



ST JOHN OF GOD

ACCORD

International Study Tour

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IMAGINING BETTER TOGETHER

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A Division of



ST JOHN OF GOD
HEALTH CARE

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Abbreviations

ACE – Access to Community Employment, Jay Nolan, Los Angeles

BOC – Brothers of Charity, County Clare, Ireland

COS – Circles of support

IHR – Institute of Health Research, Lancaster University, England

JNCS – Jay Nolan Community Services, Los Angeles

KCI – Kendrick Consulting International

LAC – Local Area Coordination, Perth, Australia

OCL – Onondaga Community Living, Syracuse, New York State

PCP – Person Centred Planning

QOL – Quality of Life

SJOGA – St. John of God Accord

SU – Syracuse University, New York State

INTRODUCTION

Twenty years ago, the baby boomers with a little help from Generation X, played an important role in deinstitutionalising disability services available in Victoria. Those efforts to imagine better challenged what was then, the gross devaluation of human life. People were moved into smaller institutions cleverly disguised as homes and educational and/or vocational facilities. People were unnaturally grouped with other disabled people, bereft of choices beyond what services offered and limited in their capacity to engage with their local communities and social networks. The current 'group' model of disability supports has, for too long, been widely adopted by the sector including the largest portion of services currently offered by St. John of God Accord (SJOGA). Operating services for large groups of people with disabilities fails to recognise people as unique individuals and retains their status as people currently marginalised by society.

Perhaps it's easy to pass today's service delivery paradigm as being adequate, especially when we compare it to what was happening twenty years ago. Compared with institutions, today's model would appear progressive by comparison. Our challenge today is to imagine better. Perhaps with Generation Y entering the workforce, there is a marked re-evaluation of practices? Fresh eyes entering the workforce are asking: why do we talk about being person centred when services are more program centred? Why talk about 'maximising opportunities' when we still have relatively low expectation of the people we support?

The challenges of reorienting disability services to personalised options are at our doorstep. Now more than ever, we bathe in the rhetoric of individualisation with a sense of hope. We dart about seeking definitions of this term in the hope of finding a direction that will enable the enigma to be operationalised. By its very nature, individualisation is a slippery term. It is a journey through which each destination looks different for each person. The process of operationalising individualisation is consequently reliant on defining the values that underpin it. These values are then transformed into behaviours that, in turn, facilitate our organisational transformation to individualisation. Our core business becomes to design, develop and implement each person's support as a potentially unique service arrangement.

The pursuit of individualised goals is widely accepted by the sector both here in Victoria and internationally as both a worthy and achievable as defined by the *Disability Act 2006*. As well as strengthening the rights and opportunities of people with disabilities, this act has prompted the Department of Human Services to individualise funding packages so that people accessing services have greater capacity to purchase services that best reflect their unique support needs. Internationally, this approach has, by and large, been successful in better meeting people's support needs. However, in Australia it remains in its infancy. This initiative will challenge support organisations like SJOGA to provide personalised, flexible and responsive services beyond the traditional group models we currently operate. Organisations that fail to embrace developing their capacity to deliver person centred services risk an unintended disservice to the people they support and unprepared exposure to the new 'market' of service provision created by individualised funding.

In trying to define what our own journey towards individualisation might look like, SJOGA commissioned a formal service evaluation by Kendrick Consulting International (KCI) to identify key decisions the organisation should consider before moving to personalised options. As a relevant safeguard, the evaluation recommended several SJOGA leaders to enlist seasoned people with extensive experience with service transformation. That recommendation triggered a recent study tour of international support agencies and research centres that have either reoriented or are in the process of reorienting to personalised options. Our exposure to the values and operations of such organisations has triggered many questions that will facilitate our ability to imagine better over the years to come as well as providing some insight and inspiration into how this transition can be successfully achieved.

SJOGA SERVICE EVALUATION

Consultative Review with Michael J. Kendrick PhD

“The goal of person centred services has been widely accepted by leaders in the disability sector both here in Australia and internationally. This direction has been explicitly endorsed by Accord in recent times in its service principle of individualised support response, or “Built for me”. Accord is seeking to ensure that its service recipients become as well positioned in coming years to be able to fully take advantage of progressive practices in the sector.”

Kendrick, M (2007) SJOGA Consultative Review, Kendrick Consulting International, P.3

In recent years, the concept of designing and operating services collaboratively as individual service arrangements has become part of the mainstream thinking of the sector. The goal of personalized or ‘person-centred’ service would now be considered by many in the sector as a worthy and practical goal for services to address. Nonetheless, many agencies have found it challenging to transform their group and fixed models of service into individualised options. Part of the difficulty they face is an absence of methodological clarity as to how personalised services can be implemented coupled with a paucity of local success stories and organisations that could profitably serve as mentors and examples.

In November 2007, SJOGA commissioned a service evaluation by Dr. Michael J. Kendrick (Kendrick Consulting International) to assist with its transition to personalised services. The review involved interviews with all key staff at Churinga—one of SJOGA’s day service programs—and senior and support staff. Family members, regional staff from the Department of Human Services (Victoria) and service users of Churinga were also consulted. In addition, over thirty person centred plans were examined as well as various key organizational documents including the:

- SJOG organisational development and design paper for Victoria
- SJOG/Accord Divisional Operational Plan
- 2005-2008 strategic plan and
- Existing program manuals.

An offer to meet with key stakeholders on a confidential basis was sent out by the evaluator and several stakeholders such as service users, family members and staff responded. Dr. Kendrick is recognized as an international expert on these directions and the intent of this review is to obtain his recommendations regarding:

1. The relevance of this goal for the future of Accord's services.
2. The best ways to transition from today's service models to more individualised ones and the likely time frames needed to accomplish this.
3. How to ensure that organisational values and service quality are maintained in such a transition and properly embedded in future service models.
4. How the key stakeholders in such a transition may be suitably engaged in the transition process.
5. Key decisions and investments that may be required of Accord to make personalised options more widely available to its service recipients and;
6. Any specific organisational change recommendations that may be pertinent to achieving success in service reorientation to individualised options to meet service principle: ‘Built for me’.

Key Recommendations to emerge

1. Begin the process of converting to individualized options with a small cohort of service users with an emphasis on depth, quality and learning and defer taking on greater numbers until SJOGA has developed the internal capacity to reliably do a good job.
2. An Individualised Support division should be established within SJOGA to manage the anticipated emerging individualised supports situation. In time, these divisions will be the focus of the majority of effort within SJOGA's portfolio of programs.
3. An ethical partnering ('Right relationship') policy be developed and promulgated in regards to SJOGA's relationship with service users and families. Ideally, this should include such persons in its formulation and dissemination.
4. SJOGA to formulate and implement several small joint demonstration projects of creating individualized supports in conjunction with the Victorian Department of Human Services.

