation of our existing service approach. We wanted to make sure that our approach facilitated empowerment, choice and the active and meaningful participation of the people with a disability who chose our support, in the community.

When I became CEO in mid-2008, Amicus looked like most other Day Services in that we operated Monday to Friday, 9am to

3pm, with six weeks of leave each year and most of our support occurred in a facility base. We had a menu of activities that people choose from each year that were really based on filling peoples' days and allowing them to socialise with other people with a disability. Even the limited community supports involved people starting at the facility in the morning and travelling back for a long lunch then back into the community prior to travelling back for a 3pm pick up to go home.

Our supports were predominantly congregate with people often supported in groups of between five and seven adults with up to two staff, dependent on the needs of individual. We did have a small number of people who were considered difficult to serve because they "didn't fit the traditional model," who had funding for individualised support. This individualised funding was an attempt from our funder to try and "integrate" them back into the segregated group based service.

The people with a disability we supported and their families were largely content with the service model that they were being provided, and held no strong expectations or aspirations for Amicus to support them to achieve a fuller life with greater community inclusion.

At the beginning of 2010, a major reform occurred in the Day Service sector in the state of Victoria, which saw the transition of all block funded day services placements to Individual Support Packages. At the time, there was some significant government investment initiatives in encouraging organisations to be more creative in the services they were delivering and support the empowerment and inclusion of the people they served. While these initiatives did create some changes for the sector, these were isolated and voluntary in nature and, in reality, many people with a disability continued to use their individualized funding to purchase essentially the same services they already received.

So while the reforms did provide some extra impetus for change, they were not a strong external driver and individualised funding at that time did not have a big impact on peoples' purchasing decisions within Amicus. While we had already started some very early work on empowerment and greater community inclusion, we were working with largely content participants, families and staff.

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After attending a 10 day event focused on systems change with Dr Michael Kendrick, I was no longer content to see what could only be described as wasted opportunities and lives, and this was really the beginning of the change in our organisation's leadership approach. So we adopted strong leadership, with a vision and values that underpinned the self-direction and community inclusion of the people that Amicus served. This was absolutely essential from the very beginning to educate and lead our participants, families, staff and community and create a different picture of what could be possible beyond the traditional disability service offering.

Based on what I had gained through my time with Michael, I really wanted us to work with people "one person at a time" but it was really quite difficult for us to get "buy in" initially because people didn't see the need, weren't aware or informed of different approaches or even feared an exclusively community based response. So we started small in our conversations, focussing on people who were already receiving one to one support, and instead of trying to integrate them back into a model that did not meet their needs, we developed a personalised response with a greater focus on community inclusion. Concurrently, there were some key strategies or decisions that the organisation made that also started to create very small incremental changes in our facility and group based supports.

In the early days of our transformation we focussed on trying to develop the capacities that we felt we would need to have in place to get people better lives. We worked on self-advocacy and empowerment of the people who chose our support and their families. We planned better, which is much easier with no menu of services for people to choose from, and we had real unscripted conversations about the person and their passions, what was most important and what a good life would look like.

We promoted self-directed planning so wherever possible the person and their family would take the lead and we trained our staff in providing person directed support. We provided lots of information about the different ways that people can use their individualised funding to "mobilise" their supports, including a range of resources in Easy English, and delivered training sessions to develop peoples' understanding and capacity. This meant that people had the tools to understand how much funding they received and how much an hour of service cost in a group and as individualised support.

We moved away from facility-based responses, and had a much

stronger focus on real community participation. This included meeting staff in the community and not at the centre base and starting and ending support at community venues or events. This led to a significant reduction in incidents as we were able to totally avoiding the whole large facility based chaos and time spent waiting at the beginning, middle and end of the day. We also refused to develop 'special programs' and replicate what could be found in the community. For example, I was asked for approval to purchase some power tools to have a woodwork program, but instead we supported people to become involved in the local Men's Sheds. Men's Sheds are a community based organisation offering a place for men (and women) of all ages and abilities to come together over a shared interest in woodwork.

We reduced the sizes of our groups from two staff to between five and seven participants to a one-staff-to-three-or-four-participant ratio (dependent on needs). Given that people were meeting in the community the need for transport was significantly reduced, but as we were still operating from an office base that was located a distance from our central business district we did purchase some small sedans initially. But this had the added benefit of restricting the size of the group to how many could fit in the car!

We were also then able to sell our vans and buses! No more "bus therapy" or "community tourism" and this also had an immediate impact on the damaging imagery that supports a continued community perception that people with a disability need to be together and receive specialist and segregated support. It is important to note that these decisions did not cost us anymore money, we were still using the same level of staffing but just allocating the existing resource differently and the running costs of vehicles was comparable.

One of the other benefits of this change is that staff were more engaged with the people they were supporting (because they didn't have other staff to talk too) and community members were also more receptive to initiating conversations. Staff matching was also important and we spent much more time getting a match based on similar interests and participant choice.

Congregate care or group support is the service model (and facility based the environment) where people are most vulnerable in not getting their normative needs met and it is never optimal; there were always compromises that were ultimately harmful for people with disabilities. While there is a tension between improving group supports and getting people to make the leap to "one person at a time", when people who purchase group support

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make choices to use their funding differently, it often means that other people in the group also experience change. So when a choice is made to individualise some or all of their support this means that the group support they were purchasing is no longer viable and triggers a review for other people in that group. This incidental benefit has had a big impact on the pace of our change.

By 2012, we started to get some traction with our transformation efforts so we supported that with a large investment in training for participants, families, staff and our Committee of Management. We spent time with Michael Kendrick and many other wonderful leaders from around the globe. As people started to have positive and active participation in their community building, the capacity to generate socially inclusive community life opportunities noticeably strengthened. We also made a key investment in building capacity through family leadership and were successful in obtaining funding for a series of workshops directly targeted at family members to support them to develop a vision of a good life and facilitate change with their family member.

We focussed on pursuing valued community roles like employment and volunteering in the things that people were passionate about, as opposed to just turning an interest or a like into a group based segregated “activity”. Some examples of this have included supporting a young woman to gain full wage employment with a local supermarket using her excellent organisational skills and friendly customer service, as opposed to enrolling in a segregated work education program.

Another example is a school leaver who has had work experience as an artist with a leading local furniture and home décor company, who will now be considering employment and career prospects instead of arts based program in a day service, or even the young man who was supported to discover that real work in the hospitality sector is not quite as glamorous as Master Chef, but at least he has not wasted years of his life in segregated hospitality training to find this out. We also improved our supports occurring in the community – we wanted to make sure that people were meaningfully participating and not just present.

In mid-2012, we stopped offering facility-based support to any new participants. This meant that if someone wanted to purchase our services they were aware that we were only providing community based support. So while we did have some people that did not choose our services, there were many more people interested in what we were doing because of our community focus and we had people who ceased supports with other agencies to

purchase Amicus’ support.

We offered greater flexibility so support could be delivered at a time that is convenient to the participant and to take advantage of community events and opportunities in “real time”. From the beginning of 2013, the option of 52 weeks 24/7 of service scheduling flexibility was possible for all people who choose our support. In other words, we had finally stopped being a “day program.” We did not receive any additional funding to do this but our participants made decisions on how they used their funding, armed with the knowledge of how their funding worked and based on what was important to them. Examples include choosing individualised support to attend community groups like the local choir or community events like music festivals ... no more Disability Disco at 4pm on a Tuesday!

In January 2014, we moved from our facility base that was quite isolated from our community to a commercial rental property in the central business district. Given the progress we had made in our transformation, our former facility based site was no longer in use as anything other than administrative support and the location started to create some logistical challenges for us given that almost all of our support was now exclusively community based.

In mid-2015, the Board of Management endorsed my recommendation not to offer new group support opportunities and only work one person at a time with new people requesting our support. Given all of the progress we had made in our transformation and the many personal successes and achievements gained through our work as well as our organisational vision, mission and values, this decision was logical and easy to effect. It should be noted that we have continued to experience strong growth despite this change.

Some of the upcoming stages of our transformation relate to our size and shape as we start to ask ourselves the question, at what size does our organisation stop being effective in supporting good lives because size gets in the way of relationships and decision making? We currently have a working group that is exploring different organisational models (other than the traditional hierarchical structure) that will further support our work.

Amicus currently supports 163 people with a disability, of all ages. Of these, 113 people are choosing exclusively individualised supports. This figure represents 70% of people with a disability choosing support from Amicus. We then have a further 23 people who are choosing a mix of group and individualised support,

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so this brings the total number of people making a choice to purchase individualised support up to 84%. The remaining 26 people (16%) are at this point in time choosing group supports exclusively, but are fully aware of the opportunity for them to individualise some or all of their current supports at any time.

It is interesting to note the progression of our transformation in terms of percentages of people we support choosing some form of individualised support. In 2013, this was at 30%, in 2014 this was at 40% and by 2015 this was at 58% of the people we supported. If we link the increase in people choosing individualised supports since 2013, to the coinciding key organisational strategies, the cessation of facility based supports in 2014 and decision not to offer new group based supports in 2015 have had the most powerful transformational impacts. While these strategies can't be viewed in isolation of the inter-related efforts that have underpinned these successes, the rapid uptake certainly provides food for thought!

It would not be accurate to portray all 70% of the people we support who are choosing exclusively individualised supports as living their best lives just yet, as they too are on a transformation journey. What we are witnessing is the progressive development and enrichment of people's lives as they choose normative pathways and social valued roles. In a service system where poverty of vision is chronic it is no wonder that it can take people time to envision their good life!

In thinking about our early successes working one person at a time, most of the people who we worked with initially would have been considered difficult to serve and did not fit 'traditional' service responses. Many of these people had little or no family involvement, and for them the impact of the changed approach has been significant.

One young woman used to have 2 staff to support her during waking hours with an active staff member overnight prior to receiving support from Amicus. We quickly established that this level of support was the biggest problem and she was trying to communicate this but no-one was listening! Using our service approach we introduced her to regular opportunities in her community based on her passions and interests and over an 18 month period she has been able to increase her independence to the point where she no longer requires sleepover support and receives only 5 hours of support each day to live and thrive in her own home and community. These are stories that inspire others to take a chance too, which has been an equally important strategy in our transformation!

I have learnt a great deal through our transformation journey, change is not a linear process and usually does not track with your carefully prepared change management strategy! I learnt the importance of establishing strong relationships and building the capacity of all stakeholders. I learnt that not everyone is ready to be a trailblazer. I learnt that sometimes it can be tough to stay true to your vision in the face of resistance, but that you must persevere for the end results are worth it.

The progress of our agency transformation from delivering almost exclusively facility based congregate care to the majority of people we support choosing individualised lifestyles has been quite dramatic over the past few years. From our agency's experience, complementing our desire to work one person at a time with an agency transformation agenda that has promoted the empowerment and inclusion of the people who choose our support, has contributed to the pace of our transition.

Our agency's decision to no longer offer facility or group based responses means that we are not growing the problem, and can just focus on working one person at a time with new people we support, while we continue to work progressively with our existing participants and their families to strengthen their vision for a good life.

About the Author

Ann-Maree Davis has been CEO of Amicus in Bendigo, Central Victoria, Australia for the past eight years. Amicus a not-for-profit organisation supporting people with a disability of all ages to live a good and valued life. Ann-Maree has over 25 years of experience in the disability sector, having worked for both not-for-profit agencies and government, in a range of direct support, leadership and executive roles.



Ann-Maree has been involved in the individualisation of funded supports in Victoria through these various roles since 2000 and is passionate in her work to lead change that will facilitate a good, meaningful and inclusive life for people with a disability. Over the past five years she has lead a significant reorientation of the services that Amicus provides to transition from a facility based day service model to a flexible community based model of support.

Muiriosa Foundation: Our Journey with Person-Centred Options

by Brendan Broderick, CEO, Muiriosa Foundation

We are the Muiriosa Foundation, located in the Midlands region of Ireland. Muiriosa Foundation's historic roots lie in medical model congregate care provision for people with an intellectual disability, with a particular and growing emphasis on those requiring high and intensive levels of support. An initial congregate care base was developed in the late 1940s. A satellite residential service for children was developed in the late 1950s.

Two parallel, occasionally intersecting, initiatives have been promoted over the past eight years:

- ◆ A de-congregation initiative to support individuals to move from congregate care settings (living units of 10 or more) to more personalised arrangements in community settings. Since 2008, 91 individuals have been supported to move from congregate care settings to community settings (by reconfiguring the existing resource base). This group have been moved to a combination of single-person, two-person, three-person and four-person arrangements – 15 of the 91 have moved to single-person arrangements.
- ◆ A more radically personalised initiative led out by a standalone innovation division, the Person-Centred Wing, to establish a bridgehead exemplifying self-direction, inclusive relationships and the leveraging power of socially valued roles.

The shared value proposition in both initiatives is to:

- ◆ Reduce personal stress levels – it is apparent that people living in congregate settings live in quite an adrenalised state much of the time, their level of unease and anxiety geared to the most distressed and distressing person with whom they share a living space;
- ◆ Facilitate the emergence of the person, revealing their distinctive, “one-off” uniqueness;

- ◆ Design more tailored personalised support arrangements;
- ◆ Nurture and involve more inclusive relationships;
- ◆ Activate the leveraging power of socially valued roles.

