

# Claiming Full Citizenship

Self Determination • Personalization • Individualized Funding

## 2015 International Conference

October 15 - October 17, 2015  
The Hyatt Regency, Vancouver, BC

### SYLLABUS



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Presented by



**CENTRE FOR INCLUSION AND CITIZENSHIP**

THE UNIVERSITY OF BRITISH COLUMBIA

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# Claiming Full Citizenship: Self Determination, Personalization, Individualized Funding 2015 International Conference

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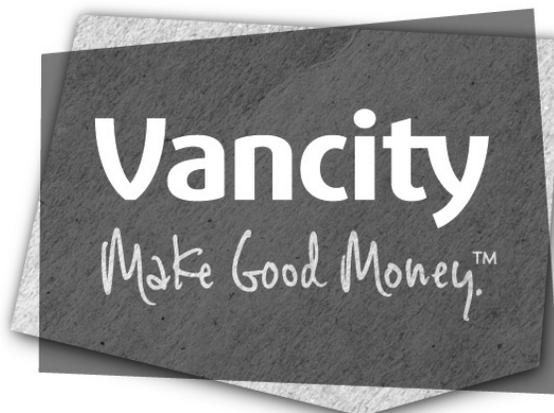
## CONFERENCE DESCRIPTION

With the passage of the UN Convention on the Rights of Persons with Disabilities, self-determination, personalization and individualized funding initiatives have a new foundation upon which to build. In countries all over the world, these initiatives are transforming the lives of people with disabilities. Like the shift from institutions to community services, these initiatives are a momentous step forward in assisting people with disabilities and seniors achieve meaningful and rewarding lives as full citizens. In October of 2015, the UBC Centre for Inclusion and Citizenship is hosting: Claiming Full Citizenship: an international conference on Self Determination, Personalization and Individualized Funding. We invite you to join us and share in the excitement and fellowship of this important event.

## LEARNING OBJECTIVES

- Evaluate the progress in achieving the vision set out in the Seattle 2000 Declaration on Self Determination and Individualized Funding
- Share lessons learned on the implementation of self-determination, personalization, individualized funding and supported decision making
- Promote cross national, cross cultural and cross sector dialogue
- Share best practices
- Support the realization of the UN Convention of the Rights of Persons with Disabilities through promoting the effective global implementation of self-determination, personalization and individualized funding
- Create a roadmap for the effective implementation of self-determination, personalization, individualized funding and supported decision making
- Foster cooperative networks across jurisdictions, sectors and interests that will continue after the conference

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## EXHIBITOR LISTING

### Alzheimer Society of BC

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and other dementias, to promote public awareness and to search for the causes and the cure.

### Communication Assistance for Youth and Adults

CAYA is a provincial resource program that provides communication support and technology to adults in BC whose speech does not meet their daily needs.

### CBI Consultants, Ltd.

CBI Consultants has created a Self-Determination curriculum which supports individuals to learn self-determination skills and achieve individualized life goals. It is composed of 57 lesson plans with worksheets and exercises that guide the participants through their Self Determined Life Planning process.

### Centre for Research on Personhood in Dementia, UBC

CRPD brings together researchers to explore the personal, interpersonal, and social influences on the dementia experience in order to find ways to improve quality of life for persons with dementia and their families.

### Community Living BC

We would like to showcase some of Community Living BC's innovative practices and products that are relevant to the conference participants.

### Community Living Society/ IF Resource Centre

The Community Living Society supports over 400 individuals with developmental disabilities or acquired brain injuries to live active and meaningful lives in communities across Metro Vancouver and the Fraser Valley.

The Individualized Funding Resource Centre Society is supporting 120 people with disabilities to access individualized funding throughout BC to enable them to fully participate in the community.

### Conversations that Matter

Conversations that Matter is an online values training website consisting of an ever-growing collection of short (5 to 15 minutes) engaging videos of conversations with the leading presenters, scholars, advocates, and parents in the community living field.

### Every Canadian Counts Coalition

ECC envisions better disability support programs to enable all Canadians with long-term, chronic disabilities to access sustained, essential supports and services.

### Family Support Institute

The purpose of the Family Support Institute is to strengthen and support families faced with the extraordinary circumstances that come with having a family member who has a disability. We believe that families are the best resource available to support one another. Directed by families, the Family Support Institute provides information, training, and province-wide networking to assist families and their communities to build upon and share their strengths. Our Vision: All families throughout British Columbia are supported, connected and leading meaningful lives in communities that equally value their citizens.

### Inclusion BC

We are a federation working with partners to build community and to enhance the lives of children and youth with special needs, adults with developmental disabilities, and their families by supporting abilities, promoting action and advancing rights, responsibilities and social justice.

### Inclusion Press International

Inclusion, Community, Diversity. We create and disseminate user friendly resources for individuals, families, and organizations worldwide, to create futures where all are gifted and belong' as contributing citizens in their communities.

### People First of Canada

People First of Canada is the national voice of Canadians labelled with an intellectual disability. We work together to educate and influence communities and government to ensure that all are fully included and supported to live as equal citizens in Canada.

### PLAN: Planned Lifetime Advocacy Network

An organization created by families here in Vancouver in 1989 that believes building a safe and connected life for our family and friends with a disability has benefits for us all. PLAN and Plan Institute together provide complete disability planning for the whole community. PLAN works hard to see people with disabilities achieve a good life, which includes caring relationships, financial security, sound-decision-making, contribution to society, and a sense of home and belonging.

### Registered Disability Savings Plan (Office for Disability Issues, Employment and Social Development Canada)

The Registered Disability Savings Plan (RDSP) is a long-term savings plan that helps Canadians with disabilities and their families save for the future.

### Representative for Children and Youth

The Representative for Children and Youth supports children, youth and young adults in B.C who need help accessing services and having their voices heard. The office provides oversight to MCFD and CLBC.

### Rooted in Rights

Rooted in Rights produces short videos and other creative content that focuses on the rights of people with disabilities. In addition, we partner with like-minded organizations to distribute content, and provide low cost creative services and consulting for those organizations.

### The Justice Institute of BC

The Advanced Specialty Certificate in Community Care Licensing is for current and future Community Care Licensing Officers (CCLOs). It covers all the knowledge and competencies that CCLOs need to do their jobs.

### Centre for Inclusion and Citizenship (CIC), UBC

The Centre for Inclusion and Citizenship is a partnership between the UBC School of Social Work, community living organizations and supporters seeking to further the full inclusion and citizenship of people with intellectual disabilities and their families locally, nationally and globally. We are the only university based research centre in Canada with a dedicated focus on intellectual disability policy and practice, and are committed to research, learning and knowledge exchange.

### Vancity

As a values-based financial co-operative, we work with our members to build healthy communities. We use our financial tools in innovative ways to create positive outcomes for our members and communities. We call that Good Money™.

### VELA

We provide information and mentoring to individuals with disabilities and their trusted others by supporting them to take greater control of their lives. We do this by exploring ideas and options that can lead to customized, inclusive and creative supports and services. This includes walking people through the process of forming a Microboard™ and accessing funds through Individualized Funding.

## RESOURCE TABLE

Narrative Inquiry in Bioethics

PosAbilities

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**James White**, Co-op Member, Vancouver, BC, Canada

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**Calvin Wood**, 1st Vice President, Executive Committee, People First of Canada, NS, Canada

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There are many restaurants in the area, as well as a food court in the Royal Centre Mall, which is located directly below the Hyatt Regency Vancouver hotel.