Service Evaluation - Recommendation 16

"It is recommended that, as an important safeguard, it would be important for key SJOGA 'Built for me' leaders to enlist several seasoned persons with extensive experience with service transformations of the kind necessitated by 'Built for me' to serve as consultants on key issues as they arise, particularly in the crucial formative three year period."

Kendrick, M (2007) SJOGA Consultative Review, Kendrick Consulting International, P.22

INTERNATIONAL AGENCIES

St John of God Accord acknowledges the need to develop professional relationships with progressive organisations as an opportunity to learn more about the successful implementation of personalised services. We have identified three organisations on an international scale that are either in the process of transformation or have successfully reoriented their services to a model that reflects the principles of individualisation. The study tour report also identifies one state government agency that has reoriented its services to respond to similar needs yet does not directly provide support services. The study tour report also highlights two Universities currently active in research and evaluation to support best practice in moving towards person centred or individualised service design.

We thank the following organisations who hosted SJOGA during the study tour. They generously offering their time and understanding of their unique journeys towards individualised supports. This report, *Imaging Better*, offers an overview of each organisation and a summary of the key features that facilitate learning for organisations in Victoria seeking to meet the challenges of individualisation.

JAY NOLAN COMMUNITY SERVICES

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The mission of Jay Nolan Community Services, Inc. (JNCS) enables individuals with Autism Spectrum Disorder and other Developmental Disabilities to live fulfilling lives as members of the community by providing support services customized to their individual needs.

Jay Nolan Community Services Inc. is a nonprofit organization established in 1975 by members of the Autism Society of Los Angeles. Initially named Programs for the Developmentally Handicapped, Inc., JNCS operated a social and recreational Saturday program, group homes and day programs. But in 1992, it began changing the way it provided services.

JNCS closed its group homes and began providing supports to people that enabled them to live in their own homes, have jobs and participate in other valued activities during the day. Today, JNCS provides an array of support services in Los Angeles, its surrounding counties and Santa Clara County, offering individualized planning guided by the needs and wishes of the person receiving services and his or her circle of support.

JNCS believes that:

- All people have capacities and gifts.
- All people need a sense of belonging to a community.
- All people contribute to a community.
- Relationships and trust are equally fundamental for inclusion to happen.
- All people can live in their own home with the right support.
- All people should be treated with dignity and respect and have a right to privacy.
- For all persons, self-advocacy and empowerment should be promoted.
- All people have the right to be free from pain, coercion and cruelty.
- All people have the right to be heard and their ideas acknowledged.

JNCS's philosophy is based on the belief that with the right kinds of support and assistance, individuals with disabilities can pursue their hopes and dreams and live to their full potential within the community. It is an ideal of inclusion rather than exclusion and segregation.

www.jaynolan.org

ONONDAGA COMMUNITY LIVING

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Onondaga Community Living, affectionately known as OCL, has its office in central New York State in the city of Syracuse. OCL provides services to adults with intellectual and developmental disabilities within the Syracuse area and nearby communities. In 1987, OCL began operating its first group home and subsequently developed two additional group homes along with a small supported employment service. As time went on, OCL began to see that there was another way of delivering services to the people it supported.

As OCL staff began to know the people who lived in the homes better, they realized how the very homes that the agency had developed were not working for each of the persons within them. New people also came into the agency and new services began to emerge that were based upon individual need and desire, not the needs and desires of a group. The new people who came to the agency were very happy with this personalized support service. Some of the staff and families of the people who lived in the current group homes began to envisage a new way of doing support for those involved.

The process of organisational change began with closing two of the group homes and personalizing the supports and households for each of the person's involved. Those at OCL had learned to listen differently to the behavioural concerns that people exhibited. Instead of trying to control someone within a group, the agency began to realize that services based upon a single person and their needs and desires would equate to a happier and more content individual.

Onondaga Community Living's mission is to empower and individually support people with developmental disabilities in the efforts to live full lives as integral respected members of their community.

This mission is achieved by:

- Listening to and focusing on each person.
- Helping each individual to build positive relationships with others.
- Supporting each individual's efforts to achieve personal fulfillment.
- Exploring and developing ways to support each individual in his or her personal pursuits.

www.oclinc.org

BROTHERS OF CHARITY

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The Brothers of Charity Services is an international, voluntary religious organisation founded in Belgium in 1807, by Canon Peter Triest. The Brothers of Charity opened their first services in Ireland in 1883 to provide for mental health needs. In 1938, they started to develop services for people with an intellectual disability and their families. These services grew steadily over the years, so that today, the Congregation is the largest provider of services for people with an intellectual disability in Ireland.

These Services are organised into six regions: South Eastern, Southern, Limerick, Clare, Galway and Roscommon. As a fledgling service independent from the mid-Western region since 2000, Brothers of Charity County Clare (BOC) find out about and respond to, the voices of service users and potential service users in their region and make those voices more evident in the shape service provision. In 2006, Brothers of Charity 'drew a line in the sand' deciding that no new people entering their service would be placed in group homes or the workshop. As existing service users saw individualisation in action, they began to imagine better for themselves.

Currently, the service comprises three core resource centres for adults in Ennis, Ennistymon and Kilrush with community homes and rented accommodation attached to each. Children's services and the training and development department are based in Ard na Greine and respite breaks are offered in Corrovorrin and Ballybeg, Ennis. The outreach team provide support to those with a challenging behaviour and professional services and administrative services are based in Banner House, Ennis.

BOC's *Personal Outcome Measures* training program alongside the '*How are we doing?*' evaluation model has enabled them to gauge the success of their work by seeking: freedom, opportunity and respect. BOC are committed to respect and value each individual and support and challenge each person to develop his/her talents to the optimum. To achieve these aims BOC will:

- Always respect and safeguard the dignity of the human person
- be service user centered: adopting the principles, spirit and letter of '*Sharing Community*'?
- Prioritize the formation of service communities throughout the services and;
- Involve parents, families and advocates in determining the future of service users.

<http://www.brothersofcharity.ie/clare/index.php>

LOCAL AREA COORDINATION

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Local Area Co-ordination (LAC) is a uniquely Western Australian strategy implemented and designed to make disability supports and services more personal, localised and accountable to the needs of the person. Established in 1988 to cover all ages and a wide range of disabilities, LAC has a clear framework and evidence base for working alongside people in their local communities.

LAC has provided support across Perth and regional areas of Western Australia and its co-ordinators are based locally in communities each providing personalised, flexible and responsive support and assistance to between 50 and 65 people with disabilities aged 0 to 60 years. LAC's aim is to build and maintain effective working relationships with individuals and families. LAC does not provide direct support: they consider a rich and fulfilling life to be the result of a number of freely given relationships, their level of satisfaction with life a reflection of the quality of those relationships.

Innovative planning and vision for Local Area Coordination will:

1. Build and maintain effective working relationships with individuals, families and their communities.
2. Provide feedback, timely information and educate all streams of support networks. Information needs to be accessed through a variety of means. This will ensure everyone is kept involved and interested in the framework and changes to the service provided.
3. Provide support networks with support along the way and practical assistance to help reach and clarify their goals.
4. Always promote self advocacy and ensure advocacy support and access is independent to advocacy.