The emphasis on inclusive relationship and social roles is in general more consciously and more effectively promoted in the Person-Centred Wing rather than in the more conventional de-congregation initiative.

The focus in this paper is on the Person-Centred Wing. This programme currently supports 45 individuals working exclusively within an individualised-supports model. Twenty-two of this 45 are supported in self-directed residential arrangements – 15 of these on a 24/7 basis.

Individuals are supported by a combination of salaried individuals recruited by the organisation and informal family and community input. Salaried staff consist of six coordinators and a pool of 70 personal assistants / direct support workers. The coordinator is responsible for the “discovery” phase of engaging with the individual, his / her advocates, family members and associated networks from which emerges in-depth knowledge of the individual and an initial sense of direction and possibility as to what a better life might look like. The “discovery” phase also informs the process of recruiting personal assistants / direct support workers, whose roles has been largely modeled on that developed within the Centre for Independent Living movement where the individual with the disability assumes the role of leader with the personal assistant taking his / her lead from the emergent will and preference of the individual). Given the compromised verbal abilities of many of those supported by the Person-Centred Wing, “discovery” is often a slow and highly iterative process. Matching personal assistants to the individual is a major preoccupation during this initial phase. Compatibility of interest and temperament is paramount. There is no general competency or personality framework to fall back on. The candidate with the capacity to provide effective and sensitive support to Individual A may be ill-suited to support Individual

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B. Candidates with strong social networks and an openness to support the individual to access these social networks as an initial step in widening and deepening inclusive networks are prioritised.

Other than where individuals explicitly convey that they do not want family members inputting into vision development, planning and designing support, families are highly involved. There is a conscious focus on ensuring that family members' contribution is aligned with typical family roles. Family members are generally not drawn into providing direct personal support – that said, one of the individuals who is supported on a 24/7 basis is supported each Sunday by members of her (luckily, large) network of siblings, as available funding can be only stretched to cover six days of the week; her family was happy to support in this exceptional manner, as they recognized the value to their sister of this highly individualised way of working in contrast to more conventional group arrangements.

At the outset we had a strong implicit sense of the direction in which we wished to take the organisation. However, we did not explicitly link motivation and strategy to “closing group provision”.

Rather the focus was on:

- ◆ The competence to make individualised, self-directed, inclusive supports an option for whoever wanted it;
- ◆ Designing and embedding individualised arrangements for those who were manifestly unable to survive within traditional group arrangements;
- ◆ Amplifying consumer demand for individualised arrangements by demonstrating compelling local, live examples.

Two distinct groups are identifiable within the Person-Centred Wing:

- ◆ Individuals and families who consciously articulate that they wish to direct and control their own lives and who wish to give a wide berth to group-based arrangements and “serviceland”;
- ◆ Individuals who have been manifestly failed (sometimes traumatised) by conventional services, including enhanced, reinforced versions of conventional services, and for whom the stakes are very high at the level of personal stress, distress, and trauma. The stakes are very high for both groups in relation to the valued outcomes of directing one's own life, and accessing meaningful roles and inclusive relationships. A significant number of this group are people with minimal if any

conventional language and with complex and intensive support requirements.

Seven years into this initiative there is a growing confidence about knowing what needs to be done, in the sense of knowing how to go about developing a deeper sense of the individual and figuring out better arrangements. Readymade solutions are and probably always will remain elusive.

Prior to 2009, we made a number of false starts. A repeated mistake was asking people to carry routine responsibilities within traditional services alongside more innovative work. Generally this involved linking a service consumer with an internal “champion” drawn from the staff pool and allocating 2-3 hours per week or fortnight for “discovery” work. In general this translated into staff seeking to hot-house new insights into and about the person through spending individualised time via occasional sorties into community settings, typically while nuancing some familiar activity, for example, visiting different retail outlets, sampling different kinds of food in restaurants. Staff seemed to spontaneously internalise a pressure that they should be getting somewhere fairly quickly and having something to show for each discovery session. Enthusiasm for these “transformational projects” ebbed. Shuttling between conventional systems-centred work and more radical person-centred engagement left everybody frustrated and demoralized. The upbeat lift associated with the sentiment that we were going to have a serious tilt at doing something very different ran out of steam, leaving a residue of pessimism and helplessness about ever breaking free from the closed-circuit loop of superficially plausible activity. Reviews of how we were doing defaulted to diagnosing intractable difficulties with “the system.” We began to appreciate that if this different way of working was to have even a sporting chance of taking off that we needed to set it up in a very different way, in a way that

- a. Generated a sense of imperative, that this wasn't an optional upside that would be advantageous but rather a breakthrough that had to happen;
- b. Anchored the work in a driving preoccupation, relentlessly pursued, which in turn reinforced momentum and resolve.

It was only when we began to recognise that people needed to be free to pursue a single-minded focus on this work that things began to happen. We set up an innovation ‘wing’ outside the structures of the traditional organisation with clear blue water separating it from mothership services. Midwifing this elevated vision (self-direction, individualised supports, inclusive

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relationships, exploiting the leveraging power of social roles) was the sole and exclusive focus. We staked out the terrain very explicitly by disseminating what expectations would-be consumers could reasonably hold us to. We also detailed the jeopardies to faithful implementation, spelling out what responses on our part would not be consistent with this orientation, for example, “falling back on traditional centre-based and group-based arrangements as initial ‘holding’ measures” or “establishing an initial bridgehead of planning and support arrangements but failing to progressively extend and deepen this initial base.” A critical feature of the work was finding the courage to abandon familiar moorings—of settings, activities, group-based activity—while holding our nerve by staying with whatever unfolded or seemed to be unfolding, including holding our nerve when nothing very much seemed to be unfolding, by way of directional leads as to what a better future might look like. A key challenge during this phase of the work was not to yield to the urge to resolve exposure to uncertainty and tension by foreclosing on premature lines of action, opting again for the comfort and cover of superficially plausible activity. There was a significant investment in mentoring and support of those involved in discovery. What also proved helpful was the decision not to set milestone targets. Rather the focus was on the depth and authenticity of the discovery process, which is predominantly grounded in action probes and mining the associated learning. This requires managers who, while ultimately action-orientated, have a high tolerance for certainty and ambiguity. Managers with strong command-and-control instincts are poorly equipped to nurture this kind of work.

Value Base

The values which have guided and sustained this work are the typical values of citizenship; autonomy / self-direction; belief in the uniqueness of the individual – and the capacity of each to contribute; inclusion; the primacy of relationships in underpinning *the good life*; the enriching, protective, and leveraging power of socially valued roles. While we have taken care to ensure that we attract people open to this value base and invest significantly in inculcating these values, we have learned that it is better not to sell the vision of *the good life* by adopting an evangelical tone. Curbing our instincts to moralise and blame conventional approaches was an important discipline to acquire as indulging these reflexes often triggered non-productive encounters with families and staff who felt their lifelong contribution was

being invalidated and dismissed. A gentle-but-sustained focus on *what might help make for a better life?* achieves the necessary effect without activating high emotion, protest, and resistance.

Costs

Funders and commissioners display a high level of interest in cost profiles and trajectories associated with the Person-Centred Wing (often conveying a more immediate and robust curiosity about the cost base than about the value which this way of working adds to the lives of individuals, and wider considerations of cost effectiveness). In our experience costs associated with more conventional group-based arrangements tend to be stable, in the medium-term, trending upwards, almost never downwards, over time. The cost profile associated with the Person-Centred Wing is more dynamic. A profile of costs spiking during early-installation phase followed by phases of declining cost is frequently seen in the Person-Centred Wing. Declining cost is sometimes associated with the individual acquiring new competencies and confidence. It can also be associated with the emergence of strong informal networks who ‘keep an eye out’ and are available to ‘lend a hand’ from time to time. More generally declining costs result from a less over-protective orientation to risk management and a diminishing tolerance for squandering resource on our part.

Where 24/7 support is required the costs will generally exceed group provision costs, though often the differential is marginal – high costs in group contexts tend to be driven by the need to buffer highly incompatible residents from one another, confining and containing fallout, resulting in expensive life-wasting stalemate. The major efficiency advantage in this model flows from the recognition that very many people who are supported in 24/7 group-provision arrangements neither want, require – nor flourish in – such blanket surveillance-supervision-‘support’ and can be effectively and safely supported through more carefully deployed, cost-effective allocation of resource. Our experience thus far suggests that the enhanced costs of 24/7 arrangements is more than counterbalanced by the savings flowing from over-supported individuals in group provision. Indeed, we hypothesize that the more the referral base for this model aligns with the general characteristics of the typical disability-sector population, the more the assumption about counterbalancing savings being available is likely to hold up.

While supportive of individualised funding, there is an irony in reporting that in our work to date we have not focussed much

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energy on “unbundling resources,” that is, re-configuring group-indexed resources to disaggregated individual resource packages. Rather the focus has been on identifying zones of inefficiency across all fronts of activity to create financial savings that could be migrated to where they are needed to support strategic objectives. In acknowledging this we are not suggesting that this is an optimum or generally applicable strategy – its range of applicability may not extend beyond initiating changes on the margins of a relatively large traditional service. Only 15-20% of our arrangements are individualised ones. Thus far we have taken advantage of the risk-buffering capacity inherent within pooled resources. The resource-consumption profile of arrangements has often been dynamic and volatile, especially during the early stages. Working within the constraints of a fixed level of individualised funding would have introduced additional challenges and might have impeded the pace of movement by introducing more difficult calls in relation to risk appetite. Developing cooperative structures to pool individualised funding packages might be a useful strategy for counterbalancing risk when scaling wider organisational changes.

Lessons Learned

Reviewing our progress and impasses over the past seven years, the main lessons learned are:

- ◆ It is not necessary to ‘fix’ people to support them to get a better life;
- ◆ One does not need a detailed 20/20 vision sense of where one wants to take things before making a start;

- ◆ All plans should be viewed as provisional, working hypotheses that are likely to require significant adaptation. More important than any plan is the sense of urgency and resolve about the imperative to support the person access a better life;
- ◆ Not having a background in disability can be very freeing for those directly supporting the person (paid and unpaid). They are much more likely to be able to see the wood for the trees than people who have been moulded and grooved in the assumptions and working practices of conventional services;
- ◆ Work with the person on the current chapter in their lives in his/her life. Be careful about over-investing in future-proofing every support arrangement. When designing support plans for people with disabilities we tend to get hooked into trying to eliminate uncertainty. The prioritising of certainty over uncertainty, and the trade-offs that flow from this, will severely short change the individual, just as it would short-change each of us in our own lives.

About the Author

Brendan Broderick has been CEO of Muiriosa Foundation since September 2002. Prior to taking on this role he had worked as a clinical psychologist in the Irish midlands for over twenty years in the areas of intellectual disability, residential child-care, and mental health. The work reported on in this paper owes much to the subversive inquiry, mentoring, and network introductions of Michael Kendrick.



Our Transformation as an Organization

by Christopher Liuzzo, Associate Executive Director (Ret.), the Arc of Rensselaer County, New York

The Arc of Rensselaer County in New York State is anything but a “transformed” agency. It still has a goodly contingent of legacy services, including group homes and congregate day programs. It has, however, been on a long, slow journey of movement away from those services, toward more individualized and self-directed supports. During my 18-year tenure there, my colleagues and I were able to downsize almost all our group homes and we were able to close four of them, including one for ten persons and two that housed eight persons each. We almost always (emphasis on “almost”) were able to do so with no new resources and were occasionally able to support more persons with the same dollars available to us before the downsizings and closures. And, it is important to note that we did not “close” a group home by creating smaller ones. For the most part, when people left congregate settings, they moved into their own apartments or a setting shared with one other person. Frequently, the new support structures included some form of life-sharing with non-disabled persons. In all, more than 40 persons were able to depart group living situations and move into more personalized supports.

On the one hand, these are not exceptional outcomes, especially considering 18 years of effort. On the other, it is important to consider the New York State context. Virtually no other New York state provider of which I am aware achieved anything even approximating these outcomes. In fact, many New York

state providers not only did not achieve such outcomes but continued (and still continue) to develop new congregate living arrangements.

In this article, I will describe the values and beliefs underlying our efforts at agency transformation. I will also identify some of the key strategies and tactics we employed.

Most of the leadership of the Arc entered the I/DD field in the early to mid-1970’s, right at the time of the Willowbrook Consent Decree. This was a court supervised agreement between the state government and external advocates to close a large residential institution. Like so many other young people, we were imbued with a sense of social justice. Our mission was to free people from the confines of the institution. The group home seemed to us at the time, a wonderful social innovation and we devoted our efforts, over many years to develop more and more of them. But, as we matured, we came to understand that we had not achieved anything close to the justice we sought. As Otto Scharmer (2009) puts it in his *Theory U*, we “opened our minds” to see that, year after year, we piled up meaningless service plans, ineffective behavior plans, and were contributing to what Wolf Wolfensberger (1972) called life-wasting. Most people we supported had few (in fact, often no) meaningful relationships, saw their staff come and go by the dozens, had no control over who they lived with, no say about who provided supports, and, with honest scrutiny, were not treated as individuals. A so-called Individualized Service Plan for Person A was, and often remains pretty much the same as for Person B (if you don’t believe this, simply examine the “valued outcomes” across Individualized Service Plans. They are remarkably similar).