BREAKFAST/BRUNCH

- 1. **Bellagio Café** | 733 Hornby Street 604-408-1281    \$\$
- 2. **Café Crepe** | 1032 Robson Street 604-488-0045    \$
- 3. **Mosaic Bar & Grille** | 655 Burrard Street 604-639-4770    \$\$

NORTH AMERICAN

- 4. **Earls** | 905 Hornby Street 604-682-6700    \$\$
- 5. **Milestones** | 1145 Robson Street 604-682-4477    \$\$
- 6. **Vancouver Art Gallery Café** | 750 Hornby Street 604-688-2233    \$\$

WESTCOAST&SEAFOOD

- 7. **Blue Water Café** | 1095 Hamilton Street 604-688-8078    \$\$\$
- 8. **Joe Fortes** | 777 Thurlow Street 604-669-1940    \$\$
- 9. **Yew Restaurant and Bar** | 791 W Georgia St Vancouver 604-692-4939    \$\$\$



STEAK

- 10. **Gotham Steakhouse** | 615 Seymour Street 604-605-8282    \$\$\$
- 11. **Hy's Encore** | 637 Hornby Street 604-683-7671    \$\$\$
- 12. **The Keg** | 742 Thurlow Street 604-685-4388    \$\$

THAI

- 13. **Thai House Restaurant** | 1116 Robson Street 604-683-3383    \$
- 14. **Tropika** | 1128 Robson Street 604-737-6002    \$\$
- 15. **Sala Thai** | 102-888 Burrard Street 604-683-7999    \$\$

FRENCH

- 16. **Le Crocodile** | 909 Burrard Street 604-669-4298    \$\$\$
- 17. **Le Gavroche** | 1616 Alberni Street 604-685-3924    \$\$\$
- 18. **The Hermitage** | 1025 Robson Street #115 604-689-3237    \$\$\$

ITALIAN&MEDITERRANEAN

- 19. **Cin Cin** | 1154 Robson Street 604-688-7338    \$\$
- 20. **Villa De Lupo** | 869 Hamilton Street 604-688-7436    \$\$\$
- 21. **Zefferelli's Restaurant** | 1136 Robson Street 604-687-0655    \$\$

CHINESE

- 22. **Victoria Chinese Restaurant** | 1055 W Georgia Street 604-669-8383    \$\$
- 23. **Kirin Mandarin** | 1166 Alberni Street 604-682-8833    \$\$
- 24. **Shanghai Bistro** | 1128 Alberni Street 604-683-8222    \$\$

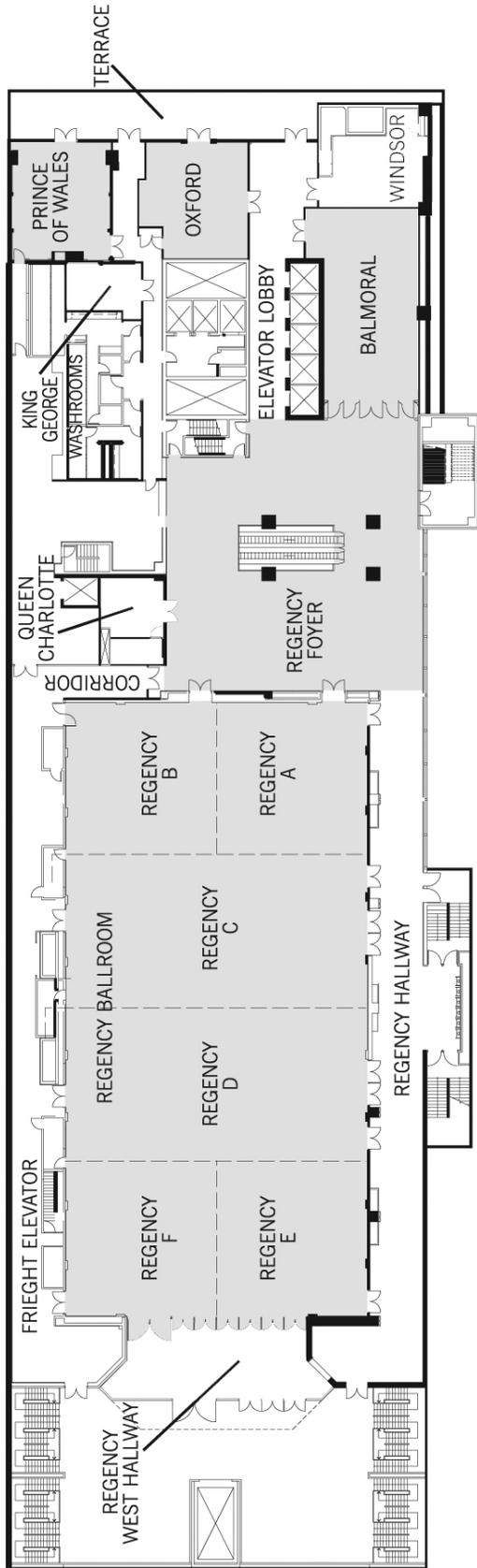
JAPANESE

- 25. **Kamei Royale** | 1030 West Georgia St. (upstairs) 604-687-8588    \$\$
- 26. **Miku Restaurant** | 1055 West Hastings Street 604-568-3900    \$\$\$
- 27. **Sapporo Ramen** | 518 Hornby Street 604-689-2922    \$

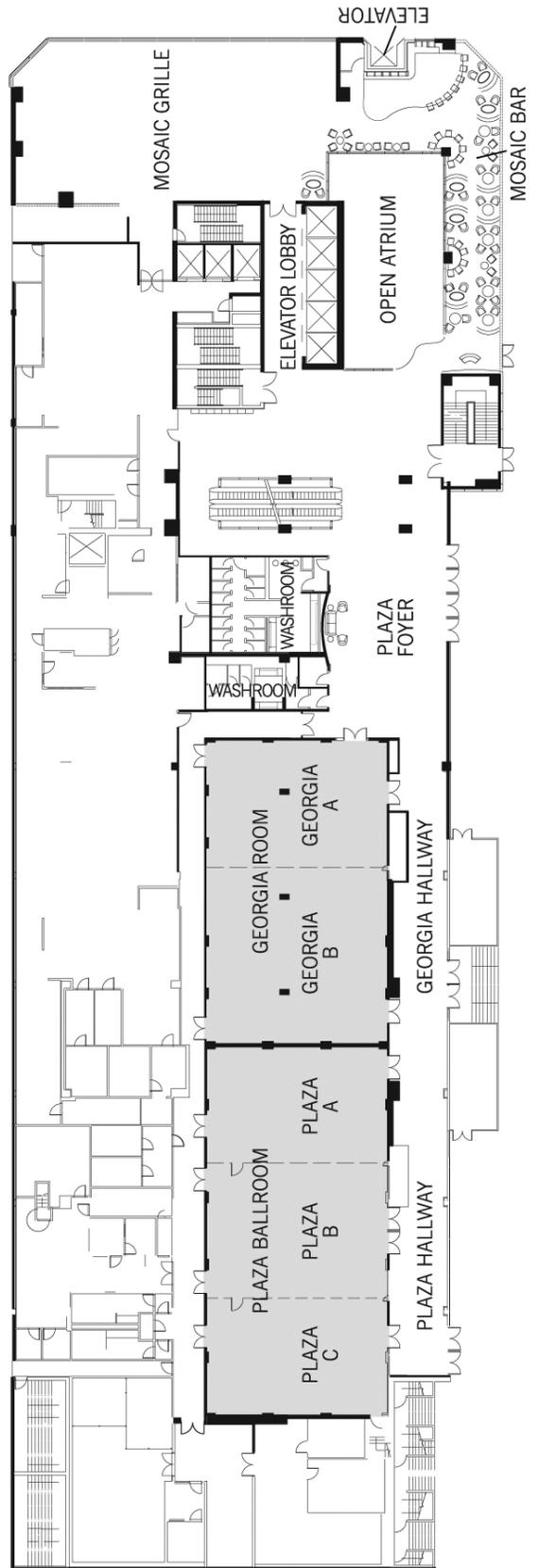
CASUAL

- 28. **Cactus Club Café** | 588 Burrard St. 604-684-0933    \$\$
- 29. **Joey's** | 820 Burrard Street 604-683-5639    \$\$
- 30. **Mahony & Sons** | 1055 Canada Place #36 604-647-7513    \$\$

CONVENTION LEVEL (THIRD FLOOR)



PLAZA LEVEL (SECOND FLOOR)





## PLENARY “What’s the Story, Morning Glory”

Linda Jordan, Ellen Goodey

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Ellen will talk about how she has led an “ordinary” life, by being included in local mainstream schools, college and her community, by making her own decisions and determining her own support using an individual budget.

Ellen will stress the importance of friends, natural supports and adult relationships and how using person centred planning and a circle of support has enabled her to be clear about her ambitions and the support she needs to achieve them. Ellen was recently Maid of Honour and witness at her best friend’s wedding in Jamaica, demonstrating how a group of childhood friends have supported each other into adulthood with great love and appreciation of each other’s gifts, talents and needs.