The role for Local Area Coordinators is to:

1. Contribute to building inclusive communities.
2. Create partnerships.
3. Collaborate with individuals, families, local organisations and the broader community.
4. Assist individuals to strive towards independence and utilise personal and local community networks. This will help maintain and direct the goal orientated process.
5. The LAC initiative operates as a service coordinator rather than a service provider, which involves co-ordinating the support to the person with the disability and their families/carers to plan, select and receive needed supports and services.

<http://www.disability.wa.gov.au/publication/lacsupport.html>

A PARADIGM SHIFT

Motivation for change

Change is usually motivated by problems that threaten an organisation's financial position within a specific market: 'success' is therefore often defined by profitability. In the social services sector, we have no goods to sell and the outcomes for the people that we support are often less tangible and more emotive. As one organisation visited described, '*We are in the good karma field*'. Consequently, the motivation behind change to personalised support options was felt more than heard through conversations with the organisations we visited. More often, it was a CEO or an executive's unwavering vision and belief that there was something better out there.

"We worked the way we did because we always had and it was better than the way we worked before, but, I always knew there was something better out there." Mary Kealy, BOC.

Leaders of the organisations we visited were often the motivators of change. These transformational leaders spoke of the heart-wrenching perspectives of the people they support and their families, arguing that services provided not only weren't working but were a violation of human rights that often destroyed relationships with families and communities. Jeff Strully (JNCS) stated that 'people cared, but what was happening wasn't good'.

Staffing issues pose a problem within the Victorian disability and welfare sectors. These issues are often described as the inability to attract competent, qualified and professional staff. By contrast, the organisations visited did not consider staffing to be a problem. Client behaviours, family contempt, staff practices were all considered to be a result of a system that was failing. This situation made boards unhappy, generated expensive operational systems and did not meet the intrinsic needs of the people supported families or staff.

The vision and mission of these leaders was impressive regarding the way people with disabilities should be treated. Essentially, the need and desire to create an environment that valued people matched the unwavering belief that it could be done. Problems along their respective journeys to individualisation were acknowledged as part of the process that strengthened their sense of purpose. All organisations faced opposition to what was considered radical change in comparison to the traditional services being offered within their respective communities.

Changes to individualisation were not driven by state policies or directions of funding bodies but were the product of the values and belief that people deserved better lives than the ones they were currently living. Inspirational leaders operationalised these values without additional funding. These organisations imagined better and achieved better with the same funding local traditional services received. A lack of resources is often used as an excuse for not taking initial steps towards service reorientation. The services we visited demonstrated that challenges only exist to be overcome. Importantly, seeing the tangible results of overcoming challenges in the improved quality of life for people supported, removes feelings of uncertainty.

Drawing a line in the sand

“The initial steps toward personalised support alternatives were like approaching a cliff face and preparing to jump into unchartered waters” Pat Fratangelo, OCL.

Each organisation altered services at differing paces with differing levels of preparation. Jeff Strully (JNCS) stated the question organisations had to ask themselves before jumping into personalised support arrangements was ‘can you handle that kind of uncertainty?’ The journey for Jay Nolan was taken by committed and concerned staff and inspirational leadership. There was little ambiguity about the task at hand or proposed outcomes. Statistically, the organisation can boast of some extraordinary outcomes as it completely reoriented its accommodation options for nearly 100 people in two years and, in a further two years, individualised day options. It would be easy to assume such achievements were possible only when working with people who are higher functioning. Yet within their accommodation network, 90% of the people at JNCL have access to 24-hour support. There are no prerequisites for people having the opportunity to live independently and this was showcased in all services visited. While there are definite assessments to determine need and vulnerability for individualised accommodation, such assessments enable people to live in their own home with the right supports in the right environment.

Pat Fratangelo (OCL) moved ‘one person at a time’ ensuring that resources were built for each individual and that timing for everyone was perfect. The journey for OCL still continues today. Their attention to detail is highlighted in their philosophy and practice. OCL have discovered that they have made considerable progress in improving individual’s lives. Today’s challenge is to continue responding to the ever changing needs of people. This demonstrates that their journey with people has no set outcome. With this in mind, we can reflect on the goal that quality of life is not a destination but a continual process of imagining better and actively searching for what an individual’s life might look like, one person at a time, day by day.

A common theme with all these organisations is that a support system should not drive the change, the service user should. While the staff and board of OCL made progress in helping individuals transition from the group home, they recognise that much is still missing such as social life, stability of living situations, housemates, new experiences and friendships. OCL sees its work as ongoing and unfinished.

Mary Kealy (BOC) began with building resources in the community, shifting staff perceptions through training and building roles around people. She ‘drew a line in the sand’ in 2006 by saying that ‘the abuse of today is not letting people choose where they live’. New referrals were not sent to group homes and workshops; rather a process was set up to facilitate people’s choice of where to live. This was achieved but soon *everyone* wanted these choices. The pace of moving people out increased along with staff anxiety. Mary Kealy cautioned that ‘when things happen too quickly, we risk going back to the old ways’.

Key components to success across these services include:

- External expertise: Michael Kendrick was considered by all to be an initial inspiration but it was the local networks he established that proved to be an ongoing and necessary support for the change process.
- Internal relationships: the most vital component to success was the building of relationships with families, communities and staff to establish effective circles of support that would support individual’s to shape service delivery.

Key Features

Choice vs. Control

The word choice is something we often see from the rhetoric offered by generic disability agencies. When we explore this concept further, it highlights an opportunity to choose from the set options an agency offers. This is certainly the case when we reflect on a traditional day service offering a range of fixed group-based options for people during set periods of time. The idea of agencies building and operating services as pre-determined models of what's available both challenges the ideal of real choice and begins to explore what might be a far more useful relationship between a person receiving services and the agency providing them. This is something we have not quite digested fully nor explored with any conviction here in Victoria yet commonly referred to as a 'right relationship' by the agencies visited during the study tour (Kendrick 2003).

In defining this delegation of authority with 'choice', the agencies visited demonstrated an understanding of working with people to identify choices that create opportunities to make valued contributions to their community. Giving choice to the people we support is unachievable in the current paradigm of service delivery that offers options within group settings and resource allocations. Historically, choice has often been a 'sacred cow' for some staff who may not see their role as supporting people to make decisions that build competencies and positive social imagery to give people the best chance of being valued.

Do organisations allow people to make poor decisions? How does an organisation maintain a person centred approach yet intervenes when people may be on potentially self-destructive paths? Although individualised, the services we visited also have days when people communicate frustration with not being understood or when they are exposed to the challenges of daily life. In these circumstances, people are not labelled as being 'challenging' then dutifully medicated and possibly physically restrained. Of particular interest is the way organisations considered that it was *them* who were challenging for the individual and not the individual being challenging to their service structure.