Our work was not supposed to be about Habilitation Plans, clinical reports and the other trappings of service systems. It was and is about social justice and we were failing. Yes, we had freed people from the institutions, but we saw we had to redefine what we meant by justice. It had to include sincere efforts to stop the life-wasting. We had to confront the truth that we were not engaged in deep listening to the people we supported and that we had to learn to do this. We needed to stop creating standardized models of service and learn to co-create individualized support designs with people and their families. We needed to reconstruct

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our relationships with people and learn to ethically partner with them, to engage in what Michael Kendrick calls “Right Relationship.” As Kendrick puts it, this means a relationship that is not “at,” “over,” “to,” or “on” another person. Rather, Right Relationship is being “with” another person, identifying with that person, experiencing the world as that person experiences it and co-designing a unique support structure with that person.

And, crucially, we had to own that this work was ours to do. It would not be incentivized by the state (on the contrary). We could not look outward for leadership. And, we could not insist on new resources, the sad “show me the money” bromide so often employed as an excuse to avoid doing the right thing. In short, we had to work on ourselves. In Wolfensberger’s words, we needed to stop being “do-gooders.” We had to learn to be “gooder-doers.” In addition to opening our minds, we had to, as Scharmer puts it, open our hearts. Absent open minds and open hearts, Right Relationships are not possible.

Because we could not expect new money, we adopted the strategy of *reshaping* our existing resources. We were already flush with them! They simply needed to be reinvested away from the standardized settings in which they were bound up and moved to individualized bundles of resources wrapped around one person at a time, with the ability to be reshaped as a person’s needs and wants changed. They had to be like the Gumby toy...able to flex and move with the person.

We understood that reinvestment of existing resources would require enormous effort and so had to accept that organizational growth, as typically understood, would be nominal, if at all. Reinvesting existing resources and growing the organization are almost mutually exclusive activities. The focus of growth had to be on us...as leaders, as persons...rather than the organization. Again from Scharmer, we had to “open our wills”, to allow new service designs to emerge from skillful and empathic deep listening. It was our job, as John O’Brien (2011) wrote, to “make hope palpable” for persons who, sometimes desperately, wanted to change both the nature of their lives and their supports.

Eschewing growth had a corollary: slowly getting out of the property business. Long before the current focus on separating property control from service delivery, we had adopted the practice of no longer acquiring property. Two of the group homes we closed were sold (one became a lovely B and B) and the proceeds reinvested into new support designs. We believed that property ownership (and therefore, maintenance) was a

distraction from our real work and necessitated a diversion of resources that could otherwise go to people into roofs and furnaces.

I am often asked “how” we were able to accomplish what we did. In the course of our work, the last question we asked ourselves was “how are we going to close this group home”? In the beginning, the “how of it” was the least important question. As Peter Block (2003) put it:

If we were really committed to the pursuit of what matters, we might be well served to hold a moratorium on the question, ‘How?’ ... It would force us to engage in conversations about why we do what we do. ... It would create the space for longer discussions about purpose, about what is worth doing. It would refocus our attention on deciding what is the right question, rather than what is the right answer (pp. 2-3)

Most organizations are full of very smart people solving very complex problems every day, yet seem stymied by the prospect of reinvesting resources from congregate to individualized supports. Perhaps that is because they focus prematurely on “how” to do it and have not internalized the “why of it.” As Beth Mount and John O’Brien (2015) put it in *Pathfinders*, they are incredibly busy working “in” their organizations rather than “on” them. Agency transformation requires a heavy dose of the latter.

Which brings us to *practice*. We all have an intuitive sense of what that word means. It is “the repeated exercise in or performance of an activity or skill so as to acquire or maintain proficiency in it.” How can one develop the skills of deep and empathic listening, of co-creation, of reinvestment, if those skills are not practiced with rigor each and every day? “Working on” an organization requires honing a skill set quite different than that required for “working in” an organization. Honing a skill set requires disciplined, intentional practice. Not once in a while, for a “special project,” not only to cope with some emergency. Every day.

In *Outliers*, Malcolm Gladwell (2008) discusses practice and the 10,000-hour rule: that to truly become a master of any skill, expertise science tells us that one must devote at least 10,000 hours of practice to it. In his book, *Bounce*, Matthew Syed (2010) takes that even further. Not only are 10,000 hours necessary, but the practice must be deliberate. It has to stretch us beyond what we already know how to do. Practicing what we already can do does not deepen our internal selves. Buying and building more group homes is not a new skill set. We can do that in our sleep.

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Neuroscience tells us that when we practice a skill, our neurons literally change over time. We know that we can practice empathic listening and that, with practice, we can actually change our neural network and become more empathic listeners, no matter how unempathic we may have been when we started out. The old adage, “fake it till you make it” (which may take 10,000 hours) turns out to be quite true.

I believe that organizations have their own neural networks. What they practice, day in and day out, reinforces and strengthens those networks. If what they practice is enlarging market share, imposing their will upon those they claim to support, and writing hundreds of life wasting service plans, then their neurons will be very strong in those areas...and after 10,000 hours, that is all they will know how to do.

At the Arc, we decided that we had to be intentional about practicing the attributes and skills required to move away from congregate supports. To get multiple people to 10,000 hours meant starting yesterday! And, as we practiced, we cautioned ourselves against trying to achieve that old bugaboo of scalability. Trying to do that can be a death knell. One can practice a lot, on a very small scale. One can practice the requisite skills every day, even if only around one person or one group home. Practice a lot; practice small.

To initiate practice requires what is actually a simple leadership decision: to draw a line in the sand around even just one person. To say “no more” life wasting for this person. To say, now we will begin to deeply listen to and co-create with this person. To say, we will try to discover what the Good Life is for this person and then to partner with that person and do our very best to build that Good Life. This will take practice. Every day. Because you have to get to 10,000 hours.

Neural networks are not prone to easy change. Decades of congregate practices have left deep furrows in our personal and organizational neural networks. These furrows are home to our mental models about people with disabilities and their supports. Practice reshapes the furrows and modifies our mental models. In *Talent Is Overrated*, Geoff Colvin (2008) explains how the principles of deliberate practice can be applied to organizations. Practice helps organizations build rich mental models. One benefit of a rich mental model is that it can “free up mental resources to work on what’s really important.” Or, as Block put it, to focus on the “why.” Understanding what is really important will reveal the skills and attributes needed to reshape our mental models.

Engaging in transformational activity is no mean task, and is filled with fits and starts. Some lessons we learned are:

- ◆ Life wasting is a stubborn and pervasive enemy. It requires courageous leadership to identify it, call it out and fight it. All too often, people’s Good Lives are held hostage to years spent learning meaningless skills and engaging in useless activities. They are told, in effect, they have to earn the Good Life. Putting an end to this paradigm is perhaps the first and most important line in the sand leaders must draw.
- ◆ Structural innovation (such as downsizing and closing congregate settings) is not social innovation. Michael Kendrick is fond of pointing out that we can be very good at “disappointing people one person at a time.” Structural change may be a necessary condition for social change, but it is insufficient. The latter requires the “working on” skills that practice brings.
- ◆ Innovation and stability are not mutually exclusive. The Arc maintained an excellent fiscal and regulatory track record while engaging in transformative activities.
- ◆ Not being able to see the end point is ok. There will be those who never despair of asking “what if.” Trying to answer every “what if” will leave you mired at square one. Do your due diligence, of course. But being diligent does not mean being omniscient.
- ◆ Don’t ask “how are we going to do this”? Concentrate on “why” and on practicing the requisite skills. Smart people will figure out “how.”
- ◆ Ideology can be and often is hamstringing. Of course there will be compromises, so beware of ideologues. The perfect is the enemy of the good.
- ◆ Just as skills, like empathic listening, can be sharpened, so can personal and organizational attributes. Of these, the two most important are courage and perseverance. For centuries, humans have practiced the congregation and segregation of “the other”, including people with disabilities. The deck is stacked against personalized supports. Fear and a lack of staying power will doom efforts to disaggregate services. Leaders can practice courage and perseverance.
- ◆ Intentionality breeds serendipity. When new and better questions are asked with intentionally practiced courage and perseverance, new answers will emerge, often from surprising and welcome new places.

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About the Author

Christopher Liuzzo's work is grounded in values informed by Social Role Valorization and person centered practices. He has played numerous advocacy and administrative leadership roles since the mid 1970's. His work includes the co-founding of advocacy organizations dedicated to individualized supports. The New York State Independent Living honored him with its System Advocacy Award for his efforts in advancing supported employment. Among his major interests is the reinvestment of resources from congregate settings to individualized and self-directed supports. He retired from his role as an Associate Executive Director of the Arc of Rensselaer County (New York) where he led initiatives to downsize and close congregate living settings. He is now a consultant to organizations especially interested in moving away from congregate services to individualized supports. Chris maintains a special interest in advancing life sharing arrangements between people with and without disabilities.



Dane County, Centers for Medicare & Medicaid Services (CMS), and Individualized Services

By Dennis Harkins, with Monica Bear and Dan Rossiter

It ensures the individual receives services in a community to the same degree of access as individuals not receiving Medicaid Home and Community-Based Services. That is the bar that this rule sets for integration for individuals in the community. It is a significant and important measure that people should keep in mind whenever they discuss this rule.

— Ralph Lollar, Director, Division of Long Term Services and Supports, CMS

Since the Home and Community Based (HCBS) Waiver rule was promulgated, State bureaucracies have been working overtime creating plans to convince CMS that their State's current system of group homes and sheltered workshops meet its requirements. Such States might better use their time by visiting Dane County, Wisconsin, where the intent of this rule has been the foundation of its service system for more than thirty years.

In January, 1974, forty years prior to the promulgation of this significant and important measure, Dane County became one of 72 Wisconsin Counties newly responsible for providing community services to people with developmental disabilities. Wisconsin Counties inherited a system in the very early stages of deinstitutionalization. They assumed responsibility for thousands of people in state, private, and county institutions; more than a hundred 8-12 bed group homes recently developed by the state; a relatively small number of people living in proximity to one another within apartment complexes; and day services and sheltered workshop facilities that had been developed over a number of years, primarily through the efforts of parents to provide meaningful activities for their sons and daughters who had been ignored by public services during our long era of institutionalization and segregation.

Dane and other counties were responsible for continuing, expanding or transforming this system. Wisconsin's strong emphasis on local control at that time gave counties the

opportunity to choose what to emphasize as the state became an early leader in the national movement to develop community services. For those readers too young to remember, group homes and sheltered workshops were at the time considered positive alternatives to the preponderance of institutions in which most people with intellectual and other developmental disabilities resided if not living at home with their families.

Dane County initially used the more than adequate new state funding to further develop this system, opening new homes and expanding the number of people within congregate day facilities. By 1984, more than 100 adults lived in 8-12 bed group homes, while more than 400 people remained in institutions. Another 50 people were living in Adult Family Homes. Not exactly the access to community that Ralph Lollar envisioned in his description of the purpose of the still new CMS rule.

Fast forward to 2015. Dane County supports 1405 adults with developmental disabilities. Despite more than two decades of funding constrictions, 66% of those individuals are living outside of their family homes. The 400 people living in institutions has been reduced to 35, all of whom have guardians who have rejected the offer of community living. Of the 104 people living in group settings, 93 are living with 2-3 other people rather than 7-11 others. These individuals are typically older, and have families and guardians involved in supporting these now smaller settings. Quite remarkably, 806 individuals are using Self-Directed Support funding to purchase the assistance they need to live in their own homes, alone or with housemates.

Pause for a moment and consider these numbers. Nearly half of the 806 individuals were once counted within the 400 living in institutions. Many carry a variety of labels that in other localities would suggest continuing institutionalization or specialized

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group homes as a necessary service. Each 1 of the 806 represents a person who has a lease of their own home (or, for 65 people, a mortgage); and, flexible support tailored to their needs, typically with assistance from a supported living agency. Within Madison, Stoughton, Black Earth, Middleton, and a variety of other Dane County cities and small towns each 1 of these 806 individuals lives as a neighbor, a friend, a co-worker, a citizen who happens to receive *services in a community to the same degree of access as individuals not receiving Medicaid Home and Community-Based Services*.

Citizens of working age in America typically want to work. By 2015, the number of people in Dane County spending their day in a sheltered workshop or day center had fallen to 195. Of those who left or chose not to enter those facilities, 49 people owned their own micro-enterprises or small businesses, while 849 businesses provided paid employment to 841 people. More than 60% of Dane County adult citizens who receive services within the developmental disabilities system work or are small business owners. Dane County is by no means satisfied with this percentage.