Ellen has used an individual budget since she was 16 - she is now 33. Initially the budget was small and Ellen used it to support her social life. When Ellen moved into her own flat at the age of 24, her budget increased so that she could employ a number of people to provide the support she needs.

Ellen employs a job coach to support her around work and career development, a cleaner, a personal fitness trainer and a few “personal assistants” for specific purposes.

Linda, who is Ellen’s mother, will describe the key factors present in Ellen’s environment that made it possible for Ellen to be included and empowered.

Ellen and her family live in a borough of London with a very diverse and poor population. There was a strong social action ethos and strong policies around anti-racism, sexism and homophobia. This meant that for Ellen’s and other families it was possible to point out the irony of continuing to segregate disabled children for their education purely on the basis of socially determined labelling. Part of the local landscape was a strong disabled adults’ lobby, which quickly joined forces with the parents and within a very short time a radical policy for inclusive education for all was being implemented. Ellen has been a beneficiary of this policy.

The early experiences of implementing inclusive education policies contributed to the growing national debate around inclusion and personalisation and an increasing awareness that segregation in education should be seen as a human rights issue as long stay institutions were in the 1970s, rather than encased in technicalities and arguments intended to provoke fear. Changes in the direction of national policy during the late 1990s have meant that policy around inclusion in education has stalled and over 1% of the school population in England (and in the UK as a whole) continue to be segregated for education.

While progress is clearly slow, there are more opportunities available in English law now to put in place the kind of support that Ellen has had and for a growing awareness of the importance of inclusive education in this. Legislation has brought children’s and adult services together in a way that is beginning to influence policy and practice in the early years informed by the experiences of adults. There is an expectation that children, young people and adults who are eligible for additional support should/can receive this as a budget to purchase self determined support,

The political and economic environment now is obviously not easy. Continued implementation of a personalisation agenda will need a concerted effort to turn the debate fully into one about human rights and citizenship and for people working in all human services to break free of fear and do what they know is right. Person centred planning and personal budgets are useful tools in helping us to achieve the necessary change.

The Learning Objectives of the Session:

- To hear from an adult with a learning disability leading a self determined life - to reinforce what is possible
- To hear about an example of a personal or individual budget enabling flexible and appropriate support
- To understand the socio/political success factors that enabled Ellen and her peers to lead self-determined lives
- To catch a flavour of policy and practice in the UK

## PLENARY **Australia's National Disability Insurance Scheme: Its Design, Progress, Campaign Lessons, Challenges and Opportunities**

Bruce Bonyhady

On April 19-20, 2008, the then Prime Minister of Australia, Kevin Rudd, invited 1,000 Australians to a convention in Canberra. Those Australians represented Indigenous and regional Australia as well as fields such as business, academia, the arts, science, medicine, the environment, the public service and the community sector. The convention they attended was called the Australia 2020 Summit.

The idea behind the Summit, Rudd said, was to 'help shape a long term strategy for the nation's future'.

The nation's disability sector was not represented at the Summit. I made a submission to the Summit, but was not invited to attend. That's because, at the time, disability issues were shut out of mainstream Australian policy discussions.

In the lead up to the Summit, I lobbied several of the delegates to the Summit to encourage them to put forward the central idea in my submission – the establishment of a National Disability Insurance Scheme (NDIS) – in the hope that if their own pet idea to reshape Australia's future did not cut through they would put forward my suggestion.

At the Summit, 138 recommendations were made to the Rudd Government. One of those recommendations was to establish the NDIS. Ultimately, the Commonwealth only adopted one of the 138 recommendations – the NDIS.

In other words, the only truly big idea that entered the public discourse at the Summit and then flourished was the one that snuck in the back door.

How did an unwelcome idea promoting equity of opportunity for one of the country's most marginalised groups fight its way into the heart of Australia's political life?

What lessons can be learned from the long and winding journey of Australia's NDIS?

To answer those questions, I intend to outline the three phases of the NDIS – from its genesis to its design to its ongoing implementation and governance.

### 1. Genesis

Australia first considered adopting a social insurance system to support Australians with a disability in the 1970s. Without bipartisan support, though, that forerunner to the NDIS failed to gain traction after the dismissal of the Whitlam Government in 1975.

By 2008, the disability movement had learned the lesson of 1975. For an NDIS to be accepted it had to be bipartisan. The disability sector – which has a history of division between groups representing service providers, people with a disability and carers – had to be united. And their case for change had to be supported by hard economic data; it had to be an economic reform as well as a social reform because all public policy changes in Australia must run the gauntlet of Treasuries and Finance Departments.

Between 2008 and 2011, a number of important steps were taken:

- Shut Out, a report documenting the lives of hundreds of Australians living with a disability, was commissioned and published;
- The independent Productivity Commission was asked to investigate the bona fides of an NDIS;
- Three peak bodies representing service providers, people with a disability and carers united to form a new body, the National Disability and Carers Alliance; and
- The Alliance oversaw Every Australian Counts, a grassroots campaign that aimed to change Australians' attitudes towards disabilities.

Together, these steps created a momentum for change that was local and national, political and personal, economically conservative and socially progressive.

By October 2011, the Council of Australian Governments (COAG) – comprised of the Federations one national, six state and

two territory governments – agreed to the first steps towards implementing the NDIS.

### 2. Design

The central ideas of the NDIS are that disability support should be reframed as insurance rather than welfare, that supports should be based on functional needs and that the Scheme itself should facilitate individual control and choice.

Insurance schemes are fundamentally different to welfare models. They seek to minimise costs and maximise opportunities over a person's lifetime rather than minimise costs in a single fiscal year. The long-term focus of insurance also closely aligns with the needs of people with disability and their families and carers.

The NDIS provides individualised support to those who acquire a disability before the age of 65. It supports people with a permanent and significant disability that affects their ability to take part in everyday activities.

The Scheme is individualised. Participants in the Scheme receive supports they need to live as independent a life as possible in their community, education, employment, and health and wellbeing.

The NDIS gives participants more choice and control over how, when and where supports are provided – as well as the certainty that they will receive those supports over their lifetime. It also focuses on early intervention where getting early supports can reduce the impact of disability on an individual.

The NDIS is equitable, efficient and seeks to maximise the independence and social and economic participation of participants.

### 3. Implementation and Governance

In March 2013, the NDIS Act was passed unanimously by the Australian parliament, creating both the Scheme and the National Disability Insurance Agency (NDIA).

The Scheme commenced operations on July 1, 2013, and is currently being trialled in seven trial sites across Australia. The NDIA administers the Scheme.

The Standing Council on Disability Reform, a COAG Ministerial Council made up of Treasurers and Ministers responsible for disability from the Commonwealth and each State and Territory, is the decision-maker on the National Disability Insurance Scheme policy issues.

The NDIA holds all funds contributed by the Commonwealth, States and Territories in a single pool, manages scheme funds, administers access to the scheme and approves the payment of individualised support packages.

The Board of the NDIA is responsible for the performance of these functions and strategic direction of the Agency. The Board is advised by the National Disability Insurance Scheme Independent Advisory Council.

When the NDIS is fully implemented in 2019-20 there will be around 460,000 participants and government spending on disability will have doubled to around \$22 billion (1.0% of GDP).

### Conclusion

There are many challenges and especially enormous opportunities ahead, including sharing our experiences and incorporating international best-practice into the Scheme.

Ultimately, though, the most telling lesson from the story of the NDIS is the power of 'and'.

Previously, the disability sector had adopted an 'either/or' mentality to reform. Disparate groups representing service providers, people with a disability and carers continually jockeyed for pre-eminence, arguing the case for their segment rather than the sector as a whole.

The establishment of a National Disability and Carers Alliance put an end to that divisive approach. The disability sector became a movement, a campaign was created that spoke of the needs of people with a disability and families and carers, and a marginalised issue became a mainstream issue, and the momentum for national reform became irresistible.