With new disability legislation in Australia, challenging behaviour is now termed 'behaviours of concern'. While the notion of positive behaviour support has become widely accepted a best practice in the sector, we develop behaviour support plans, listing functions of behaviour such as to 'control one's environment' or 'competing for attention'. We identify predetermined models of support as limited in their capacity to be proactive. By operating fixed models of service with the expectation that people will fit into a model, we continue to see people challenge the generic nature of service.

Another interesting reflection on control from the study tour is the assumption that the people we support need 'consistency'. People who have little control over their environment will always adopt the second best strategy of preferring to be in a situation where they anticipate what might be happening *to* them next. This gives rise to our understanding that consistency is a need when it is much better interpreted as perhaps an alternative to control.

Person Centred Planning

The phenomenon that is known as person-centred planning was not evident in the operation of the organisations visited, at least not in the way we understand it here in Australia. Our own fascination in the new document more commonly referred to as the person-centred plan (PCP) is widely regarded as the tool that will facilitate the movement towards a person centred service being available to its recipient. That assumption creates the illusion that people who have a PCP may in turn be entitled to a better service. While a PCP presents an opportunity for people receiving services

to have their needs recorded, it offers very little in changing the culture in which services mobilise the proposed outcomes of a plan.

Living within a service that adopts the values and behaviours of a person centred culture is far more important than being extended the opportunity to annually record what might be possible. Person centred planning as we know it focuses solely on the *process* of including the people we support in the development of their plan. However, very little is offered in relation to guidance for its content or any outcomes. Even when the plan is written and outcomes are designed in a person centred way, little value can be achieved. The disability sector is at risk of seeing the illusion of choice in operation within a framework of limited and predetermined options.

The organisations visited do not have a template document written in first person language. Instead, these organisations have adopted a culture of spending the time to *understand* people through their daily interactions. Such processes are not formalised but delivered through their values of person centred living that offers staff as willing to learn more about the uniqueness of the individuals they support, what their needs are and how possibly the agency could accommodate such needs today. An organisation's response is never crystallised into a set model of working with each person; instead emphasis is on an organisation's flexibility and responsiveness to ever changing needs. This approach is something we can all relate to in the way we all live today.

Within the organisations we visited, the only formalised events are the circles of support meetings. These circles take place approximately every four to six weeks when a group of people committed to learning more about the person get together to imagine better with the person receiving services. During this meeting, everyone identifies what's working well in a person's life, what could be better and, importantly, what new things have been learnt to date. An important feature of the circles was the presence of staff delivering supports to contribute to imagining better given they are the key feature of a service aspiring to meet people's changing needs. This is in stark contrast to local planning attempts where a plan is facilitated and designed by a contracted agency and given to another agency to mobilise.

Raising expectation: Contribution and Challenge

Among other features of individualised service design, we observed a much higher expectation of the people we support during our tour than would be present in a traditional service. There is an expectation that people have a contribution to make, that people can live in their own home, that the people we support do have something to offer in freely given relationships and that people can sustain a vocational placement. Given the right environment, the right support and understanding of what's important to a person, all these things are possible.

When we explore societal expectations, contribution is high on the list. Although there are varying degrees of valued contribution, making no contribution is certainly devalued. Here in Australia it would be fair to say that there is little value attributed to people who do not contribute to their local community. The fact that we do not translate expectations of non-disabled people to the people we support highlights the low expectation we have.

During the tour, we spent time with people being supported in jobs either as volunteers, paid staff and small business owners. Taking on a valued 'role' was something that not only enhanced people's esteem but gave them a unique identity. The roles of volunteer, employee or small business operator challenge societal expectations of people receiving services. We were impressed by the investment in a strengths-based approach to supporting people to make contributions, which consisted of identifying the unique skills and talents people had and importantly, where in the real world they could be shared and appreciated. The work of services visited could be defined then as being services designed, developed and implemented with people to respond to real needs. More often than not, these needs included valued roles, a unique identity and autonomy, control, freely given relationships, contribution and challenge.

The acknowledgment, preparation and exposure to the social challenges of life can serve the personal development of the people we support. The alternative is protecting people from life experiences driven largely by low expectation, pity and a model of care. We have a tendency to ask ourselves in each situation if we are 'setting this person up to fail?' This comes from a parenting model of protection and care. It comes from good intentions but devalues and limits the experience of the people we support. We live in a free society, people get to choose their friends, clubs get to choose their members and sometimes it is very ugly and unfair... that's life. We have witnessed agencies embrace such candour and without resigning to its challenges, they actively educate, prepare and support people to be the best they can be. We will never change society's perception of disability by demanding greater compassion yet pursuing valued contribution, valued identities and roles will bridge that gap.

Interdependence

In attempting to define what a good life may look like, a key feature was the pursuit of freely given relationships. Given that most of our lives are made up of interdependent networks, people resigned to services are often exposed to having paid staff as sometimes the sum total of their networks. If not handled sensitively, this model will leave people bereft of opportunities to explore genuine and sustainable relationships.

Freely given relationships is heavily invested in by the organisations visited. Staff delivering support continuously ask themselves whilst active in their support, 'who else is here in this environment that we can connect this person with?' Furthermore, this is not something that is done randomly. Instead, staff seek to identify people who have similar interests and needs which facilitates the best opportunity for a new relationship to bear fruit.

One young man who has a particular interest in movies spent more of his time watching DVDs in his room, talking about movies he'd seen and imitating characters in movies. The process of 'imagining better' soon evolves into a community version where the young man now enjoys going to the cinema weekly with his support worker to see a film. This would be regarded in many circles as a huge step yet as the imagining better continues, we identify the individual is dependent on the paid worker to both facilitate the event physically and emotionally. Identifying other people that share similar passions allows the support to evolve into finding people to do that activity with the person as a freely given relationship. The support worker could resource film interest groups that go to the movies and support the individual to attend with the common interest group and facilitate conversation that allows the person to connect. Over time, this relationship has the potential to become both genuine and sustainable as the persons unique identity grows within the group.

This is something organisations did very well and although not every investment paid off, the ones that did, have a profound effect on people's esteem. Hearing similar stories identified that the art was in the matching of people and activities coupled with the belief that it can work. Presenting people as unique individuals to the community and not as part of a 'disabled group' is critical to facilitating integration. This philosophy is extended to the housemate role identified within most living arrangements hosted by the agencies visited. The idea of having a positive role model to share a house with was seen as a critical success factor for the individualisation of accommodation services.

Socially inclusive programs

The Victorian disability sector's goal of moving towards a socially inclusive model of support highlights the difference between community presence and community engagement. Being 'in' the community is not the same as being 'part' of the community, which is evident when we compare a traditional attempt to those witnessed during our visits. The tour provided us with great examples of identifying a unique environment where a person has the best opportunity to develop an identity that leaves any disability peripheral to the contribution they offer.