In 2015, 96% of those citizens receiving services in Dane County accessed an individualized Self-Directed Supports budget to direct their own supports, many with involvement of guardians or support from friends and family. Outside of that individualized budget, Dane County funds both support brokers to assist each individual and a robust system of specialized services designed to fully advance the human experience. These supports are critical in addressing individual impairments that would otherwise limit people's access to citizenship and community. Most of the initiatives described below preceded or were created along with Self-Directed Supports and are often missing within such systems elsewhere:

- ◆ **Behavior consultation available to both adults and children.** By working proactively with the individual, the family and/or support team, a positive approach to behavior challenges is present. Additionally, psychiatric consultation is available, both through the University of Wisconsin Waisman Center and the Dane County Mental Health Center.
- ◆ **A Crisis Response system available 24 hours a day with up to 25 staff trained in behavior intervention available at a moment's notice.** As part of that system, a Safe Home provides a short-term safe, calm environment to individuals in crisis, often avoiding more expensive and traumatic institutional stays and emergency detentions.

Assisting people to be safe in their home. Responsive Solutions Inc. runs an Adaptations and Modification program which evaluates, organizes, plans and provides help to assure a safe and appropriate environment for people with physical accessibility needs and behavioral challenges, enabling an individual's continued participation in community life through making homes, apartments, and work places safer. Sound Response, a supplement to direct staff support through the creative use of technical/mechanical support is further utilized in people's homes. These supports include speaker phones, pagers, motion detectors, smoke detectors, various burglar alarm systems, personal assistance systems, and door and window sensors, to name just a few. Strategically located staff are available within a ten minute response time after typical work week hours. Sound Response has enabled people to be less dependent upon in home staff, increasing personal freedom and decreasing service costs.

- ◆ **Availability of needed medical expertise.** The Wellness Inclusion Nursing (WIN) Program, established to provide nurses as consultants to residential and vocational team members, families and health care providers focuses on restoring, maintaining and promoting maximal health and independence. The WIN nurses provide consultation with individuals, support brokers and agency staff, working together to provide individualized education and training on topics such as healthy diets; managing diabetes, seizures, and bowel protocols; and identifying and connecting with physicians, therapists, other medical specialists, home health services and hospice.
- ◆ **A Legal Advocate.** People with developmental disabilities are at an increased risk for being victims of sexual abuse, domestic violence, financial exploitation and other crimes. Dane County created a Legal Advocate position in 1999, to enable people with developmental disabilities (and those who support them) to respond effectively when they are victims of crimes. The primary responsibilities of the Legal Advocate include
 - Technical and emotional assistance to the victim when negotiating the criminal justice system and auxiliary services;
 - System advocacy for the issues of victims with developmental disabilities;
 - A bridge between the criminal justice and the human service system; and
 - Education of both human service providers and law enforcement.

The Legal Advocate serves as a liaison to law enforcement, the District Attorney's Office, and Victim/Witness personnel and

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assists criminal justice workers in identifying the unique needs of victims of crime who have developmental disabilities, especially in the area of communication.

A program that grew out of parent participation/leadership formed in 1998 to help parents think about the “how’s” and “what’s” of home ownership. Movin’ Out, in partnership with people with disabilities and their allies, creates and sustains community-integrated, safe, affordable housing. Movin’ Out housing counselors manage a wealth of information and provide information and referral to resources covering a wide range of housing issues including home ownership, down payment assistance, home owner rehab, rental assistance, fair housing, and accessibility.

As mentioned previously, Dane County regularly seeks to learn from others. The work of Mike Green and the Asset Based Community Development approach gave birth to LOV-Dane (Living Our Vision, Inc.), a family governed, family-led organization committed to creating capacity and generating solutions outside of the traditional human service system. It envisions a future in which adults with disabilities live as independently as possible in communities to which they contribute through productive employment, engaged citizenship, and caring, reciprocal relationships. LOV-Dane’s community-organizing model places a high value on nurturing interpersonal relationships for collective action. The talents and energy of members drive actions and decisions at all levels.

As supported employment and self-employment became prevalent, getting people to and from their jobs became an issue. Two approaches help alleviate the problem. The County partners with the City of Madison to provide, in addition to the regular bus routed system, a door to door option. In addition, there is a need to help individuals access and learn the routed system. Mobility Training and Independent Living provides assistance in the use of public and specialized transportation, pedestrian safety and orientation to work and community environment.

Further emphasizing employment, Dane County created the Supported Self-Employment/Micro-Enterprise (SSE) program as an alternative to traditional supported employment and sheltered work. This program addresses the movement, communication, stamina, and behavioral barriers to employment often faced by individuals with significant disabilities. Dane County has seen that these micro-businesses can create employment opportunities for individuals who have had limited success in traditional employment. SSE identifies barriers and assets

to self-employment. Through an individualized approach, recommendations are made to overcome these barriers in order to establish or grow an individual’s micro-enterprise.

This article is not written to boast of Dane County’s accomplishments. One factor that has led to those accomplishments is a collective humility, as well as an at times agonizing scrutiny and self-criticism of the many shortcomings that can make life difficult and limiting for the 1405 individuals receiving services and another 45-50 people on waiting lists. If Ralph Lollar were to visit Dane County, he would have no difficulty finding individuals and family members who would share with him where and how county supports and services were falling short of his description of the intent of the new CMS rule.

Despite Dane County’s shortcomings, few long-term care systems in the United States or elsewhere have created the outcomes briefly described above. How and why this transformation has occurred and been sustained is the focus of the remainder of this article, with hope that readers from other systems will learn from Dane County’s evolution, adapt that learning to their own unique circumstances, and surpass Dane County in enabling all those it serves to lead good lives as members of their communities.

We described above the nature of services, particularly residential services, in 1984, but we left out a few pieces. By 1984, there were also 115 people living in their own homes, with support from a small number of new Supported Living Agencies. The first of these, Options in Community Living, had incorporated in 1981. It was created by staff from an agency that was previously serving people in clusters within a few apartment buildings. Believing that these clusters provided physical presence in the community, but similar to group homes, made it difficult for those individuals to know and be known by their neighbors, staff began helping individuals move to other apartment buildings or rent their own homes, alone or with a chosen housemate. Options soon after began supporting people from ICF-MRs, nursing homes and State institutions.

This learning was critical. For no more average cost than supporting a person within a group home, Dane County learned from and with Options that it could enable people to live in their own homes, with support tailored very specifically to the needs of each person. As important, they learned what is now obvious — people’s chances to live like anyone else in the community increase when people live as much as possible like anyone else in community.

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In 1984, Julie Pratt, then Community Services Manager for the Dane County Unified Board, convened a work group on Residential Services for People with “Severe” Disabilities. The group consisted not only of county representatives, but also of individuals who received services, family members, advocates, and service providers. The group looked back at 10 years of services, and looked forward to the next five.

They reflected upon what they had learned from PASS and other Normalization related values-based trainings and learning led by John O’Brien, a frequent visitor to Dane County; from a Wisconsin Developmental Disabilities Council funded project in which Terri Johnson focused on sharing those values with individuals, families and service providers; and from the Developing Individualized Service Options project, in which Marcie Brost led intensive learning into how to actually put those values into practice with a small number of individuals with quite challenging needs for support. They learned they were now supporting people within small settings of 3-4 people or in their own homes through supported living whose needs were similar to and sometimes greater than those of the 400 people still living in institutions.

- ◆ Summarizing the recommendations within their 25-page report, Dane County used this time of reflection to commit to:
- ◆ Promote the inclusion of all persons served into the daily life of their communities;
- ◆ Individualize all residential services;
- ◆ End placements into institutions and promote the development of community alternatives for all those living there;
- ◆ Focus on continuity, stability and continually learning state of the art approaches to respond to people’s impairments or challenges;
- ◆ Continue to meet as a group to learn, improve, and adapt the system.

Similar learning occurred within those first 10 years related to where people spent their days. In addition to the powerful influence of the values-based trainings noted above, vocational alternatives to day centers and sheltered workshops were influenced by the pioneering work of Marc Gold, and by the influence of Lou Brown, Anne Donnellan, and others from the University of Wisconsin in emphasizing inclusion and community vocational opportunities within Madison area schools. These influences led to the development of supported

employment within Dane County, and by 1984 several small and exemplary supported employment agencies had been formed and local businesses were employing individuals who had long been considered unable to work.

By 1985 Dane County’s services were just beginning to look different than other places in Wisconsin and across the nation. The essential ingredients for sustained transformation to individualized services were, however, now in place, including:

1. Make a clear and unwavering commitment to community, not as rhetoric, but as a diligent practice to do the hard work towards enabling every person served to have the opportunities to be and be seen as a valued citizen, neighbor and co-worker.
2. Share this commitment and the values it is based upon across the system through continual attention to partnerships with individuals served; their families and friends; service providers; businesses and neighborhood leaders; municipal, county and state officials; and other citizens. This commitment includes initiating discussion, if not always dialogue, with those who have differing opinions about this commitment.
3. Extend this commitment to every citizen in a state, county, or private institution. Exclude no one.
4. Invest in employment. In person and in writing Tom Nerney later emphasized to Dane County the importance of employment and generating income as the single most cost-effective way to enable individuals to increase their sense of self-worth, and enhance their connections to other citizens. Regardless of budget challenges or cuts, Dane County has fought for and each year maintained a promise to high school graduates: “If you leave high school with a job, we will provide the support you may need to continue it.”
5. Learn, innovate, transform, evolve. Learn, innovate, transform, evolve. Learn ...
6. Create a coherent life span approach. Keep kids at home and in neighborhood schools; assume they will work when they grow up; provide support to help them do so. Stick with folks through the end of life, through whatever circumstances arise, all with the same community focus.
7. Think in decades. Federal and State systems will change. Challenges will continue. Leaders will come and go. Stand on the shoulders of families who fought to create services when none existed, who later fought for inclusion in schools and in community; of individuals who have courageously and doggedly persisted to make lives for themselves despite challenges the system created for them; of service provider

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staff and leadership who believed in those individuals and learned from them; and of the partners that can always be found in government, and in our communities.

Most of the foundational elements of transformation that evolved within Dane County are free, or cost little, at least in terms of money. None are unique to the drinking water in Dane County, although the specifics of how they evolved are certainly influenced by local history, culture, challenges and opportunities, as is true within all systems.

With these ingredients in place, Dane County partners collectively transformed the system they inherited in 1974. They virtually ended the use of institutions by 1995, and they recognize the work to do for 35 more people whose guardians remain unconvinced. They gradually replaced large group homes with smaller settings, the large majority of people now living in their own homes. They gradually reduced the number of people spending their days in community rehabilitation programs by effectively offering and incentivizing support for employment. They spent several years, from 1998-2003, converting a highly-regarded system of individualized supports through contracted services agencies to one based upon Self-Directed Services, in which each person has an individualized budget and assistance of a support broker to determine how that budget may be used to enhance their life in their neighborhood and community.

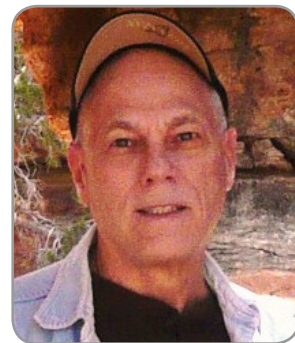
Dane County today faces an uncertain future as it hopes to sustain and improve upon its services and supports. It remains a temporary outlier within Wisconsin's managed long-term care/ SDS system, a status which will likely change early in 2018. The change will provide a welcome end to waiting lists, but neither the capitated Family Care managed care program nor the state's IRIS SDS program have to date achieved outcomes as successful as Dane County in terms of where people live, work, play and contribute in community. The county is responding to these future uncertainties by bringing people together to learn, innovate, transform and evolve within the new challenges and opportunities ahead.

We close this article by asking for the reader's assistance. We ask that you take a look at the lives of people where you live and work, those who receive services and support and those ordinary citizens who do not. Do all share the same access to community, the same opportunities for citizenship? We ask that you reflect upon Dane County's efforts. Where the places you live and work have already gone beyond those efforts, build upon that and

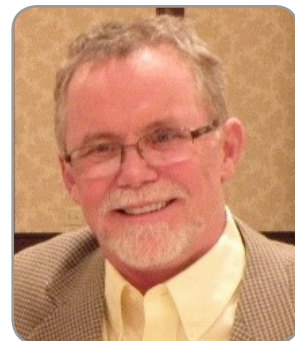
tell those stories. Where those places fall short of what we have described as possible, learn from Dane County's efforts, and over time help Dane County evolve and learn from yours.

About the Authors

Dennis Harkins is a former Wisconsin state bureaucrat, who has observed, assisted and impeded Dane County's system evolution for the past forty years. He most recently served as Project Manager for the development of Connections for Lutheran Social Services of Wisconsin. Connections provides support to individuals utilizing Self-Directed Services, and has adapted the organizational structure described by Frederic Laloux in *Reinventing Organizations*. Dennis currently provides consultation on integral long-term care through A Simpler Way, Inc. and may be reached at dwharks@gmail.com.