# PLENARY Transforming the HealthCare Terrain from Biomedical to Citizenship Discourses

Ruth Bartlett

This plenary talk will be in three parts

## 1. Introduction

I will begin this talk with a true story about an 89 year-old British woman named Manuela Sykes. In February, 2014, Ms Sykes won the right to return to her flat on a one-month trial basis after a court protection heard she was miserable in a care home. Unusually, the judge ruled that she could be named in media reports, in line with her wishes and because it was in the public interest. I'm beginning with this story because it exemplifies the key theme underpinning this talk, which is that ideas associated with citizenship (i.e. rights, belonging, recognition) are becoming more vital and visible within health and social care.

## 2. Distinguishing between biomedical and citizenship discourses

Biomedical discourse tends to dominate healthcare. Such discourse is characterised by the language of 'finding a cure', managing symptoms, and treating the disease and patient. Items that exemplify the biomedical discourse will be shown.

In contrast, the discourse of citizenship focuses upon the status, rights and responsibilities of individuals, especially in regard to the state. Recently, the notion of 'inclusive citizenship' has been crafted to emphasise the importance of recognition as well as rights (Lister, 2007). Items that exemplify the citizenship discourse will be shown.

In this talk I argue that we are entering a new era of healthcare, where ideas associated with citizenship (e.g. increasing patient power, upholding rights, deliberative democracy) are becoming more vital and visible.

## 3. What does 'claiming full citizenship' mean in the context of healthcare?

Being recognised as an individual worthy of respect; freedom from discrimination and despair; having opportunities to influence decisions that affect you: an example of this would be deliberative democracy and the involvement of people with mental health problems in policy and strategy making (Mulvale et al. 2014); connecting with others and campaigning for social change (Bartlett, 2012).

### Learning Objectives

1. Gained a critical awareness of current thinking about citizenship in the context
2. of healthcare and persons with dementia
3. Developed an understanding of the transformative potential and parameters of citizenship
4. Opportunity to reflect on the meaning of citizenship in the context of healthcare

### References

- Bartlett, R. (2012). The emergent modes of dementia activism. *Ageing and Society*, 34(04), 623–644. doi:10.1017/S0144686X12001158
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- NHS Citizen website <http://www.nhscitizen.org.uk/>

# A1i

## What IS a Microboard?

Linda M Perry, Jeff Moulins

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### Learning Objectives

At the end of this presentation the participants will have:

1. An understanding of what is meant by the term "Microboard"
2. Familiarity with the unique characteristics of a Microboard
3. An appreciation the importance of the Principles and Functions that are the cornerstones of the Microboard philosophy
4. A sense of the variety of ways Microboards can be used.

### Introduction

Microboards have been in operation in Canada for over 25 years. The process that has been used to explore this option has been one of attraction, not promotion. As a result, the growth of Microboards has been slow to take off in other parts of the world. This workshop will give a wide audience the opportunity to understand the concept and clarify the relevancy for a broader population.

### What are the essential components of a Microboard?

This conversation will explore what are the unique characteristics of a Microboard and how they can be applied for support and/or service.

### Stories of Microboards

Examples of existing Microboards will be used to demonstrate the concept in real life terms.

### Conclusion

Microboards offer the individual and their trusted others and opportunity to create a completely person-centred support that is directed by that individual with assistance from a close network of friends and family.

### List of References

- [www.velacanada.org](http://www.velacanada.org)
  - <http://youuniverse.org>
  - <http://conversationsthatmatter.org/microboards>
  - <http://incommon.tv/portfolio/i-f-works-my-life-my-supports/>
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## A2i

## Rhetoric and Reality in Active Citizenship and Community Living in Europe

Julie Beadle-Brown

This paper draws on the European project *Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model (DISCIT)*. The main aim of the project was to develop recommendations to promote and sustain the development of active citizenship for all people with disabilities and this presentation will focus specifically on active citizenship through de-institutionalisation and community living in Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK.

The findings presented here included three main phases:

In Phase 1 the project team reviewed the research literature and other published and official documentation, legislation and statistics related to community living available for each country, using a template completed by partners in each country. Phase 2 involved interviews with between 20 and 24 people with disabilities in each of the nine countries, within 3 different birth cohorts (1950, 1970 and 1990) and across four disability groups - those with visual impairments, those with mobility impairment, those with intellectual disability and those with mental health conditions or psychosocial disabilities. This paper will draw on the findings from these interviews related to people's living and support situation and their participation in their community.

Task 3 comprised a series of semi structured interviews with informants from each country who were judged to have some expertise or knowledge around disabilities issues. Eighty-four informants were interviewed across the nine countries. Those interviewed included representatives of innovative community care services and community based organisations, including disabled people organisations (DPOs) as well as representatives from official or government positions at national, federal/regional and local level. Some academic informants, as well as disabled people themselves were also included. The interviews aimed to establish the interviewees' views on the situation of people with disabilities in each country and in particular on the possibilities they have for achieving full and active participation in society. In addition the interviews focused on gaining people's opinions on the important factors (both barriers and facilitators) influencing the opportunities people with disabilities have and how they have changed over time. Analysis presented in the paper is based on interviews with 4 expert informants in each country.

The findings suggest that there have been considerable developments in the last decade towards community based support for people with disabilities, but with substantial progress still needed. In some countries institutional provision is still the main form of provision, especially for those with more severe disabilities. In all countries services for more than 30 people on one site still exist although in Norway this is for only a very few people with multiple and profound physical disabilities (e.g. following an accident) and in Sweden only in the form of acute services for people with mental health problems. Even in countries where the process of closing the older hospitals has completed, a trend towards re-institutionalisation has been reported.

In terms of the experiences of people with disabilities who were interviewed, one of the key findings was that of variation – variation between country and between disability groups. Those with intellectual disabilities tended to have experienced, in particular those who were older, more segregated settings and even now experienced less choice about where to live and who to live with. All groups however reported issues around choice over the support they received – how, when and from whom they received it. The most common difficulties experienced in terms of living in the community, were difficulties with physical accessibility of buildings, transport etc. and the attitudes of other people towards them and towards people with disabilities more generally.

Interviews with the expert informants identified similar issues. Seven clusters of themes related to barriers to community inclusion were identified: policy and politics, funding availability and systems, co-ordination and organisation across levels of government and other agencies, attitudes and awareness, availability and flexibility of services and support in the community, influence of people with disabilities and their representatives, perverse incentives for the maintenance of institutional provision, contradictions in the system and issues of definition and conceptualisation. Finally, the analysis highlights several facilitators of community living and active citizenship: including having a more holistic or comprehensive view of people and of disability support; better co-ordination between different levels of government; co-operation between disabled people organisations to create a unified approach to strength the voice of people with disabilities; the involvement of people with disabilities in decision and policy making at all levels; having an individualised, person-centred



# A2ii

## Self-directed Support: A Way Forward in Finland

Aarne Rajalahti

### Self-directed Support – A Way Forward in Finland

Aarne Rajalahti, Director of Development Activities  
Service Foundation for Persons with an Intellectual Disability  
Finland



### Some Finnish facts



- Population 5.4 million, GDP per capita 37 559 €
- Key features: High standard of education, social security and healthcare, all financed by the state
- One of the most peaceful, socially advanced and happiest countries in the world

1) [Global Peace Index](#), The World Economic Forum, 2015  
2) [The Social Progress Index](#), The World Economic Forum, 2015  
3) [World Happiness Report](#), The World Economic Forum, 2015



### Where are we coming from

- Institutional booming for people with ID 1950 -> 1980s
- Normalization and community based care rise since 1990s
- Independent living movement since 1970s
- Disability Service Law 1988; personal assistance introduced
- Big economical recession in early 1990s -> towards "open market", privatization, procurement
- Reform in municipal funding system 1993 -> autonomy for local municipalities for organizing services



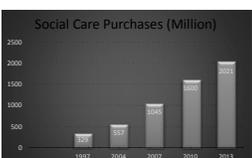
### What's happening now

- New Disability Service Law 2009; personal assistance as one key service, also for people with intellectual disabilities
- Government's Disability policy programme "Vampo" 2010 -> Strong basis for inclusion and equality, based in UN CRPD
- Housing programme for people with ID 2010 -> End of institutional care before 2020
- Several social care laws changing
- Ratification of CRPD in 2015
- Big social welfare and health care reform in 2017



### The care business is growing

- 317 independent municipalities responsible for organizing services, incl. social and health
- Health and social services take 50 - 60 % of annual municipal budgets
- Today 30 % of social care is provided by private sector
- In 1997 municipalities purchased social care services with 329 million euros, 2013 with 2.021 Mrd from private sector
- The amount of people over 75 doubles by 2030, still a big increase in demand.