Despite our attempts to get into the community and do community activities, the way we've presented people has done little to change the perceived value people with disabilities can make. In identifying opportunities for people to be part of the community, we have generically created places for people with disabilities to attend. Our challenge is to identify opportunities for a person who is particularly interested in horticulture, for example, to share their unique talents and interests with the wider community as opposed to disability specific programs that are divorced from mainstream community networks. Such a strategy has seen traditional services in Victoria target sympathetic communities for larger groups such as neighbourhood houses and churches, which run the risk of becoming a new day hub for people with disabilities should our capacity to imagine better not improve. Some genuine attempts to support people one at a time in community settings can be easily undone by sending another two people then another four. Three weeks later, it is a 'program' for the local day service and the community cease attending. Our best chance of pursuing socially inclusive lifestyles is one person at a time.

RESEARCH AND DEVELOPMENT

The Institute for Health Research at Lancaster University

The Institute for Health Research (IHR) at Lancaster University is one of the leading research centres in the UK in the field of intellectual disability. Their aim is to undertake high quality research and development that is directly relevant to supporting the inclusion and quality of life of children and adults with learning disabilities in the North West, nationally and internationally. They have close working links with, among others, the Centre for the Economics of Mental Health (Institute of Psychiatry), the Welsh Centre on Learning Disabilities (University of Wales College of Medicine), the Centre for Disability Studies (University College Dublin), the Centre for Developmental Disability Studies (University of Sydney), and the Australian Family & Disability Studies Research Collaboration (University of Sydney).

The SJOGA team (Dr Anton Mischewski and Mr Claude Staub) met with Professor Chris Hatton and Drs Janet Robertson (Lecturer in Health Research) and Sara Morris (R&D Manger for User Involvement). Chris has worked with people with learning disabilities since 1989, and has particular interests in service quality and quality of life, staff, ethnicity and religion, the criminal justice system, and mental health. Janet and Sara have worked in learning disabilities research since joining the Hester Adrian Research Centre in 1993 and have experience of applying a wide range of research methods to the field of learning disabilities. Through the UK National Health Services Research & Development strategy, Sara is committed to involving the public, service users and carers in the work it undertakes—not as 'subjects' of research, but as active participants in the research process. Involving lay people in health research can help ensure that research is relevant and accessible. Users have already played an important role in some areas of R&D in the NHS, but there is scope for further work.

Areas of Research

Research and development projects are undertaken at the IHR into many different aspects of the health and social care of people with learning disabilities. These projects are commissioned from a number of sources including: the Department of Health, the NHSE, Charities, Local Authorities, Health Authorities and NHS Trusts.

The titles below identify current and recent projects:

- English National Survey of Adults With Learning Disabilities
- Person Centred Planning
- The Mental Health Needs of Children

- Supporting Children and Families From Minority Ethnic Groups
- Supporting South Asian Families
- Researching the Needs of Families of Children With Autism
- The Quality and Costs of Residential Supports
- Residential Supports for People Who Challenge
- Psychosocial Interventions for Psychosis
- Cognitive Behavioural Interventions.
- Observational Research
- Evaluating the Impact of 'Valuing People'.

Person Centred Planning Evaluation

Person-centred planning was a collaborative project involving the Institute for Applied Health & Social Policy (King's College London), the Centre for the Economics of Mental Health (Institute of Psychiatry), the North West Training and Development Team, the Department of Psychology, Guys, Kings and Thomas' Medical School, the Department of Clinical Psychology (University of Hull). The aim was to evaluate the impact of the introduction of person centred planning across four development sites. For twenty-five people in each site, information was collected over a two year period on:

- The characteristics of people for whom plans are developed
- Outcomes for service users and their families
- The comprehensive costs of service provision
- Service level outcomes.

IHR also looked at aspects of organisational structure, culture and performance that either facilitate or act as barriers to the effectiveness of person centred planning. This information provided the first comprehensive evaluation of the impact of person centred planning.

Person Centred Planning Discussion

We presented IHR members with SJOGA's evaluation plan including the questionnaires and tools from *Valuing People* that we adapted. IHR noted that their original questionnaires were very lengthy and a large proportion of the data they collected had not been put to the best possible use. It is disappointing that through lack of continuing funding, IHR are not collecting further data on their person-centred planning project making longitudinal analyses unlikely.

IHR were impressed with our truncated version but commented that they had now adopted a very abridged questionnaire for their evaluation of In-Control program. In a collaborative discussion, the IHR team identified what they considered to be key aspects to investigate if they were to continue this longitudinal research:

- 6 monthly changes are probably too soon to identify meaningful changes.
- Focus more on the tables of change data (in the questionnaires).
- Clarify at what point in a person's life and planning is data collected i.e. Specify what is 'before' and 'after' the planning.
- Include questions that can track more precisely where the planning process is at. IHR had great problems in this aspect as about 25% of their cohort did not manage to have a plan even during the two years of the study.
- Social networking: be clear about the *quality* of social relationships and not count fleeting relationships e.g. the postie who simply waves to a person from the window.
- Include some participant-observation data in the planning process to better identify how involved people are with their plan. Address how plans are specifically operationalised.

- Explore more fully the useful questions about the benefits and challenges of person centred planning. Interestingly, these questions were asked as open-ended ones in IHR's original study.
- Include more qualitative reviews of the planning process to capture the variations of good facilitator commitment that IHR identified as crucial to successful outcomes of individual budgeting.
- Develop better measures to identify how effective and resilient circles of support are built and sustained.
- Explore in more detail the area of 'natural supports': what does 'natural' mean and what part does person-centred planning play in reshaping what natural supports are? For example, how are natural supports cultivated and sustained when a person has a history of only ever having paid support/staff in their life?

Quality of Life

We discussed Quality of Life (QOL) and how it can best be measured. We agreed that QOL does not occupy as large a focus in the IHR's research strategy as it has in the past. IHR agreed with our comments that most measures currently available were focussed on the outcomes of standard disability programs such as CRUs and segregated day programs. Such QOL measures were about individual satisfaction levels and competencies with 'old world' disability services and supports. These measures failed to identify the change in cultural competencies that new individualised programs were bringing about.

We agreed that there needs to be a focus on integrating individual indicators of QOL with core mainstream 'normal' cultural competencies in the key areas of:

- Home: living in a situation where a person chooses.
- Work & Leisure: doing activities that a person chooses to engage with including employment, education, volunteering, recreational and leisure pursuits.
- Relationships: engaging in the social relationships of a person's choosing including friends, family, significant others and intimate relations.

The future value of QOL is to integrate individual indicators with the areas mentioned above: how do individual indicators make standards QOL measures meaningful for a particular individual? Other questions that emerged from the discussion included:

- What are the critical success factors for improving a person's quality of life?
- What has effected and augmented an organisation's capacity to facilitate *good* person-centeredness?
- What has had the most effect on a person's quality indicators being met?
- Is there sufficient flexibility in organisational structures to meet the needs of person-centeredness?
- Does the workforce *understand* person-centeredness and know how to develop an organisational culture of person-centeredness?