Dan Rossiter was the Adult Services Manager for Dane County from 1989-2009, and is currently the Director of Support Brokers Consultants, Inc. an agency that provides individuals with intellectual and/or developmental disabilities and their allies, an advocate/guide/Support Broker of their choice from within their circle of friends and family. He may be reached at dan@sbcdane.org.



Monica Bear has served as Dane County's I/DD Community Services Manager since January 2010 when Dan Rossiter passed the baton. She is passionate about supporting systems that encourage multiple paths to integrated employment, community supported living, the exercising of self-direction and citizenship. She can be reached at bear@countyofdane.com.



The Story of KFI's Agency Transformation

By Gail Fanjoy

Founded over 50 years ago as a school for the area's children with intellectual disabilities, Katahdin Friends, Inc. (KFI) changed and expanded to become a regional provider of customized supports to people with disabilities, recognized and awarded for excellence. The transformation was startling, even revolutionary and involved both a shift of attitude and service delivery.

In the early '80s, KFI's management staff asked two pivotal and fundamental questions: "Is there anyone anywhere doing anything better?" And, "Why can't we do that?" It's not that we were dissatisfied with our services; we were simply intellectually curious. As a result, KFI joined national US organizations such as TASH, read the journal articles, attended conferences, reached out to the gurus of the day, and listened to our own hearts and minds. The conclusion that congregation and segregation of children and adults with disabilities was wrong came quickly. What to do about it took time.

In 1985, recognizing the need for children with disabilities to interact and be educated with typical children, KFI closed its segregated school program. Instead, we worked with local schools to transition our remaining students into their neighborhood schools. In 1987, due to the success of our job placement and supported employment, KFI closed its sheltered workshop, a stand-alone furniture refinishing business serving approximately a dozen people on a day-to-day basis. The vocational assessment service funded by Vocational Rehabilitation was moved to a local hospital in order to provide training and evaluation in a real work setting. Finally in 1989, all sub-contract work was abolished in favor of socially inclusive supported employment and KFI's day program was transformed into a service that provided broad opportunities for community participation.

The individuals we served were impacted by these changes in many ways. Charles was typical of the 28 or so people supported in KFI's day program from the early '60s through the '80s. He lived with family members – a brother and sister-in law. He came to the day program five days a week where he worked for subminimum wages cutting clothing into rags. He didn't have

much in the way of responsibilities or authority in his home, he was virtually unknown to all but his family and fellow day program participants, and he seemed to be happy in life. His family did not want Charles to work competitively and they asserted that he would live with them until the end of his life.

As the changes at KFI took shape, Charles developed other ideas. He saw some of his friends from the day program getting jobs in the community, and some of them were moving into their own apartments. Charles longed for independence and autonomy. Staff from KFI championed Charles' cause for a number of years, and in 1992, Charles got his wish. KFI took the state grant dollars we received to segregate Charles in the day program and repurposed them to pay for staff that would support Charles to live in his own apartment. This was before the advent of Medicaid Waiver dollars, and even though there wasn't much money, we had maximum flexibility to do what we wanted with it. Consequently, Charles received paid supports of just 24 hours per week, but his community friends and neighbors were what made his life enjoyable and provided a safety net.

Charles' relationships and community memberships increased with opportunities to meet and interact with community members not involved in disability services around different areas of interest: church, exercise, ceramics, volunteering, wrestling, coffee, snowmobiling, Native American culture, coupon collecting, harmonica playing, just to name a few. This was the same person who was happy cutting clothing into rags in the segregated day program! He turned out to be a beloved community member, a great teacher, a man of faith and a cherished family member.

Charles passed away peacefully in the fall of 2006 at his home, in the environment that was most familiar and comfortable to him as the Lord's Prayer was being recited to him by loved ones at his side. His obituary paid homage to all that Charles had taught us and accomplished:

Charles' move into his own apartment, his community connections, particularly through church, his kind and sincere personality, and his deep spirituality affected everyone he met. He was the personable host to political figures and commissioners who were always impressed with his home, his graciousness and his community activities. His story, which was told to countless

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people throughout the country, inspired and challenged many and created changes that improved the lives of many individuals with disabilities. He was a great example of the power of community and the ability of individuals to achieve much when given the chance.

Many others followed in Charles' footsteps and KFI effectively ended all center-based services in 1996.

Over approximately a dozen years, KFI ended its segregated school program; closed its sheltered workshop; transformed its day program into one that, while still facility-based until 1996, gave people broad opportunities to connect to the community, work, and enjoy supports in their homes; integrated its preschool program with typical kids (now closed); shut down its thrift store; closed a 4 bed group home and an "apartment program"; scrapped its vans; and, abandoned the building that housed the segregated school and day programs built by the founders of KFI.

We had a vision that people with disabilities could live homes of their own in typical neighborhoods, could work in community businesses, and could enjoy the friendship and connection with typical community members. They could lead "regular lives." Every decision was weighed against that vision.

We were not afraid to make things messy. Some organizational transitions require complex changes to staffing, supervisory structures, timelines, etc. This never became a reason not to continue. We never assumed there was a "model" that would serve all situations. Everything was individually constructed. KFI made decisions based upon unique situations and had no universal approach. We learned from our mistakes and never let past experiences hinder trying the same thing again.

Our early influencers included Syracuse University professor Wolf Wolfensberger, who enlightened us about the principle of normalization (later updated to become Social Role Valorization theory) along with devaluation and its devastating consequences; Lou Brown who showed us that everyone is ready for community employment, that human service agencies needn't continue to be peoples' employers; and, John and Connie Lyle O'Brien whose contributions to our thinking and actions remain alive and well today as we plan in person-centered ways. Their influence is evident today in how we use their influence to demonstrate how people can grow in relationships, increase their community presence, gain more choice and control in their life, increase the number of valued ways they can contribute to community life, and experience respect.

KFI created an organizational culture supportive of risk. Supporting Charles, a man with a significant intellectual disability who did not read, write, or tell time with just 24 hours per week of support is a great example of how bold we were. We tried to hold true to "no double standards," with the question being, "If it was my life, what would I want?" We focused on supporting people to achieve and maintain valued social roles, community employment, real homes, and meaningful community membership. Of course, we did this "one person at a time."

Core Values that Guided KFI's Organizational Change

- ◆ Staff changed their thinking, realizing they needed to support people in ways that made sense for them, instead of fitting them into existing programs or service models. We emphasized the importance of dealing with a person's whole life.
- ◆ We acknowledged the connection between vocational and non-vocational supports for people. Staff understood that where people live determines work-related opportunities or limitations.
- ◆ Staff were passionate about getting community jobs for people they supported, even though they had no idea initially how to eventually accomplish this goal for each person.
- ◆ Staff set the expectation that people could work and would find jobs, that they could live in their own homes, and that they could belong to communities.
- ◆ KFI viewed the individual with a disability as the primary customer. While families, as well as funders, were extremely important, KFI kept its focus on the person and advocated with them and sometimes for them.
- ◆ We knew that people with disabilities should have the opportunity to decide the type of lifestyle and services they want, and people asked for things that we all have and take for granted. Home, work, relationships, health...etc.

Useful Strategies and Considerations (with Regards to Staff)

- ◆ Staff took special pride in sharing new information, setting aside time to talk about the exciting things they had discovered.
- ◆ Whenever an employee left, KFI revised the job description to be more community-based emphasizing a "connecting role" for direct service staff. This was used as an opportunity to help move the organization forward.

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- ◆ At supervisory meetings, staff discussed three successes and one lost opportunity as a way to focus on accomplishments.
- ◆ KFI invested in values-based training for staff, and more importantly, held themselves up to the principles of social role valorization.
- ◆ KFI hired people for their values, rather than their experience, certifications, or degrees; they hired people from the same community as the people they supported; staff needed to be able to describe how they were connected to their communities; staff had to demonstrate that they were knowledgeable about their community and its resources.

Useful Strategies and Considerations (with Regards to Services)

- ◆ When staff started delivering services differently (personalized, community-based), they asked for help from staff who were more experienced. While services were being individualized staff were expected to communicate and collaborate with one another about an individual's support needs.
- ◆ KFI stopped providing vans and staff began using their own vehicles, people took cabs (northern Maine's answer to public transportation), or used other non-group arrangements including rides from community members.
- ◆ KFI used ordinary community venues, not just for jobs, but for all aspects of a person's life (e.g., health clubs, adult education, volunteer opportunities).
- ◆ The agency remained mindful of the age-appropriateness of the activity, both in terms of the activity itself, but also in terms of the time of day in which non-disabled persons of similar age would routinely engage in the same activity (i.e., adult evening swim time at the public pool versus kiddie swim time in the mornings), and always considered the dignity of the person supported.
- ◆ The agency gave staff permission to use their personal connections on behalf of the people they were supporting.
- ◆ KFI paid better for the results it was seeking. During the years when KFI had "a foot in both worlds" staff that worked in personalized community connector roles made more money per hour than staff that supervised groups of people

doing sub-contract work. Even today, the hourly rate paid to direct support staff that assist people to pursue and achieve competitive or self-employment is higher than the rate paid to support someone to have a leisure life.

KFI continues to offer citizens with intellectual and developmental disabilities a full range of supports including job development, supported and customized employment, community life engagement, and supported living. Today, we have offices in both northern and southern Maine. Our employment services continue to meet with great success and include jobs for people with more complex disabilities. And for people who once would have faced a bleak future in an institution, foster or group home, they are moving into homes of their own – including home ownership.

Services to people with disabilities have undergone many changes. From the early days of segregated schools and adult programs that sheltered and protected to the current philosophy that calls for community participation and inclusion, KFI has kept pace with and often led the way with innovative services for people with disabilities in Maine. The founders of KFI had the vision and knowledge that people with disabilities were also people with abilities. Their dreams for their own sons, daughters, and fellow citizens helped shape the lives of those served by KFI today.

About the Author

Gail Fanjoy is the CEO of KFI where she has worked in a variety of positions for 40 years. Gail is a member of the TASH national Board of Directors, and New England TASH Past President. She has provided leadership in Maine, New England and nationally for many years sharing KFI's transformation supporting one person at a time with customized supports which enable people to live lives as included, valued and respected individuals in communities in Maine.



Transformational Change in Avalon (BOP) Inc: “Don’t look back we are not going that way”

By Helen Brownlie

Introduction

Avalon (BOP) Inc, a vocational day service based in Bay of Plenty, New Zealand, underwent a transformational change process between June 2014 and June 2016. This narrative account describes phase one (the transition) of an ongoing service development process and describes how we transitioned 100 individuals from a segregated, custodial day-programme model, to a community-based facilitation model. It is to be understood that we have by no means arrived; rather, we have established an environment which is conducive to doing the real work of supporting people to have the good things of life.

Avalon’s inception was in 1976, when sheltered workshops were the default community service response for those people who had been relocated from the large institutions in New Zealand. With the phasing out of sheltered workshops, Avalon commenced on a journey of non-viable social enterprise and pseudo education programmes, and at no time addressed individuals and their aspirations other than on an ad hoc basis that was largely driven by staff interest.

In 2014, Avalon was supporting 100 “trainees” in a segregated, custodial day programme on a beautiful six-hectare rural setting, 10 minutes’ drive north of Tauranga in the Bay of Plenty. Avalon Board of Directors and staff were unaware at the time as to the effect of the service on “trainees,” many of whom had been attending the service five days a week for decades. “Trainees” were set up for life, with very low expectation or desire to move from this “safe; routine; training centre” that, at best, trained them to fit into a norm that has been described as a fish bowl in which individuals swam round and round, in one direction day after

day. Free transport was provided for all clients to and from the service, at an annual cost of \$130,000. The service provided a menu of activities (largely driven by staff interest) within a daily programme from which clients could choose. Many clients stayed in the same activities year after year, such as woodwork, plant nursery, art and sewing.

When asked, the majority of families were very “happy” with this service in that it provided a “safe,” “happy place” in which their “children” were “occupied with their friends.” Furthermore, the Board of Directors was satisfied that Avalon was providing an exemplary service which “relieved the burden” for families and provided a safe space for these “poor people to be with their friends.” Provider capture was prevalent in that very few people left, or were encouraged to leave, the service – other than being excluded for being a “behavioural problem.” In summary, Avalon was deeply rooted in a place, and the patterns and rhythms of its service were set to endure and withstand the winds of change.

More widely and of relevance, in 2007 a New Zealand Social Services Select Committee inquiry heard that people with disabilities often felt they had little control over the services they received. As a result, in 2013, the Ministries of Education, Health, and Social Development agreed to jointly fund a demonstration called Enabling Good Lives¹ which focussed on services carried out during the day. Enabling Good Lives provided a clear set of principles and language that paved the way for those who were contemplating change. This initiative aligned with the United Nations Convention on the rights of persons with disabilities (2008),² which saw New Zealand, amongst many countries, seeking solutions to respond to an expressed discontent by persons with disabilities in regard to service delivery.

Why Change?