### The care business is growing

- Due to the recession in the 90's NGO's and SME's opened up the private care sector – to develop community based care
- In 2007 all social and health services were put under public procurement, if not being provided by municipalities
- Since 2008 centralization trend of social care to the biggest companies, owned by international venture capitalists is going on. Tens of company buyouts annually.
- Over 200 competitive tenderings in disability services since 2007. Price is the main basis of decisions.
- New Procurement Act introduced



### Experiences from disability sector

“Competition with human rights is bad for us. Competition between services leads to less innovation and fewer options. Good new ways of support cannot be researched or developed. Money talks. Me and my friends in Finland think that we have been left out. We are the left overs of the welfare state.”  
 - Sami Helle, Learning disability rights activist, Bassist of PKN



KEHITYSVAMMAISTEN PALVELUSÄÄTIÖ

### Experiences from disability sector

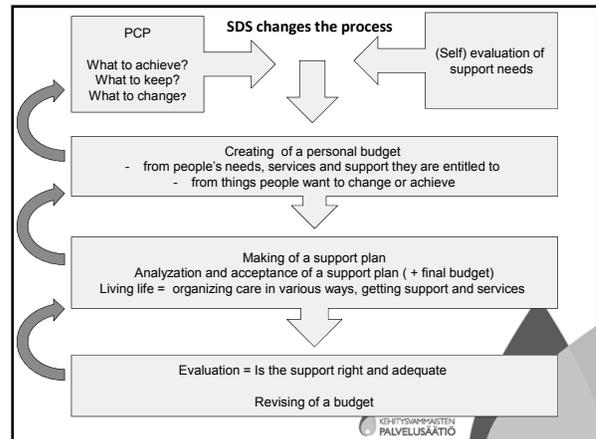
- PwD and their relatives have found public procurement of daily services extremely problematic
  - Service users are completely forgotten from the tendering process
  - Price competition leads to abnormally low prices
  - Institutional practices leave no room for innovation
  - Support needs are neglected
  - Home / staff / relationships can change in every 5 years
  - Comparisons to the situation in 1800's, where poor and disabled were given to the lowest bidder

KEHITYSVAMMAISTEN PALVELUSÄÄTIÖ

### How could PwD use their strenghts in their lives?

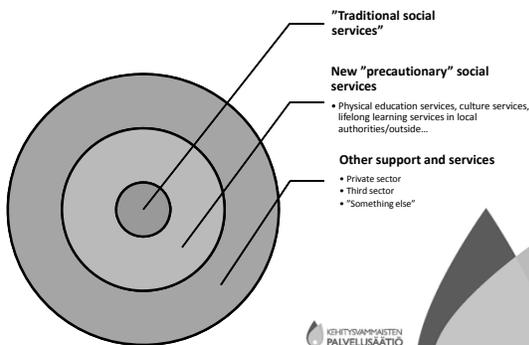


Pertti Kurvinen, Pertti Kurvinen Eurovision Song Contest finalist, 2015



KEHITYSVAMMAISTEN PALVELUSÄÄTIÖ

### Support and services can be arranged in different ways



KEHITYSVAMMAISTEN PALVELUSÄÄTIÖ

### Some difficult parts

- Many people don't know what's POSSIBLE and what options are there
- Some have very few people in their social circle, institutionalization has taken people apart from families and local communities
- For those who need it, there has to be support available for people to plan, make decisions, organize support and ensure the coverage and quality of services -> the need for good social work is always there
- "Resource allocation" and the "price tag" of services
- Some juridical aspects need to be clarified before SDS is possible in social care legislation.



### Some great points so far

(according to evaluation and research of the pilot project)

- It's possible!
- People get individual solutions and support
- Empowerment of the people with disabilities and their families during process
  - "It's like my son is suddenly more self confident and therefore taller"
  - The families have gotten new strength to enhance their family members lives
  - Many have learned new things from services
- Social workers / case managers realize the importance of the voice of a person and have moved towards real companionship and personalisation
- Circle of positive change
- Opportunities for good service providers!



### Kiitos!

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 Tel: +358 207 713 516

Resources used:  
 "Kun hoivasta tuli bisnes", HS, 2015  
 "Tiedän mitä tahdon!", KVL&KVPS, 2014  
 "Raportti yksityisestä palveluntarjonnasta", TEM, 2013




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# A2iii

## The Impact of an Innovative Community-Government Partnership: Promoting Self-Determination and Inclusion for People with Intellectual Disabilities

Judy Hannah, Joel Kilbride

**The Impact of an Innovative Community-Government Partnership: Promoting Self-Determination and Inclusion for People with Intellectual Disabilities**

**Judy Hannah, SACL**  
**Joel Kilbride, Saskatchewan Social Services**

Presented at Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding

Government of Saskatchewan October 2015 Saskatchewan Association for Community Living

### Overview

- ❖ Background
- ❖ Our partnership
  - Who we are
  - How the partnership works
  - Key features
- ❖ Lessons
  - Factors of success
  - Challenges
- ❖ Conclusion

### Background

The diagram shows a timeline from 2010 to June 2014. Key events include: SDF Advisory Table formed (2010), Joint research on SDF option (Spring 2012), Direction to explore a SDF option for CLSD clients (Winter 2012), The VVC Transition Committee Report (August 2013), and SDF Demo Project (June 2014).

### Our Partnership

- ❖ Self-Directed Funding (SDF) Advisory Table
  - Includes representatives from 11 community organizations, parents and interested individuals
  - Meets about once a month
  - Chaired by SACL
  - Worked with CUISR on two research projects exploring various aspects of SDF

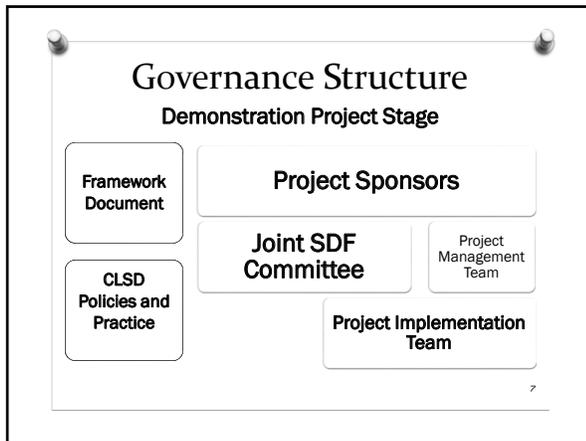
### Our Partnership

- ❖ Ministry of Social Services
  - Represented by staff from several units:
    - Community Living Service Delivery (CLSD)
    - Disability Programs Operational Policy and Program Design
    - Strategic Management Branch
  - Over the past 5 years have been working to improve quality of life and support community inclusion for people with disabilities

### Governance Structure

Design Stage

The governance structure includes: Framework Document, CLSD Policies and Practice, Project Sponsors, Joint SDF Committee, SDF Working Group, and Project Management Team.