The Future of Disability Research Projects

We asked the IHR team for their thoughts on key areas they considered important for future disability projects and what areas could form potential collaborations with SJOGA and other Australian partners.

User involvement

IHR stated that the most challenging area for research was the early involvement of the people we support and resource in the planning, design, implementation and analysis of research. The IHR team directed us to the pioneering work of Dr. Paul Ramcharan (RMIT, Melbourne) and Dr. Gordon Grant (UK) who have conducted research on this complex aspect of involving people in all stages of any project. IHR admitted that this area of involvement is the most challenging and they did not have as successful a track record to date as they would like. The bulk of their research has been more participatory i.e. involving people with intellectual disabilities in projects that were already designed.

Dr Sara Morris discussed some of her work through IHR that focussed on educating user groups and disability workers about research and how it is conducted. She cited her successful approach of conducting small group and team learning circles to increase awareness and build competencies. Dr Morris has found that *research*, in the broadest sense of the word, is a mystified term that users and staff had little knowledge concerning its value or range of methods available. Often, research is something 'done to' a group by 'outsiders' who want to find something out about aspects of that group. There is often little-to-no involvement of the subjects in the development of a research project, its analysis and application of findings.

Dr Morris cited examples in the mental health field of best practice in user-involvement:

- Centre for Disability Research: using virtual methods to develop projects.
- Centre for Mental Health Research, which is supporting projects involving people at all stages of research.
- McMillan Cancer Institute.
- In-vole, a UK disability organisation.

Action-based Research, Social Justice and Citizenship

In the spirit of Appreciative Inquiry, we asked the IHR team what they see tomorrow's research agenda is for the disability sector internationally. The IHR team offered the following:

- Research on disabilities tends to follow innovative practice rather than lead and foster innovation and;
- Research, to date, has focused on bio-psychological individual competencies.
- Exceptions to these trends exist but IHR agreed that there was a dearth of research work on disabilities outside of psychology and social work disciplines. For example, management studies, arts, education, sociology and urban studies have few specialists who focus on intellectual disabilities.

We discussed the pros and cons of having a dedicated research centre focus on disabilities versus merging disabilities into mainstream disciplines such as: sociology, arts, humanities, business, management and urban geography, for example.

The IHR team's response was whole heartedly towards an action-based research model that draws on cross-disciplinary teams. Such a model does not presume prior research questions being set by 'the experts' but develops collaboratively the scope and methods of a question with all parties involved. Broadly speaking, action-based research privileges a democratic team-based approach instead of an expert driven top-heavy model of distinct groups of the active 'researchers' and the

passive 'researched'. There are few examples of successful action-based research projects specific to disabilities that the team could identify. Most successful examples are found in the international development, community renewal and mental health sectors.

Social Justice and Citizenship issues were raised as key research frameworks for future work. These two areas are the substantive research domains of *tomorrow's research agenda*. They demonstrate a strategic direction towards equality and normalisation that socially progressive areas of the disability sector are currently moving towards.

Organisational Culture

The second major area of research in disabilities for the future is in organisational culture change. Professor Hatton stated that there is virtually no research identifying how the disability sector can transition from a closed support system to one of open networks and person-centeredness. Given the momentum being gained by the enterprising work of In-Control and individualised funding, there is still a great deal of nay-saying by the majority of the disability sector about organisational change towards individualised support (IS). While there is growing encouragement for the principles and benefits of IS, there is a flood of negativity among UK service providers about how to reorient traditional services and staff towards individualisation. Professor Hatton identified some of the key questions involved in this research of organisational change:

- What does the workforce mean in this new model?
- What are the resources it will need? Financially, OH&S and culturally.
- What are the new qualifications? What is its new composition?
- How can research reflect on the link between organisational culture and service innovation to meet the diverse needs of person-centeredness?
- The agency of the circle of support (COS): if the COS is so central to some agencies in person-centred planning, how does it become so effective? What are its critical success factors? This is not to search for formulas but identify underlying principles that manifest in positive outcomes for people's lives.
- How do evaluations of organisational culture feedback into cultural change?
- The IHR team identified emerging forces in the response to individualised support and the work of In-Control. While there is buy-in from government and that 'every council will have to change', there is subtle grass-roots resistance from civil servants and local government areas. A key piece of research is needed to identify how to 'work with the fears' at local levels in the adoption and implementation of individualised support.

Education

IHR have robust educational and teaching arms. Their flagship course is a virtual learning program in research methods that attracts a wide range of international students from Africa, Asia and Europe. The team rank this course among their most successful and cite the impressive quality of postings by students and learning outcomes being identified. Professor Hatton says he has been on a 'steep learning curve' with the range of fresh questions posed in, for example, the area of ethics in research because of the broad international student base that this virtual course has now attracted. Among the key benefits of this course, he cited the 'increase in research awareness' and the 'demystification of disability courses'.

Reflections

We were surprised at the lower than expected level of collaborative research involvement IHR had with local disability organisations. This is, in part, due to IHR's emphasis and expectations on being a key teaching faculty (which they do extremely well and are very innovative) and the competitiveness of the UK health funding sector, where disabilities competes with areas such as health promotion and biomedical research.

IHR saw merit and comparability with the collaborative research areas of:

- User-involvement in research
- Disability organisational culture change with a focus on outputs rather than outcomes i.e. procedure and process over standardised outputs.
- Building bridges over time, especially through Professors Jim Mansell and Eric Emerson, who respectively hold co-chairs at Australian universities.

Areas that SJOGA can learn from IHR

- IHR has an extensive and progressive research agenda that offers much for SJOGA, especially in the area of person-centred planning and social inclusion strategies.
- IHR offers a number of practitioner-based courses for the disability sector that would be valuable to explore with the potential to replicate aspects in the Victorian sector.
- The team's lessons in all aspects of evaluating person-centred planning will be invaluable for our efforts including implementation and administration of evaluation tools, analysis of data and comparison with UK findings.
- SJOGA is developing qualitative measures for our evaluation, an area not conducted by IHR. It will be invaluable to inquire about what types of qualitative measures they would use for such a project as ours.
- Professor Chris Hatton is a board member for In-Control UK. His insights and perspectives on this peak organisation will offer us important guidelines for how such an organisation might be established in Victoria through SJOGA.
- We will learn about what is in their research pipeline and canvas any interest for collaborations, although Professor Eric Emerson is officially in charge of this aspect and he is currently visiting Melbourne (March then November 2008).

Syracuse University: The Centre on Human Policy, Law, and Disability Studies (CHPLDS)

The Centre on Human Policy, Law, and Disability Studies (CHPLDS) is an expansion of the Centre on Human Policy, which was founded by Dr. Burton Blatt in 1971. The Centre is a network of academic programs, centres, student organizations and affiliated faculty whose research, teaching, and advocacy seeks to promote the rights of people with disabilities locally, nationally, and globally, and to facilitate a critical examination of disability as an aspect of diversity in society.