In 2014, Helen Brownlie joined the Avalon Board of Directors, bringing a broader view of how Avalon could better deliver on

- 1 Enabling Good Lives Newsletter, October 2013, available at: www.enablinggoodlives.co.nz
- 2 United Nations Convention on the Rights of Persons with Disabilities, available at: www.un.org/disabilities/convention/conventionfull.shtml

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its Ministry of Social Development contract for vocational day services with a focus on community inclusion and participation. With the exit of the then general manager, Helen joined Tania Wilson, Business Manager, in a co-leadership role for operations. Of note is that neither Helen nor Tania had direct disability experience but, rather, came with established credibility in the areas of change management, project management, marketing and business acumen. A starting point for Helen, Tania and Avalon Board was to fully understand the business, including costs, programme content, service delivery and so on, and this prompted a comprehensive review of the service.

Following the review, the Board was presented with a well-documented factual account of current realities and the impact of these realities on future viability. At this time, another new board member, Paul Curry was appointed and this, along with a looming fiscal crisis, set the stage for making a decision to either close or to change the service. Helen and Tania both held a profound truth about what was possible (the internal motivators) to better meet contractual requirements but it was the fiscal crisis (external motivator) that provided the leverage to get the Board to make the decision to change to a new model of service delivery.

In summary, the strategic imperatives for change were:

- ◆ New government direction for disability services, including Enabling Good Lives
- ◆ Notice from funders of the future with an intention for services to report on individual outcomes rather than activities of group programmes -a move from output to outcome
- ◆ Requirement for a service model that was more conducive to supporting individuals to choose a life of value in their own community
- ◆ Fiscal viability

The decision to change and transition to a new organisational vision and service model was announced by the Board in February 2015.

Changing ... To What?

The table on the next page contrasts the key changes and features of the new and old organisational vision and service model.

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Transformational Change in Avalon (BOP) Inc: “Don’t look back we are not going that way”

VISION

Old vision

To be the service provider of choice

New vision

Lives of value

SERVICE MODEL

Segregated custodial programme model

Large isolated, segregated space, with full kitchen facilities, group rooms and gardens and workshops

“Trainee”

Tutor-educator role

Ad hoc, generalised planning

Direct service

Compliance, with low expectation

Time-wasting, diversional activity

‘Hands on’ approach

‘Doing with’

Managed safety

Individual

Minimal family involvement

Free transport service, some door-to-door transport

8am to 4pm hours of operation (including pick-up and drop-off)

Paucity of trainee notes

Trainees under a wage exemption scheme or limited to volunteering within the service

Policies and Procedures and Forms incomplete; outdated and irrelevant to new service model

IT capability and capacity inadequate and unable to support staff

Individualised community-based facilitation model

Small communal space, with the Avalon office, in the centre of Tauranga, with facilitators working remotely

“Client”

Facilitator role

Comprehensive IPlanning, involving clients and their Circle of Support

Indirect service

Competency enhancement, with high expectation

Purposeful, goal-directed, time-framed activity

‘Lightest touch’¹ approach

‘Working for’

Managed risk

Individual and their Circle of Support

Direct, ongoing family involvement

No transport

No set hours, no set space

Comprehensive client database, which captures detailed goal-directed activities and outcomes

Clients in paid work or volunteering within the community

Complete re-design of all policies and procedures

Full upgrade of IT software, hardware and support

All staff have their own computer and or “surface pro” and mobile phone and have remote access.

Articles from our Contributors

Transformational Change in Avalon (BOP) Inc: "Don't look back we are not going that way"

Preparing for Change

In order to establish a pattern of [commitment](#) and intention, much work was done to engage stakeholders in an ongoing process up to and beyond the closure of the site and transition to the new service. Our stakeholders included: clients (note the change at this early stage to "client" rather than "trainee"); parents and family members; staff; residential and supported living providers; funders; volunteers; and the Avalon Board.

Clients

A morning meeting was introduced, which all clients and staff attended five mornings a week for the eight months prior to the transition. Language was reframed, new language was introduced and ample time was allowed to ensure those who wanted to speak had the support and opportunity to do so. Any examples of movement towards autonomy, and referencing into the community was highlighted and celebrated. This meeting provided a platform to stand; to speak; to be heard; and to connect with others in sharing and demonstrating the vision. Additional meetings were held and facilitated to ensure an understanding of what was to come and address any fears and or excitements that arose. Another very powerful intervention was to train a small group (15 clients) in Peer Support. This had the effect of raising hope and giving a sense of responsibility by some clients for the success of the transition. Peer Support began to occur naturally onsite.

Families

For parents and families, a series of forums were held on different days at different times to optimise access to these. They were well attended and much outrage and fear were voiced openly over several meetings. Of significance was the apparent lack of knowledge about the disability sector, the strategies of the government, and the fiscal situation of Avalon. Most noticeable however was the strong view held by many parents (mostly of older clients) who were unable to consider a future with their children gaining autonomy; independence; work or any other valued role that would allow them to have the good things of life in their own community. The most outspoken family members were engaged by Avalon to ensure quality of communication to parents and families and risk management around the transition. This proved to be an extremely effective impetus for many families in making the leap of faith to the new and in establishing new patterns of commitment and intention.

Following the initial meetings which were focussed on information and feedback, a group of family members were invited to form a family reference group and this group continues to meet with Avalon management to provide ongoing feedback and advice on the service development.

Staff

Thirteen support staff and five administrative staff were deemed necessary to cover the old programme effectively. With external human resource advice, roles were redesigned and a robust, transparent and very rigorous restructure process took place over three months. Of the thirteen support staff, two resigned and two declared they would not go forward. However, the latter two stayed on to support the programme until the transition took place, resulting in six facilitators transitioning to the new service. Of the five administrative staff, three came through to the new service.

Staff were inducted into their new roles and attended training in Enabling Good Lives; how to establish Circles of Support; and a two-day introduction to Social Role Valorisation (SRV).³ A matching process occurred between clients and facilitators and work began by the facilitators to better understand who our clients were. Of note was the sense of shame expressed by some facilitators as they grappled with the fact that they had little idea who their clients were, despite having been with some five days a week for a number of years.

Volunteers

A total of nine volunteers were supporting the old service, as 'gap-fillers' and back-up for staff absence. Four volunteers transitioned to the new service.

Other providers

The leadership team of Helen and Tania met with every provider of residential and supported living services. Some providers were challenged by the new service model in regard to the impact on their staff rosters, of clients having different hours and the removal of transport provision. Furthermore, there was some hesitancy around attending the scheduled IPlanning meetings, which, wherever possible, included any people who had influence over the success of the transition for the client.

³ Social Role Valorisation was formulated in 1983 by Wolf Wolfensberger; see: www.socialrolevalorization.com/en/.

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Funders

Helen and Tania met several times with service contract managers, who were extremely receptive to the change. Avalon provided reports and updates wherever necessary.

Avalon Board

The change was informed by a change management programme of which the components are shown below. For each component there was a detailed project plan with time-framed deliverables. Each month the Board received a report on outcomes for each deliverable, along with the identification of any risks or red flags. Communication to the Board throughout this period was critical and the change management programme outcome reports served to grow a compounding confidence by the Board. The results of some of these reports were also relayed to families and staff.

This narrative focuses on the transition for clients and hence cannot provide details for each of the components in the change management programme. However, it is worth highlighting the significant resource required to develop a complete new set of

organisational policies and procedures to fit both the new service model and the new health and safety legislation that came into force in New Zealand in early 2016.

Planning the Transition

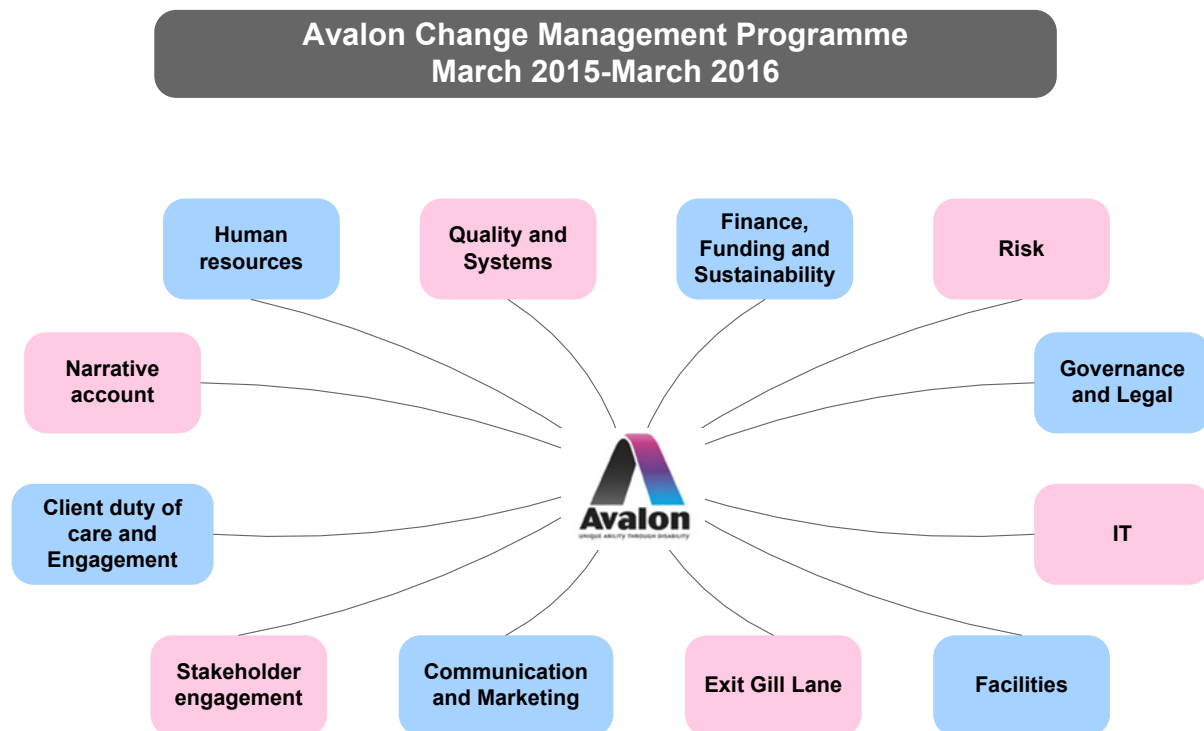
A decision was made that the old site would formally close on Thursday, 15 October 2015, and that the new service would commence on Monday, 19 October 2015.

It was recognised that the first eight weeks would be dedicated to a settling-in phase for all stakeholders.

Supporting the clients' transition

Planning to support the clients' transition included:

- ◆ Individual IPlanning meetings with every client, their identified Circle of Support, their facilitator and either or both Helen or Tania, to identify the following:
 - Goals for a life of value



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- Specific goals for the transition and eight-week settling-in phase
- Anticipated risks and mitigation strategies
- Level of independence with using a bus, with contingency plans
- Abilities with communication, including mobile phone, email and land lines
- Accuracy of contact details
- ◆ Development of individualised programmes that included: confirmation of the risks identified in the IPlanning meeting, a transport plan, contact details and pre-arranged courses such as transport, computers, mobile phone usage, orientation to the community
- ◆ Detailed transport planning, including bus routes, times and places for pick-up and drop-off, commitment to clients and families that a staff member or peer support would accompany those clients who required support
- ◆ Practice using buses prior to the transition date
- ◆ Design of courses to increase the clients' competencies and confidence in utilising public transport
- ◆ Role development for clients in terms of communication regarding safety on the bus, what to do if they get lost, and how to make emergency calls and to whom
- ◆ Ensuring ongoing support for increasing client competency in using mobile phones
- ◆ Sending letters to all families and relevant service providers with contact details, including mobile phone numbers, transport details and an overview of the individual client's programme for (only) the first eight weeks

Supporting the facilitators' transition

Planning to support the facilitator' transition included:

- ◆ Attendance by either or both Helen or Tania at every IPlanning meeting
- ◆ Constant monitoring of written communication between facilitators and families
- ◆ A focus on transparency and honesty in regard to potential impact of the looming transition
- ◆ Ongoing meetings – both group and individual – to support and encourage facilitators, identify any risks and develop risk mitigation strategies

- ◆ Providing adequate time for facilitators to clear their office space and orientate to the new space

Formal Closure of the Old Site

The ongoing morning meeting for clients provided adequate time (eight months) and space for both clients and staff to process and deal with their individual emotional responses to the transition and the closure of the old site on 15 October 2015.

A garage and plant nursery sale, to which all clients were invited, provided a milestone along the pathway to closure.

The formal ceremony to officially close the old site coincided with Avalon's annual general meeting (AGM). Of note is that the preparation ensured that this ceremony was one of celebration and story-telling.

The First Eight Weeks

The first eight weeks of the new service were characterised by lots of surprises (some individuals embraced the change with excitement and others withdrew to have some time out); peer support workers who excelled in supporting others; individuals who, for the first time, mastered using the bus; clients securing paid and/or voluntary work – on their own; the complete absence of behavioural problems; the positive impact of increased physical activity on clients' moods and functioning.

Overall, the first eight weeks was a period of high excitement and celebration of achievement, and a noticeable 'blossoming' of some clients in response to 1:1 contact or being in small groups of 3–4 during the day.