### Key Features

- ❖ Community members are involved in the development of operational policy
- ❖ Community members are involved in the work at multiple levels:
  - Development of the framework for the initiative
  - Development of policy
  - Training of the Ministry staff
  - Management of the demonstration project

### Key Features

- ❖ The Ministry service delivery front-line staff is involved in developing operational policy
- ❖ Regular and open communication:
  - Collaboration happens through regular meetings at all levels of governance structure
  - Ability to have informal, off-the-record discussions
- ❖ Collaboration extends all the way to the participants of the demonstration project and their families

### Factors of Success

- ❖ Previous history of collaborative community-government engagement in Saskatchewan
  - Development of Saskatchewan Assured Income for Disabilities (SAID) program
  - Valley View Centre Transition
- ❖ Previous instances of engagement created environment where authentic dialogue is possible

H2

### Factors of Success

- ❖ Continued political will to engage the community in collaborative policy development
- ❖ Changes in understanding of inclusion and support for individuals with intellectual disability among families and in the society
- ❖ Strong leadership and championship of the initiative in the government and community

### Factors of Success

- ❖ Continues commitment of resources on both sides:
  - Funding to cover costs of participation for the community members
  - Administrative support
- ❖ Preference for face-to-face communication and hands-on involvement

## Challenges

- ❖ The natural limitations to shared decision making:
  - The extent of innovation is bound by existing provincial legislation
  - Government retains ultimate decision making power and control over financial resources
- ❖ Making both partners publically accountable to one another and for the success of the initiative

## Challenges

- ❖ Negotiating and balancing the conventional roles of community organizations and government employees
  - Advocacy
  - Stewardship of public money
- ❖ Increased amount of time required to achieve milestones
- ❖ Maintaining the collaborative nature of work past the demonstration project phase

## Conclusion

- ❖ We are currently testing the designed process for the SDF option
  - Involves 8 participants and the SDF Facilitator
  - Started in June 2014 and end in December 2015
  - Contracts for SDF have been signed with the Representatives of 2 participants
- ❖ Information gathered during the project will be used to inform the future development of the SDF option

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## A3

## Independent but Not Alone: Supporting People with Intellectual Disabilities to Make Decisions around the World

Anna MacQuarrie, Klaus Lachwitz, Connie Laurin-Bowie

The workshop session will highlight the issues identified in the report and the vision and roadmap people with intellectual disabilities and their families have created for achieving the right to decide and advancing the implementation of Article 12 of the UN Convention on the Rights of Persons with Disabilities.

The session aims to:

1. Enhance knowledge on the status and implementation challenges of CRPD Article 12
2. Establish a connection between supporting people with intellectual disabilities to make decisions and the need for self-advocacy
3. Increase knowledge about the role of families, organizations and governments in advancing the right of people with intellectual disability to make decisions

Background information for the session

Inclusion International's global report, *Independent But Not Alone*, will be the central document for this presentation. Launched in June 2014, *Independent But Not Alone*, is a global report on the right to make decisions. Over 600 individuals and 80 organizations from more than 40 countries contributed to a participatory research process to help document the barriers to decision-making that people with intellectual disabilities and their families experience in their daily lives. The report, launched at the 2014 UN Conference of States Parties, has had significant impact on the global dialogue on advancing legal capacity. It has informed partners, UN agencies, and governments about the efforts needed to make lasting and substantive change. Further, the report has ensured that the perspectives of people with intellectual disabilities and their families are being heard at the global level.

The report, *Independent But Not Alone*, broadens the dialogue on legal capacity from one of legal reform to one that recognizes legal reform must be complemented by strategies for individuals, families and organizations to build community supports and supports for decision making.

*Independent but Not Alone*, confirmed findings in previous global campaigns: people with intellectual disability and their families have identified that they are Voiceless. They have told Inclusion International: "Without a Voice we are Powerless". It's global reports have confirmed that securing the right to make decisions is linked to building and developing self-advocacy. Efforts in India and some countries in Europe have demonstrated that peer support is proving to be a significant element in building personal identity and demonstrating that an individual can make decisions. Further, the efforts would suggest that it's important to start with small day-to-day decisions and build from there. It is clear that until someone is seen as a person and treated with respect the leap to seeing the individual as a decision maker is too-wide for many to make.

Key messages received during the campaign include:

- Self-advocates: we want to be heard and we want to make decisions about how we live our lives.
- Families: we need help in supporting our family members with intellectual disabilities to have the right to decide.
- Organizations: we should respond to peoples' "wills and preferences" and work as agents of change to create inclusive communities.

Key findings from the report include:

- Invest in empowerment, self-advocacy and strengthening a collective voice – people are safest when they have control in their lives
- Independence does not mean "alone" – people are safe when they have relationships
- Families have a critical role to play in building the social connections necessary for supported decision making
- Family based organizations must play a leadership role as agents of change in community
- The Right to Decide cannot be achieved without community inclusion
- The Right to Decide is about more than the removal of guardianship and substitute decision making : legal reform must go hand in hand with strategies for building community supports and supports for decision making

# A4

## Taking Control of Our Lives: The Process of Program Development and Engagement of People with Dementia using Theories of Social Citizenship

Lisa Loiselle, Deborah O'Connor, Jim Mann, Bill Heibein

### Taking Control of our Lives

THE PROCESS OF PROGRAM DEVELOPMENT AND ENGAGEMENT OF PEOPLE WITH DEMENTIA USING THEORIES OF SOCIAL CITIZENSHIP

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**Lisa Loiselle**, Murray Alzheimer Research and Education Program (MAREP), University of Waterloo, Waterloo, ON  
**Elaine Wiersma**, Centre for Education and Research on Aging and Health, Lakehead University, Thunder Bay, ON  
**Jim Mann**, Self-advocate, Vancouver, B.C.  
**Bill Heibein**, Self-advocate, Thunder Bay, ON  
**Deborah O'Connor**, Centre for Research on Personhood in Dementia, University of British Columbia, Vancouver, B.C.

### Learning Objectives

- Provide an understanding of best practices for a collaborative planning process
- Share the experiences of various knowledge user groups

*"...Self-management is the true, blunt concept of it. We have to learn to manage ourselves...and what other term can you use? Sometimes in our journey it has to be the truth, and that's maybe a bit blunt for some folks. But it's the truth. To get the best out of life, we have to manage ourselves in the most productive manner...self-management—it's managing yourself to give yourself the best that life can give you..." [Person living with early stage dementia; from the Self-Management project]*

### Personal advocate experiences

- Jim Mann

### Social citizenship

- ...a relationship, practice or status in which the person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions, and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level (Bartlett and O'Connor, 2010, p. 37)

### Our philosophy

<p><b>PHILOSOPHY: Social Citizenship</b> <small>(Bartlett &amp; O'Connor, 2010)</small></p> <ul style="list-style-type: none"> <li>*Growth</li> <li>*Social Position</li> <li>*Purpose</li> <li>*Participation</li> <li>*Solidarity</li> <li>*Freedom from Discrimination</li> </ul>	<p><b>METHODOLOGY: Authentic Partnerships</b> <small>(Deyou et al., 2012)</small></p> <p><b>PRINCIPLES:</b></p> <ul style="list-style-type: none"> <li>*Genuine Regard for Self and Others</li> <li>*Synergistic Relationships</li> <li>*Focus on the Process</li> </ul> <p><b>ENABLERS:</b></p> <ul style="list-style-type: none"> <li>Connect and Commit</li> <li>Create a Safe Space</li> <li>Value Diverse Perspectives</li> <li>Establish and Maintain Open Communication</li> <li>Conduct Regular Reflection and Dialogue</li> </ul>	<p><b>LEARNING FRAMEWORK: Dialogue Education</b> <small>(Wells, 2008)</small></p> <p><b>Key Principles:</b></p> <ul style="list-style-type: none"> <li>*Safety</li> <li>*Inclusion</li> <li>*Necessity</li> <li>*Relevance</li> <li>*Respect</li> <li>*Engagement</li> </ul> <p><b>8 Steps of Program Design:</b></p> <ol style="list-style-type: none"> <li>1. Who?</li> <li>2. Why?</li> <li>3. So What...</li> <li>4. When?</li> <li>5. Where?</li> <li>6. What?</li> <li>7. What for?</li> <li>8. How?</li> </ol>
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### Our process

Research

## Researcher experience

- Deborah O'Connor
- Lisa Loiselle

## Our process

Curriculum development

Advisory hubs in Thunder Bay and Waterloo, Ontario, and Vancouver, British Columbia

- 20 people living with dementia and 20 care partners and service providers
- The groups met monthly for between one to two years
- Iterative process of talking about what self-management meant to them, deciding on key topic areas for the program, and talking more about those areas to get to the essence of what was important about this topic

## Practice partner experiences

- Kathy Hickman [curriculum developer, Education Manager, Alzheimer Society of Ontario]
- David Harvey [Public Policy and Programs, Alzheimer Society of Ontario]

## Our process

Curriculum pilot

- 3 sites—Guelph, Thunder Bay, Ontario and Vancouver, BC
- 8 weeks
- 14 people living with dementia and 10 care partners
- Intended to be a process evaluation
- Participant observations during sessions
- Focus groups after each session
- Facilitator reflections after each session
- A final focus group to reflect on the program

## What works



## Personal experiences

- Bill Heibin [video]

## References

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: towards social citizenship*. UK: Policy Press.

Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loisele, L., & Sadler, L. (2012). *Moving beyond 'patient' and 'client' approaches: Mobilising authentic partnerships in dementia care*. *Dementia: The International Journal of Social Research and Practice*, 11(4), 428-450.

Vella, J. (2008). *On teaching and learning: Putting the principles and practices of dialogue education into action*. San Francisco, CA: Jossey-Bass.



## A5ii

## Citizenship for Young People with Dementia

Anne Therese Lotherington

## Abstract:

Because citizenship often is attended with cognitive capacities and the individual's ability to take active part in society, a person with substantial need for support, such as a person with dementia, may be considered unable to maintain citizenship. Hence, an alternative way of understanding citizenship is required, an understanding that goes beyond citizenship as pertaining to the individual. In our endeavor to develop such an understanding we draw on material semiotics, and translate ideas from this thinking onto the field of dementia and citizenship. We argue that citizenship is about relations and should be understood as an emergent effect of interaction between human and non-human agents in networks. This means that citizenship for a person with dementia is a result of how people, practices and things interact, and that the research must depart from the practices in which the person with dementia is enrolled.

The focus of the paper is citizenship for young people with dementia. Claiming full citizenship for this group requires such an understanding because their connections with society go through multiple relations that we need to understand. These relations perform citizenship. Our analysis demonstrates how different networks of care may perform citizenship differently.

The empirical material consists of qualitative interviews with spouses of young people with dementia and relevant others in their networks of care. The spouse is of particular interest thanks to a unique intake to the relations of the person with early onset dementia.

## Learning Objectives:

1. Develop an understanding of citizenship within a relational perspective
2. Reflect on how gender and technology perform citizenship
3. Discuss how material semiotics provides a new understanding of citizenship

## Summary of presentation:

## 1. Introduction: What's at stake?

- About young people with dementia
- Diagnosed before age 65
- Extent
- Gender differences/similarities
- Living with dementia – relations
- Citizenship for young people with dementia and their loved ones (family, friends, good neighbors etc.).

## 2. Data and Methods:

- Qualitative study
- Interviews with next of kin
- About the data material

## 3. Changing Care Practices:

- The formative dementia trajectory
- Complexity of relations: Who and what involved, when?
- (In)dependence

## 4. Questioning the Concept 'Citizenship':

- Traditional understandings: What's the problem?
- Individualized, demanding cognitive abilities
- Excluding people with dementia
- Broadening the concept: Introducing Bartlett and O'Connor's 'Social Citizenship' to include people with dementia
- One step further: Citizenship as collective and mutually constitutive – a form of distributed cognition. Analyze the mutual constitution (or not) of citizenship for both the young person with dementia and those they care for and care for them.





# A6

## Sustainable Person Directed Service Models in Today’s Political, Economic and Social Systems: Exploring Provider Practices, Outcomes and National Trends

Caitlin Bailey, Julie Bershinsky, Marian Saulino, Gail Godwin, Kristen Loomis

**Abstract :**

Although there has been a substantial decrease in the number of congregate service models, agencies still struggle to provide individualized services to people that ensure choice and active participation in their communities. Leaders in agencies striving to provide person-directed supports face barriers related to economic and political systems and frequent lack of organizational level buy-in. These barriers hinder efforts to effectively improve and ensure true quality services.

The two presenting agencies will describe how their organizations’ structures and services operate in the context of current political, social and economic environments related to outcomes experienced by people receiving services. Their experiences will be framed in relation to data from two national research projects in the U.S. NLCDD will outline barriers faced by leaders in disability supports organizations. HSRI will present data from the National Core Indicators project that paints a broad picture of the effect of services on people’s lives.

This collaborative project begins to bridge the commonly-existing gaps between providers and researchers by exploring similarities and differences between the operations and outcomes of successful models of individualized supports and national developments in services and outcomes in U.S. The challenge is for researchers and the public (including supports agencies) to increase collaboration to ensure that research remains relevant to the people who are most affected by it.

Participants will learn about best practices in providing services, the effect these practices have on outcomes, and how these outcomes compare to national level data and research.

**Learning Objectives**

1)Participants will learn about best practices in providing services, the effect these practices have on outcomes, and how these outcomes compare to national level data and research.

**Synopsis**

This collaboration between two organizations providing entirely person-directed services and researchers from National Leadership Consortium and Human Services Research Institute explores organizational practices that ensure quality individualized services, systems barriers faced and how practices and outcomes relate to national research about people using supports and obstacles identified across disabilities services.

## A7i

## How our Model of Self-Direction has Changed Lives (Bespoke Lifestyles – Queensland, Australia)

Dianne Mandeville

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### Bespoke:

- individually designed
- one-off
- person-centred

### Lifestyles:

- It is about creating 'good', meaningful, rich, inclusive lives.

### Bespoke Lifestyles

- Works throughout Queensland
- Private company and not a funded organisation
- No disability support programs and no support workers
- Began with three part time consultants and 17 participants in August 2010
- 112 participants with an annual support budget of around 9 million AUD
- Core business is self-direction/self-management

### Our model

- Small team & low overheads
- Consultants mentor participants
- Shift in power from the organisation to the participants
- Non-onerous and user-friendly methods of accountability
- High level of trust that people are quite capable of managing their own lives, finances and supports

### Thinking differently

- Primary focus is not on the funded dollars but on expanding ideas and thinking about how best to use funding to improve people's lives
- Gently challenge people to expand their views & think outside the traditional disability support systems & 'programs'
- Support to live a typical life in community
- Often people start with the service/support that is offered and then try to make this fit their lives

### Changing the paradigm

- Disability services have become an industry
- Many of the systems and policies that are introduced with good intent and to respond to risk, actually contribute to labeling and isolating people
- Fear of litigation and risk management can stifle innovation and lead to a narrowing of opportunities
- The purpose of policies and procedures need to be questioned
- The yardstick for how we do things needs to change to what is ordinary and the norm

### Creating our model

- Involved a paradigm shift
- Not simply a matter of adapting old systems to make them fit
- Required developing completely new systems and not too many of them!
- Self – Direction vs Self-Management
- Self – Direction describes a person who routinely makes the vast majority of key decisions so that he/she considers him/herself to be fully in control of the support he/she receives
- Self – Management describes the responsibility for the management and administration involved in funded support

### What is different for our participants?

- Choosing support
- Tailoring support
- Managing support
- Flexibility, consistency & reliability

- Able to carry goals to fruition
- Collaborative approach
- Open lines of communication
- Job satisfaction for workers
- Empowerment
- Changed lives

#### Essential Elements

- Vision
- Lifestyle planning and goal setting
- Putting plans into action
- Building informal networks
- Sustainability and succession planning

#### What people want:

- to live their lives in the same manner that we all want
- an individual life based on their own interests and skills and for their lives not to be regimented
- to be in control and to be listened to
- to have the flexibility and freedom to make their own choices in life
- to be useful
- to form real connections
- to build relationships and have friends

#### What do people want support to look like?

- Support to be integrated into the everyday running of their lives
- Support to be personal
- Support not just to be a job for people
- Consistency and to build long term relationships with their workers
- Workers to be almost like part of the family

#### Living a valued life in community

- Contributing
- Being respected
- Sharing ordinary places
- Choosing
- Belonging
- Having a valued role

#### What has changed for people?

##### Our participants have:

- moved into their own homes in the community
- gained employment or developed their own businesses
- developed friendships and widened their informal networks of support
- commenced courses of study
- been able to travel and for some, had their first ever holiday
- increased skills and level of confidence and independence
- higher expectations
- experienced improved health
- improved communication
- reduced anxiety
- increased their self-esteem
- reduced and sometimes eliminated difficult behaviour
- Generally people have told us that they are now much happier.