The Centre on Human Policy (CHP) began as a Syracuse University based policy, research and advocacy organization involved in the national movement to insure the rights of people with disabilities. Since its founding in 1971, the Centre has been involved in the study and promotion of open settings (inclusive community opportunities) for people with disabilities.

CHP staff and associates include educators, human services professionals, people with disabilities, graduate students, and family members of children and youth with disabilities. The CHP has had an Advocacy Board composed of people with disabilities, parents, and interested citizens that serves as an independent voice on behalf of the rights of people with disabilities in the community.

The CHP has been involved with a broad range of local, state-wide, national and international activities, including policy studies, research, information and referral, advocacy, training and consultation, and information dissemination. The CHP's work now continues and expands as part of the new Centre on Human Policy, Law, and Disability Studies.

Onondaga Community Living in collaboration with Syracuse University

Onondaga Community Living has embarked on a new collaborative venture that makes it unique among USA disability services: the instigation of an adult agency. OCL in partnership with Syracuse University (SU) has spent over two years learning from many people and their families about their true goal and commitment to go to college. Together, OCL and SU are about eighteen months into a service that will allow six students with disabilities to participate in college-level classes. They have learned much from the On Campus Program through Syracuse City School District, which is a leader in an inclusive college level program for students with disabilities. With this new service, OCL maintains its current direction of personalised supports.

Each student will develop their own educational plan and will register for classes just as any other SU student does. Students will take regular classes and will be paired up with 1:1 staff support called Campus Mentors that will assist him or her with classes, adaptations, note-taking, presentations, assignments and studies. Each student will also be paired up 1:1 with a SU intern that will assist each person with the social aspect of college life. All of this will be coordinated by one full-time Special Education Teacher, Ann Atkins, who has expertise in inclusive educational services.

Ann works closely with each student's support team and the variety of professors and classes, to ensure that each student is best supported, based upon their unique learning style and are able to participate as fully as possible in each class. Ann also works directly with other professors, administrators and departments within SU to work collectively towards an inclusive educational experience on the SU campus for each student.

Students continue to be supported through the summer as OCL continues to work one-on-one with each student in locating a summer job placement, based upon each person's personal interests and educational goals. Ann works with the OCL Director of Vocational Services to ensure a smooth transition to the vocational portion of OCL. During this time, each student continues individualised supported as they work to pair their educational knowledge with experience that is either paid or volunteer.

Ann has been in the coordinator's role for about fifteen months. She has been instrumental in establishing the key procedures of this college program. There have been a number of tensions involving how OCL covers agency hours, different billing requirements and generating interest in a broad range of college classes. One of the success factors Ann noted about the program to date is the importance of having the applicant's interest to participate at a high level. This includes selecting people who have:

- The 'gumption' to do the work of the chosen course, much like having the tenacity required by every student for any academic course.
- The will to overcome physical issues to attend class (it does snow in Syracuse for about three months of the year and it proved this to us on our second day there!).
- Capacity to develop a transferable communication system to share with others: Ann described the process of developing individualised 'choice-boards' with students.

Vital to the success of this program is:

- Establishing appropriate levels of support to students for their course needs.
- Establishing better strategies to develop greater social connections for students.
- Cutting through university red tape to 'audit' of courses for students.

Auditing courses means having access to the course notes and requirements (assignments and lectures) so that Ann can provide adequate tailored support for students to participate fully and complete all requirements. This audit results in developing necessary communication and 'choice-

boards' for students. Ann stated that there is a need to create structures for collaboration between OCL and SU as SU are not completely aware at this stage of the added responsibilities of OCL in creating positive outcomes for their students to perform well academically and participate fully in all levels of college culture.

Onondaga Community Living—Involvement in Research

OCL has collaborated in the past with La Moine College on levels of service provided by disability organisations and with Professor Steve Houlburn (New York State). This project measured changes in people's lives resulting from person-centred planning. As Professor Houlburn is a quantitative researcher, this made for a difficult collaboration given OCL's preference for qualitative and participatory research methods.

OCL's key current research needs are about:

1. Personalised support: the positive impacts on people's quality of life; economic impacts and manageability at an organisational level.
2. People with significant needs: this group is vastly under-researched and little is known about what works in these contexts in terms of aggregate data.
3. Demonstrating that what OCL does works. Pat discussed current funding structures that are about to change from 'daily rates' to 'annual budgets'. This change was of concern to her because of the complex changes to regional 'one-size-fits-all' models being introduced. Simply put, rates will shift from an organisational rate that is currently in place to an average regional rate. In short, research would be evidence for the limitations and disadvantages of these new changes being introduced.
4. The compelling qualities of leaders and support professionals as catalysts to make things happen in individualised support frameworks.
5. The organisational culture of successful organisations to create, deliver and sustain individualised support.
6. Community resources: how to effectively tap into other community funds other than those dedicated specifically for disabilities.
7. How to grow 'natural community supports'.
8. How to develop greater inroads for full citizenship to the people supported by OCL.

Leadership

Given there are some 5000 disability organisations delivering services to people with developmental disabilities in the USA, OCL estimated that only 1% could be considered to deliver personalised support in the way done at OCL and JNC in LA, for example. Pat discussed concerns about the future of disabilities especially those organisations doing individualised support in terms of grooming new leaders. Currently, the 1% of disability organisations has ageing leaders (relatively) but she is acutely aware of there being no modelling and mentoring of 'new blood'. She talked about the issues of values and attributes of new leaders for the individualised support they do. To address these issues, OCL have adopted a management policy of creating leadership at all levels of the organisation. To a large degree, the CEO is minimally involved in matters of administration, process and decision-making except where it affects the strategic directions and dealings with Regional Office (the USA version of our Victorian Department of Human Services). Direct service staff have relative autonomy concerning decision-making in these vital matters. A distinguishing organisational characteristic of OCL is leadership at all levels and having a culture of 'figuring it out even when our back is to the wall'.

Syracuse University

When Pat started out with her new vision of OCL, she approached SU who greatly assisted in the planning of a USA study tour of progressive disability organisations. In terms of OCL's current relationship with Syracuse University (SU), it is evident that there is cordiality between key personnel but there appears to be no ongoing collaborative program of student- or staff-led research, training and development. The notable exception is the college placement program with Ann discussed above. In terms of having PhD and post-graduate students involved in work, student placements and internships, there were none happening on a regular basis notwithstanding several projects that have happened in the past.

Areas that SJOGA can learn from Syracuse

- How Syracuse established and developed its research centre and teaching program will provide an important case study for a Victorian research centre.
- Syracuse University has an extensive and progressive research agenda that offers much for SJOGA, especially in the area of person-centred planning and social inclusion strategies.
- Syracuse University offers a number of student practitioner-based courses for the disability sector that would be valuable to explore with the potential to replicate aspects in the Victorian sector.
- SJOGA is developing qualitative measures for our evaluation. It will be invaluable to inquire about what types of qualitative measures they would use for such a project as ours.
- We will learn about what is in their research pipeline and canvas any interest for collaborations.