For those clients who were unable to manage transport independently, family meetings occurred to ensure alternative means of transport – other than Avalon – were secured.

Nine Months On

As of July 2016, 18 clients are attending tertiary education; 20 clients are in paid work; 28 clients are volunteering; 25 clients have received 1:1 computer tuition; and 12 clients are involved in literacy courses. Between 2014 and October 2015, a total of six clients left the service, five as a result of the change and one due to relocating.

Avalon has now adopted a pathway approach to client skill and knowledge acquisition and competency, whereby clients may

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be initially worked with one-on-one to gain confidence and a skill, which progresses to a small group run by either an Avalon facilitator or a well-briefed external facilitator, with the ultimate goal of clients participating in mainstream courses.

A new IPlanning cycle is underway, which focuses on evaluating previous client goals, expanding the client's Circle of Support, setting goals that are more aligned to the attainment of valued roles and, most importantly, holding Circle of Support members to account for the negotiated and agreed support they said they would provide. Given that previous IPlanning focused on the transition, this new IPlanning cycle requires facilitators to have a vision of how a client's life might look once they have 'graduated' from the Avalon service – in effect, the facilitator is challenged to consider the client's life once they (the facilitator) have been made redundant.

There is still a small cohort (10) of clients who rely on direct contact with facilitators. This is evidenced by their continuing to attend a small programme at the Avalon office. The majority of this group are serviced by a separate Ministry of Health contract, which addresses these clients' high and complex needs.

For those clients yet to establish themselves fully, there is a decreasing tendency for them to "float by the office" to "see what's happening". This group has been identified as requiring more intense facilitation in that they are inclined to do nothing if there is nothing organised for them to do, despite their capability. Facilitators are constantly required to resist the temptation to occupy this group.

Facilitators continue to grapple with a fluid, dynamic working week in which they are totally autonomous to work in a high-trust relationship with Avalon management.

The client database requires honing to reflect client outcomes more accurately, and Avalon continues to contribute to the adaptation of the database to fully meet our requirements.

Avalon must continually strive to support clients individually rather than as a small group. Wherever possible, the image that clients portray must reduce any potential stigma.

Weekly staff meetings continue to focus on facilitators' mindfulness in terms of the risk of reverting to old habits. Facilitators present clients at these meetings to gain perspective

and input from the team as whole. Fortnightly supervision further supports facilitators and Avalon will continue to support training opportunities as they become available.

As identified in the change management programme, stakeholder satisfaction surveys about the transition have been conducted, analysed and reported for clients, families and staff. The return rates were exceptional, and indicate a high level of satisfaction from all three stakeholder groups. Family forums continue and provide information and education about disability sector and the service.

John Armstrong, an accredited senior SRV trainer, conducted a full service evaluation in June 2016, and his findings in regard to the transition were very affirming. John also identified some clear recommendations for the future and these will inform and guide the next service development phase.

Looking Ahead

Several factors have been identified to focus on for the next stage of service development, which include:

- ◆ Securing fiscal viability through LEAN thinking and, in particular, resisting the temptation to provide more facilitators as client numbers increase
- ◆ Working towards 100% 'pull through' service whereby all stakeholders expect clients to graduate from the service
- ◆ Honing the scope of the service to better inform stakeholders as to what will be provided and, more importantly, what won't be provided
- ◆ Continuing to develop facilitators, particularly in the areas of Lightest Touch and visioning a life after Avalon
- ◆ Increasing our volunteer database to 100 and establishing a robust volunteer programme. We have recently appointed a specific position for this.
- ◆ Having the 'hard conversations' with clients and families who are reluctant to move towards valued roles and work
- ◆ Paying greater attention to potential clients having an established Circle of Support prior to entering the service
- ◆ Identifying specific, specialised programmes for clients that Avalon can develop for role development to independence, competency enhancement and "life-tasting".

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Summary

In summary, Avalon has successfully transitioned 94 clients from a segregated, custodial day programme to a facilitated, community service in a period of 10 months.

On reflection the critical success factors of this change are: buy-in from the Avalon Board; full and ongoing engagement with stakeholder groups; detailed and rigorous planning; well-written

factual reports; design of effective, fit-for-purpose tools; regular, open and honest communication and feedback; transparency around risks and successes; securing external expertise where required; and, most importantly, providing a platform for clients to stand, speak and be heard.

- 1 The Lightest Touch, Interactionz, available at: <http://interactionz.org.nz/>

Spectrum: The Story Of Our Journey

By Susan Stanfield, Spectrum Society for Community Living

A small group of friends and family members of people with disabilities started the Spectrum Society for Community Living in 1987 in Vancouver, British Columbia, Canada. Three co-directors (Ernie Baatz, Susan Stanfield and Aaron Johannes) have led the organization from the beginning. Each of us had worked in traditional, group-based services run by large agencies and we saw a need for smaller, more personalized service options in keeping with the move toward increased community access and inclusion that was gaining momentum in the 1980s.

Spectrum's first three homes, purchased in 1988 and 1989, were funded as four-bed group homes, but we used the funding to purchase duplexes, to provide a more intimate living arrangement for two people in each suite. "Smaller is better" was the theory, and indeed the smaller settings did have a more home-like atmosphere than the group homes we had worked in. The people moving into these duplex suites were coming from the largest of our province's three residential institutions, which were all in the process of closing down.

While Spectrum was operating on a smaller scale compared to some of the more established service providers, the fundamentals of our service model were much the same. The underlying assumption was that people needed an agency managing all aspects of their care, including owning and operating the homes they lived in. Before long, we started to see some of the limitations of this model. While the individuals had more choices and more personal attention than they ever had in the institution, they were nonetheless living in agency-run resources, not their own homes. They were "residents" who had been "placed" in these resources with no choice over with whom they lived. Schedules and binders found their way into the kitchens,

bathrooms and living areas. The duplex suites started to feel like mini group homes.

As time went on, some of the relationships between the residents (and between residents and staff) became strained. Because the funding was attached to resource, Spectrum had the dual role of both service provider and landlord, with various competing interests to satisfy. We wanted to see each person in an optimal living arrangement, but the funding model, and by the 30-year mortgages the funding was now tied, constrained the choices we were able to offer.

We came to realize that for people to enjoy a truly inclusive life as full and equal citizens, they needed to have authentic choice and control over important life decisions, like where to live and with whom to live. They needed to have the freedom to make changes if things weren't working for them.

Since 1989, we have not purchased any more homes. We have, however, supported about 80 people to move into homes of their own, including rental apartments, houses, cooperative housing, subsidized housing units, and in a few instances private homes that families have purchased or a separate suite in the family home. The housing options available to people mirror the full range of options that are available to anyone else in the community. About half of these arrangements are supported with individualized funding; the rest are still funded through residential service contracts, but we have separated out each person's share so almost everyone now has an individualized budget. If people want to move or make changes to their support, they are free to do so, and their funding moves with them.

The people supported by Spectrum range in age from 19 to 76 years, with all levels of care and support needs. Most have experienced group living or day programs in the past, and they came to Spectrum looking for something different. Many were referred to Spectrum after a previous placement broke down, or because their unique needs were not being met in traditional services (challenging behavior, dual diagnosis, complex health care).

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Spectrum's services have grown from supporting 12 people in 1989 to 140 today, and almost all of this growth has been in individualized rather than congregate service arrangements. In 2014 the four residents from our first duplex moved into homes of their own, the culmination of individualized planning processes that led to each person opting for a different living arrangement, and we closed that resource. Just as we have moved away from congregate living, Spectrum has also resisted opening a group day program, instead focusing on inclusive activities in each person's local community. We encourage the use of generic services and natural supports as a first option, with paid supports augmenting rather than replacing the support that is available to anyone else in the community. So instead of starting with the assumption that people need a day program, we start with the assumption that people need a good life, and look for the opportunities within each person's community and network. That's not to say people don't need support, but they might not need Spectrum staff supporting them around the clock. A number of people work at paid or volunteer positions, with or without support. Many belong to community organizations or take part in typical activities at their local community centre; some are pursuing post-secondary education, while others are focused on learning skills for independent living. It is not uncommon for people to need less paid support over time, as they expand their networks and build their repertoire of skills and interests.

How much Spectrum will continue to grow, and how quickly, is a question that comes up for us a lot. We regularly receive requests to develop new services. Clearly there is strong interest in individualized options, especially from the current generation of youth who are transitioning to adulthood. We are sensitive to the potential risks to individualization that come with continued growth, the potential for standardization and "one size fits all" solutions to start to creep in. We've worked hard to develop systems that minimize the bureaucracy and keep decision-making as close as possible to the person. This is a work in progress. Some of our service arrangements operate quite independently, with Spectrum very much in the background in a supporting role. For others, the relationship ebbs and flows, as we discover how best to work together and as people's life circumstances change. Spectrum has all the usual compliance requirements that need to be satisfied – contractual requirements, employment standards, accreditation – and we are working within the same funding guidelines as other service providers. Our individualized services meet or exceed all of the compliance requirements and cost the same as or less than traditional services.

Making the shift to individualized services is an organizational effort. It's not about designing a new model to add to our menu of services, it's a fundamentally different approach to service. We are constantly learning from our experience and adapting our practice as we go. Some of the key elements have been:

Communicating a clear vision – in 2010, we embarked on a comprehensive strategic planning process, meeting with a dozen stakeholder groups over the course of that year to gather feedback and hear their perspectives. The themes that emerged reinforced and helped further define the path we were already on, namely shifting from agency-directed to more personalized, network-driven supports. The result was a new mission statement and clear goals for the next three years that people rallied behind and took ownership of. The time and effort that went into this process was hugely beneficial in articulating a distinct vision for Spectrum that became the impetus for reviewing all aspects of our operations to assess how our day to day practice aligned with our stated vision, and make the necessary changes to bring about greater congruence.

Partnering with families – family involvement has been a core value at Spectrum from the beginning, but in recent years we've been focusing more on these relationships as a partnership, where the scope of involvement is defined on an individual basis rather than presumed to be all encompassing, as it often is in traditional services. We see our role as standing with families, and supporting their natural authority and their capacity to do the things families typically do for and with one another. Often families tell us this is a refreshing change from dealing with service providers who have presumed authority over all aspects of their loved one's life and paid lip service to their involvement or discouraged it outright.

Leadership development – having the right people in the right roles has been critical. The skills needed to develop and nurture a personalized support arrangement are very different from the skills needed to manage a group home. As our services evolved, so too did our leadership team, and this sometimes involved moving people into different roles or recruiting new leaders who shared our vision. We have invested in leadership training and made it a priority to create time and space for our leaders to meet regularly, exchange ideas and learn from each other.

Connecting with like-minded organizations and leaders – we have made a point of connecting with leaders

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in community living and other sectors that are having similar discussions (aged care, mental health services), both locally and abroad. We welcome opportunities to host visitors from other jurisdictions or share our experiences at conferences and training events. We have invited leaders with expertise on personalized supports to consult with us and give us feedback on our services. We have visited like-minded organizations across North America and participated in leadership exchanges with some of these organizations, which always prove to be energizing and great learning opportunities.

One person at a time – each situation is so unique; there really are no cookie cutter solutions. The importance of listening with an open mind to the people and families we're supporting cannot be overstated. We did not start by announcing a plan for wholesale change; we started with one person who wanted to make a change, and then another, and then another. Through their example, more people started to come forward, and the momentum grew. The service arrangements that evolved were as different as the people themselves.

The right match – recruiting staff who are a good fit for the person they'll be supporting is crucial. In a congregate service, there is an expectation of interchangeability; that all the staff can work with all of the program participants or residents. Staff all receive the same training and have the same job description. In a personalized service, the support will look very different from one person to the next. Rather than recruiting for a particular credential or skill set, the focus shifts to recruiting for someone with shared interests, and the right relationship. We have hired artists, musicians, fitness instructors who may or may not have any prior experience supporting people with disabilities, but who made a connection with one person and saw that person as an individual with strengths and gifts to share rather than seeing the person as a client. Some of our best staff came from fields outside of the human service system. About half of our staff now come through personal referrals, many of them through connections made by the person or family themselves.

The right match can also refer to the support arrangement itself, being creative about how and when support is provided, and balancing paid supports with natural or unpaid supports. Not everyone needs or wants 24-hour support, and in fact many people have reduced their paid support over time as they've become more connected and expanded their network of natural supports.

An organizational effort – transforming to individualized services has been a process of agency transformation. All parts of our organization, from our Board of Directors to our finance and human resources departments, to our monitoring and quality assurance systems, have been part of this transformation. Our finance team has helped us figure out how to individualize the budgets and simplify the process for dispersing and tracking money. Our human resources team regularly involves people in interviewing and selecting their own staff, and in fact nobody gets hired into a permanent position any more without being vetted by the person and/or family. Our vision for our administrative support is that it truly is a support rather than a hindrance to individualization. We strive to keep the paperwork to a minimum, and have moved to online reporting as much as possible so our staff and leaders can complete their reporting requirements remotely without having to come to the office.

Network development – some people already had strong networks of family and friends, but others did not. An argument that we sometimes hear in favour of group homes or congregate day programs is that they provide a social network for people who might otherwise be isolated. Everyone needs people in their life who care about them, and for most of us that means family and friends. If people don't have a network, it's a priority for us to help them build one, to expand and deepen their connections so that they are not isolated and so they have trusted allies who can support them with planning and decision-making.

Small projects as a vehicle for agency transformation – we organized a number of small projects that showcased examples of successful individualized services and engaged people who wanted to explore this further, using a co-learning model. The participants, in turn, took their learning back to their teams and spread the word on individualized services, which had a ripple effect through the agency. People were able to see real life examples and hear from each other what was involved in transitioning to a different kind of support. These small projects were a great way to engage people at all levels of the organization, and to channel the interest of those who were already excited about individualization. We should note that not all of the projects were equally successful, but the learning was invaluable and always pointed to areas for further learning and development.

Spectrum's foray into individualized services is a journey we've been on for nearly 30 years. We're still learning and we are by

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no means at the end of the journey. Most people now have an individualized service arrangement, but a number of people still share their support or live in homes that are not their own. Some of these arrangements have been in place for many years, and the people who are supported or their families do not wish to make a change. In some cases staff have been resistant to change. The transitions have not always been easy. A lack of affordable housing in Vancouver poses a significant barrier. And of course dealing with various funding bodies and bureaucracies can be challenging. Minimizing the bureaucratic demands, and keeping the bureaucracy away from the person, requires constant vigilance, as we work in an environment of seemingly endless government restructuring and regulatory changes that tend to favour standardization over individualization. Individualization requires those in positions of authority to stand with the person as equals, and share their authority, and this means being willing to stand up to forces that would disempower these relationships.

Our hope would be that other service providers take up the challenge of transitioning to individualized services and that they become the norm rather than the exception.

About the Authors

Ernie Baatz, Susan Stanfield and Aaron Johannes

are the co-directors of Spectrum Society for Community Living, overseeing supports to 140 people living in and around Vancouver, British Columbia.





NEW!

Welcome to **TASH Amplified**, TASH's new podcast series. This series seeks to transform research and experience concerning inclusion and equity for people with disabilities into solutions people can use in their everyday lives.

Season One Episodes

A Brief History of PBIS

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Building Communities to Support People with Disabilities

Faith and Flourishing: Equipping Your Church to Reach Out to People with Disabilities

Presentations on Recreation and Leisure for People with Disabilities at the TASH Annual Conference

Faith and Flourishing: Welcoming Children with Disabilities and their Families

Faith and Flourishing: Hidden in Plain Sight

Barb Trader Reflects on a Lifetime of Accomplishment in Disability Rights

www.tash.org/amplified

2016 TASH Conference

Well, St. Louis, you treated us well!

Earlier this month, we hosted our 41st annual conference at the beautiful Union Station Hotel. We had nearly 800 attendees, 300 speakers, and two concerts. Every hour on the hour, we were treated to a light show in the hotel's iconic lobby. Attendees joined us from 48 states and 14 countries, including Turkey, Australia, and Thailand.

To kick off the conference, our new Executive Director, Ruthie-Marie Beckwith welcomed the crowd at the Opening Reception. She introduced some of TASH's 2017 initiatives, such as our communication access campaign, the TASH ambassador program, and our work on the YES Center, a technical assistance center focused on transition-aged youth, which TASH was recently awarded through a federal grant. Wow, 2017 is going to be a busy year! Ruthie concluded her remarks with awarding our exiting board members and our 2016 TASH Award Program winners with their plaques. The evening continued with hors d'oeuvres and a performance by [United by Music North America](#).

We did something a little different for our general sessions this year. Each session featured a panel of experts from different backgrounds and with different outlooks on life. We had parents, policy makers, researchers, service providers, parent trainers, TASH staff, and self-advocate Chris Worth, who had the crowd rising to their feet in awe.

This year we added [Recreation & Leisure](#) to our session topics. This topic just so happened to draw a crowd to the most popular breakout session, [Love and Disability: Removing the Barriers](#), presented by Stephen Hinkle. Other popular sessions included our Wednesday Workshop [Faith and Inclusion: Embracing](#)

Inclusion for People with Disabilities in School and Community, presented by Mona Fuerstenau and Anthony Armitage. Subscribe to TASH Amplified Podcast listen to a preview of the workshop. And our symposium, [Inclusion Means Diversity & Cultural Competency](#), moderated by Natalie Holdren, also drew a crowd. Subscribe to TASH Amplified Podcast to listen to Natalie's preview of the symposium.

Our poster presentations went off with a bang this year! We awarded the following recipients with our 2016 Best Poster Presentation Award:

- ◆ [Living with a \(Dis\)Abilities in Post-Socialist Ukraine: A Fight for Equity](#) by Inna Stepaniuk
- ◆ [Fair Housing Rights and Enforcement](#) by Vard McGuire
- ◆ [A Couples Therapy Framework for Adult Couples with an Intellectual Disability](#) by Rebecca R. Kammes & Megan Lachmar
- ◆ [Video Hero Modeling \(VHM\) on Improving Self-Care Skills of Elementary-Aged Students with Developmental Disabilities](#) by Yoshihisa Ohtake

If you missed this year's conference in St. Louis, you can catch up by searching the conference hashtag [#2016TASHconf](#) on Twitter, Facebook, and Instagram. You can also view our conference photo album on Facebook.

Finally, we'd like to thank all of our attendees, exhibitors, sponsors, volunteers, board and committee members, and staff for making the 2016 TASH Conference one of the best yet. We hope to see you all next year in Atlanta, GA, December 13 - 15th!



Thank you to our 2016 Conference Sponsors:

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Minnesota

Vocational Rehabilitation Youth
Technical Assistance Center

Youth Transitions National Support
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Chapter News

Missouri TASH is deeply saddened to announce the passing of our dear friend Adonis Reddick.

Adonis was a tireless self-advocate for people with disabilities, and dedicated his life to patiently educating others about the need for a more inclusive world. Adonis had been a very strong advocate in the St. Louis area, serving on the St. Louis Arc Social Justice and Human Rights Committees, and won the National Arc of the US Self Advocate award in 2015 in Indianapolis.

In addition to his work with St. Louis Arc, Adonis led the charge in his community to make real change. He was the co-founder of the Association of Spanish Lake Advocates (ASLA), a group committed to an accessible world based in full inclusion. Additionally, he was active in the Coalition of Truth in Independence (CTI), as a member of their leadership team. CTI brings together individuals & groups from the area to work together towards collective impact. An example of this was work recently done in St. Louis city, in collaboration with Missouri TASH and many other organizations, to promote the support for the removal of sub-minimum wage for individuals with intellectual and developmental disabilities. Adonis also consulted

with local governments, agencies, businesses, and neighbors to ensure that the voices of those living with a disability were heard.

We would like to close with a quote from Adonis himself, which summed up his positive approach to life:

“Living with a disability doesn’t end your life — it just opens up different doors. If you choose the right path you will have an awesome life. You have to advocate yourself, and network with the correct people. Surround yourself in an intellectual setting, and never give up on yourself. Organize, create, and follow through with daily tasks, and events that will keep you motivated to achieve amazing success.”

More news articles about Adonis:

- ◆ http://www.stltoday.com/news/local/crime-and-courts/advocate-for-people-with-disabilities-killed-by-dog-in-his/article_390c4e4b-d54c-5070-b492-6aeaa677524d.html
- ◆ <http://fox2now.com/2016/05/11/man-killed-by-his-dog-was-advocate-for-the-disabled/>
- ◆ <http://dmh.mo.gov/dd/spotlight/docs/adonisreddick.pdf>



TASH Membership Form

Organization Name (If applicable): _____

Organizational members fill out the following fields for the Primary Contact only.

First Name: _____ Last Name: _____

Address: _____

City/State/ZIP: _____ Country: _____

Phone: _____ E-mail: _____

Membership Level

TASH offers membership at a variety of levels. Please review the details below and choose the membership level that is appropriate for you. Individual and organizational memberships are available. Membership is valid for a 12 month term. A complete summary of member benefits can be found at www.tash.org/join.

	Regular	Reduced			Organization \$385
	Professional \$165	Associate \$85	Self-Advocate, Family & Sup- porter \$35	Student \$45	
Research and Practice for Persons with Severe Disabilities, the official TASH research journal (print copy)	X				1 COPY
Research and Practice for Persons with Severe Disabilities, (online access to current and archived issues)	X	X		X	X
Connections, the quarterly magazine written by and for TASH members	X	X	X	X	X
Connections Library (includes access to 10 years of Connections archives)	X	X			X
TASH webinar archive	X				X
Reduced registration rates for TASH conferences and events	X	X	X	X	5 STAFF
Discounts for TASH Training webinars, publications & other offerings	X	X	X	X	5 STAFF
Access to TASH's professional network, forums & blogs	X	X	X	X	X
Affiliation with a TASH Chapter (includes policy and expertise, Capitol Hill Days, Chapter communications & activities)	X	X	X	X	X
Advocacy Alerts & Updates	X	X	X	X	X
	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select	<input type="checkbox"/> Select

Demographic Information

This information is collected for TASH's use only so that we can better serve our members' needs.

What is your race or ethnicity? (Optional; select all that apply)

- American Indian or Alaska Native Native Hawaiian or Pacific Islander
 Asian Black or African American
 White/Caucasian Hispanic/Latino
 Other _____

Which of the following best describes you? Select all that apply. (not applicable for organizational members)

- | | | |
|--|--|---|
| <input type="checkbox"/> General Educator | <input type="checkbox"/> Person with a disability | <input type="checkbox"/> Government – Federal |
| <input type="checkbox"/> Special Educator | <input type="checkbox"/> Parent of a person with a disability | <input type="checkbox"/> Government – State |
| <input type="checkbox"/> Education Administrator | <input type="checkbox"/> Sibling of a person with a disability | <input type="checkbox"/> Government – Local |
| <input type="checkbox"/> Transition Educator | <input type="checkbox"/> Other family member of a person with a disability | |
| <input type="checkbox"/> University Faculty | | <input type="checkbox"/> Attorney |
| <input type="checkbox"/> University Researcher | <input type="checkbox"/> Early Intervention Service Provider | <input type="checkbox"/> Public Policy Advocate |
| | <input type="checkbox"/> School-Aged Related Service Provider | <input type="checkbox"/> Other Advocate |
| | <input type="checkbox"/> Adult Service Provider | <input type="checkbox"/> Other _____ |

Please indicate your areas of interest. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> Early Childhood | <input type="checkbox"/> Community Living | <input type="checkbox"/> Assistive Technology |
| <input type="checkbox"/> K-12 Education | <input type="checkbox"/> Aging Issues | <input type="checkbox"/> Communication |
| <input type="checkbox"/> Transition | <input type="checkbox"/> Advocacy | <input type="checkbox"/> Diversity & Cultural Competency |
| <input type="checkbox"/> Post-Secondary Education | <input type="checkbox"/> Public Policy | <input type="checkbox"/> Human Rights |
| <input type="checkbox"/> Employment | <input type="checkbox"/> International Issues | <input type="checkbox"/> Other _____ |

Additional Information

Your Date of Birth (Optional): _____/_____/_____

If you are a family member of a person with a disability, fill out the date of birth of your family member: _____/_____/_____

If you are a student, please fill out the following fields:

University Name: _____ Expected Completion Date: _____

Major/Department Name: _____

If you are a university educator, what is your field of study? _____

Payment Information

Credit Card (select card type)

- American Express Visa
 MasterCard Discover

Check (make payable to TASH)

Purchase Order

P.O. #: _____

(send copy with membership form)

Card #: _____ Expiration: _____

Name on Card: _____ CVV: _____

Authorized Signature: _____

Would you like to make a tax-deductible donation to TASH?

- \$10 \$25 \$50 \$100 \$ _____

Total Payment (add membership total and donation, if applicable) \$: _____

Please submit this membership form via mail, fax or e-mail. With questions, contact (202) 540-9020.

2013 H Street, NW, Suite 715

Fax (202) 540-9019

Washington, DC 20006

E-mail info@tash.org

www.tash.org to learn more about TASH

www.tash.org/join for an overview of member benefits





TASH Connections

Equity, Opportunity and Inclusion for People with Disabilities since 1975

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please visit www.tash.org.

TASH Mission & Vision

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- ♦ Advocacy for equity, opportunities, social justice and human rights
- ♦ Education of the public, government officials, community leaders and service providers
- ♦ Research that translates excellence to practice
- ♦ Individualized, quality supports in place of congregate and

segregated settings and services

- ♦ Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- ♦ All individuals have a home, recreation, learning and employment opportunities
- ♦ All children and youth are fully included in their neighborhood schools
- ♦ There are no institutions
- ♦ Higher education is accessible for all
- ♦ Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- ♦ All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- ♦ Injustices and inequities in private and public sectors are eradicated
- ♦ Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- ♦ All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- ♦ All individuals with disabilities have the tools and opportunities to advocate on their behalf