Employment Services, Jay Nolan Community Services

The intention of Jay Nolan's Access to Community Employment (ACE) as described by Joseph Nacario, Director of Workforce Solutions, is to shift people from being 'consumers' and 'mall walkers' to individual contributors. About 23% of their client group are engaged in customised employment options. The other 67% are in facility-based programs as sub-contractors. Three of the 130 people JNCS supports run their own small businesses.

Recently, the focus of ACE has shifted from addressing locally-based individual shop managers to building relationships with corporate Human Resources departments and senior management to establish employment opportunities for people with disabilities. Current projects include meetings with the Director of Diversity at Walgreens Outreach in Chicago, Illinois.

One of the challenges noted is the employee screening background checks. This process prevents most of the people they support from entering paid employment options. Joe's strategy to address this barrier is to work with upper management in organisations. Joe has successfully worked with a large USA food store chain, Vaughan's, to develop policy about employment of people with disabilities to deal with this barrier. National Disability Institute (a Washington-based peak body organisation) is engaging in targeted training for management about the benefits of employing people with disabilities. There is added focus in this study on how employment services benefits the economy and the local community. Washington DC is ranked second in USA for highest levels of employment of people with disabilities.

In terms of current research in this area, Joe could only point to a 1991 study conducted by Professor Katie Bishop, University of San Diego, California. This study identified that 92% of employers were dissatisfied with the 'job coach' (person supporting the employee). This key finding underlines the crucial need for quality staff training as job coaches. This crucial role has shifted from what Joe calls 'psychiatric technicians' to 'job coaches'.

Interestingly, there is no current research or evaluation planned for ACE in the future. However, JNCS's ACE program initiatives include: corporate job development and relationship building strategies such as having a position of 'job developer'. This person's role is to develop an 'Amway-style' list of benefits to employers about hiring people with disabilities. This introduction is designed to generate interest that will lead to in-depth presentations.

Reflections

- No major current research project with either another disability partner or university despite cordial relations with key local academic players. There are no current PhD candidates, post-graduate placements or disability research partnerships with other organisations, government departments or universities.
- Previous research experiences have followed a pattern of being 'the subject investigated' rather than part of a collaborative team conducting innovative projects.
- Abundant experience at OCL in building natural supports and enlisting community engagement and resources but little systematic research to identify the critical success factors.

KEY LEARNINGS

It is first worth highlighting that the agencies visited operate within sectors that still largely funded as traditional services for the people they support. The agencies are stand-out examples of what might be possible when an organisation's services are actually congruent with their rhetoric and values. Their values inspired changes guided by the people they serve and not policy or departmental direction; nor did they receive additional funding.

Morale is high within their agencies and they have demonstrated competency in sustaining such service for more than ten years now. In attempting to put the journey of such organisations into the context of what is currently happening locally, we can identify some key features that offer greater insight into a way forward.

Defining the goal

The strategic direction of disability services in Victoria has been largely documented as pursuing an individualised and socially inclusive support model. The priority goal of the Victorian disability plan identifies 'reorientation' of disability services yet very little is offered about how that goal might be operationalised. Some of the business and structural framework components are defined such as individualised funding, however, the values that underpin individualisation are yet to be described as a set of behaviours that could guide us through a period of change. The sector has a clearer idea about the VISION, possibly the WHY, but HOW can still be somewhat of an enigma.

Values

Some of the key features highlighted within this document offer insight into the values that drive such change. The sector has invested heavily in adopting such values through a person centred planning *process* yet very little offered in translating such values into the daily interaction of support delivered. Recent publications on 'Role Based Planning' offer greater insight to pursuing outcomes that will make real differences in people's lives. Social Role Valorisation training also offers greater insight into evaluating services against the key features identified within this document. The need for a cultural change is evident also given the current low expectation of the people we support. Greater investment is needed in highlighting and marketing successful examples of individualised service design for cultural change here in Victoria. Sometimes we have to see it before we believe it. Although limited, there are genuine examples of investment in such work here in Victoria already.

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Individualised funding / Support layering

The value of *freely given relationships* is also highlighted as an important catalyst to pursuing such change. The focus on paid supports is still evident here in Victoria with little investment in working with families and community to build unpaid support networks. The reality of translating current day support dollars into an individualised and socially inclusive service will approximately halve a person's access to professional support (if delivered solely on 1:1 basis). This initiative will challenge organisations to invest in developing informal and generic supports as a better alternative to long term exposure to paid supports. Although challenging initially, if done well, the investment is far more sustainable over the long term as the reliance on paid services decreases. The sectors thinking needs to focus on developing supporting arrangements by firstly identifying each person's available informal supports, secondly the generic supports and finally, structuring the paid resources to sustain the investment in informal and generic supports.

Right relationships

The element of control is a key feature in a person centred organisation. The delegation of decision-making to people and their supporters working with agencies as partners should be clearly defined and offered through potential hosting of family governed serves or individual circles of support. The investment in providing families with more information about a circle of support model will facilitate greater opportunity for people, their chosen supporters and agencies to come together regularly and imagine better together. The circles also provide opportunity for unpaid people to learn more about a person's unique identity and to better explore contributions they could make. The development of a circle also facilitates conversations about how to bring other people into the circle, especially people who have similar interests.

Families have been poorly invested in through the process of change in the last few years. The contrast was evident after the study tour. In the organisations visited, families were identified as key stakeholders in change given their deeper understanding of the people they support. Greater investment is needed by SJOGA to support families to be included in strategic thinking and have them recognised as a vital resource in imagining better together. They have, for some time, been ostracised in the service planning and, more often than not, told to leave it to the professionals. Future training and vision building should include families where possible.

Housing

Victoria's current affordable housing crisis should be acknowledged in light of recent attempts to support people to exit shared supported accommodation. Internationally, agencies have experienced similar challenges yet pursued housing options beyond partnering within already devalued areas, for example, commission housing. Examples of people purchasing their own homes through affordable housing strategies with real estate and banking sectors have been a far more sustainable solution. In translating some of the funding arrangements organisations have in the USA for example, on average, they have negotiated approximately USD\$4000 per calendar month to support people in their own home. Even with currency conversion, this figure stacks up to what it would cost on average to house people in supported accommodation if we disaggregated the block funding.

It's an exciting time to be part of the disability sector given the promising policy direction of the Department of Human Services and their local agencies. Moreover, the sector is in a position to acknowledge collectively that things could be better; we have greater understanding of the challenges and more insight into the values and behaviours that will facilitate a movement towards identifying with the people we support as the people we know. In trying to summarise a rationale for such change one could explore many profound explanations. There are many reasons that may prevent us from launching into individualisation. As for reasons why we should? The simplest and most effective reason came from Mr. Jeff Strully ED, JNCS who I'm sure won't mind me quoting him as saying "*Because the time is right, and it's the right thing to do*".

FURTHER READING

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