#### What people need

- Information and knowledge
- Practical & financial support
- Mentoring
- Belief in themselves and their ability

## CONCURRENT SESSIONS A

- People who believe in them and give them opportunities
  - People who trust in their ability & judgement
  - People who believe in the person with disability and give him/her opportunities
  - People who will accept people with disabilities into their lives
- Flexible systems
- Limited bureaucracy

### What people don't need

- Negative people around them
- People making assumptions
- People who don't listen
- Sympathy or pity
- Inflexible systems/bureaucracy
- Rules & regulations for their own sake
- Patronising professionals
- Lack of choice
- Exclusion

### Practices that people do not want

- Policy of changing staff so that they do not get too close to people
- Policy that workers cannot mix a social life and work
- Not letting families have direct contact with the workers
- Not having any say in who provides the support and how the support is provided
- Workers who know best and don't listen
- Workers who overstep boundaries
- Letting policy and procedures come before common sense

### Sustainability

- Supportive networks/allies
- Good mentors
- Effective systems
- Knowledge – access to information
- Ability to source the support you need – practical and financial support
- A society that accepts and welcomes people with a disability
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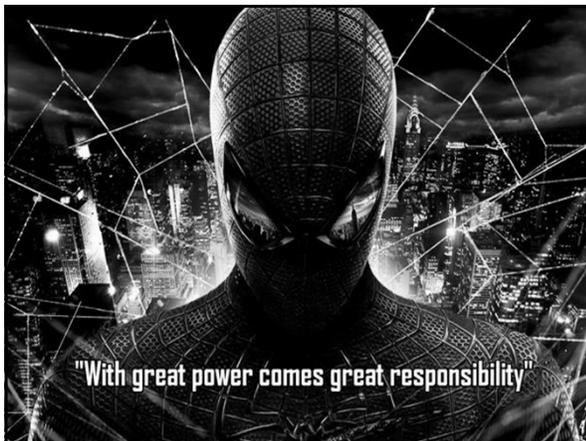
# A7ii

## The Role(s) of Case Managers in Self-Direction: Supportive Separations

Gerianne Prom, Danielle Skenadore

**The Role(s) of Case Managers in Self-Direction: Supportive Separations**

**Gerianne Prom**  
 VP, Long Term Care Services & Supports  
 Milwaukee Center for Independence

**Objectives**

- Understand self-determination theory.
- Person centered planning methods.
- Address and debunk myths.
- Review core standards for case managers in self-directed programs.
- Identify, develop and implement self-directed supports.

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**Self-Determination Theory**

**Autonomy**

- Being responsible
- Independent
- Able to speak for oneself

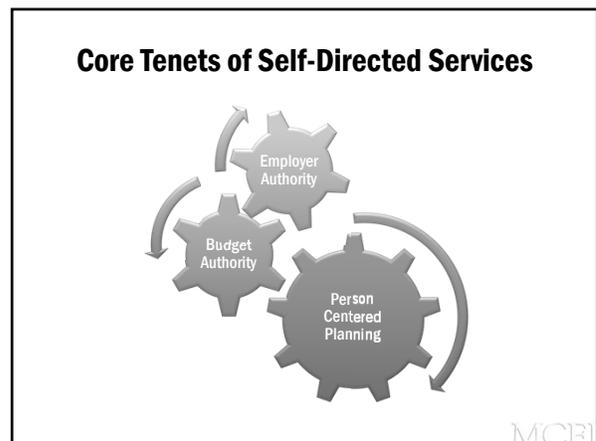
**Competence**

- The ability to do something successfully or efficiently
- A specific range of skill, knowledge, or ability

**Relatedness**

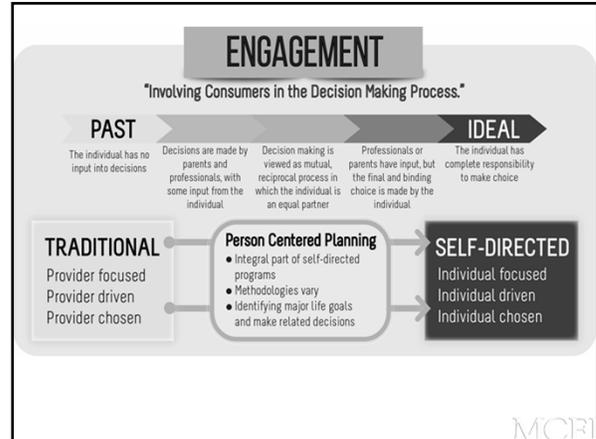
- The state of being connected or associated
- The state of having developed from the same origin
- The state of being part of the same family, community, or program

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## Person Centered vs. System Centered

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## Paradigm Shift

<u>Traditional Approach</u>	<u>Self-Directed Approach</u>
<ul style="list-style-type: none"> <li>• <i>"Professional/Medical Model"</i></li> <li>• The consumer is dependent upon the service provider to direct and deliver necessary supports</li> <li>• Provider identifies and mitigates risk</li> <li>• Provider monitors quality of supports</li> <li>• Provider initiates and terminates service accordingly</li> </ul>	<ul style="list-style-type: none"> <li>• <i>"Empowerment/Person-Centered Approach"</i></li> <li>• Individual defines his or her needs</li> <li>• Individual designates "circle of support"</li> <li>• Individual controls resources and staffing</li> <li>• Individual determines the role the service provider will play in their life</li> <li>• Individual determines quality of supports</li> <li>• Individual initiates and terminates service accordingly</li> </ul>

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## Arkansas' Independent Choices Participant Self-Assessment

**YOU DECIDE WHAT SERVICES AND PURCHASES WILL HELP YOU MEET YOUR PERSONAL CARE NEEDS.**

1. What services do you want and need?
2. What purchases will help you?

**YOU SELECT THE PEOPLE YOU WANT TO HELP YOU OR WHAT THING YOU NEED TO BUY TO HELP YOU LIVE IN THE COMMUNITY.**

1. How will you find and select people to help you in your home?
2. How do you shop for the purchases you need to make?
3. How do you plan to train and supervise the people who work in your home?
4. How will you tell your workers what you like or don't like about their work?
5. If you are not happy with the work of the worker you hire, how will you handle the situation?

**A COUNSELOR CAN HELP YOU LEARN HOW TO FIND YOUR WORKERS, HOW MUCH TO PAY YOUR WORKERS, HOW TO TRAIN YOUR WORKERS AND MANY OTHER THINGS.**

1. Are you willing to ask for help if you need it?  
 Yes  
 No

**FAMILY OR FRIENDS CAN HELP YOU MAKE DECISIONS IF YOU WANT.**

1. Do you have someone you want to appoint as your representative decision maker?  
 Yes  
 No

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## Addressing Myths

MYTH: Case managers don't need to spend as much time with consumers in self-directed programs.

MYTH: There is no oversight in self-directed programs.

MYTH: There is no way to monitor quality in self-directed programs.

MYTH: Some consumers cannot self-direct.

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## Core Standards for Case Managers in Self-Directed Programs

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### NASW Standards for Social Work Case Management

1. Ethics and Values
2. Qualifications
3. Knowledge
4. Cultural and Linguistic Competence
5. Assessment
6. Service Planning, Implementation, and Monitoring
7. Advocacy and Leadership
8. Interdisciplinary and Inter-organizational Collaboration
9. Practice Evaluation and Improvement
10. Record Keeping
11. Workload Sustainability
12. Professional Development and Competence

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### Person-Centered and Participant-Directed Competencies

**Identify as a professional social worker and conduct oneself accordingly.**

1. Describe the philosophy of person-centeredness in relation to social work values and theories.
2. Identify the roles and responsibilities of the social worker, participant, support broker, and financial management services agency in a participant-directed service model.

**Apply social work ethical principles to guide professional practice.**

1. Encourage and support the participant to identify their own goals and determine their best options even when they request another person to be involved in making those decisions or there is a legally mandated representative who is to be included in the decision making process.

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### Person-Centered and Participant-Directed Competencies

**Apply critical thinking to inform and communicate professional judgments.**

1. Describe the history of independent living, self-determination, and participant direction.
2. Compare and evaluate the effectiveness of participant direction as a service model.
3. Discuss the evaluation research on participant direction as a service model relevant to the population served and/or practice context.

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### Person-Centered and Participant-Directed Competencies

**Engage diversity and difference in practice.**

1. Understand the diverse characteristics among participants, families, and professionals (e.g., age, class, color, culture, disability, ethnicity, gender, gender identity and expression, immigration status, political ideology, race, religion, sex, and sexual orientation, etc.).
2. Describe how diverse characteristics are sources of strengths for and/or may create barriers to accessing services and supports.
3. Explain how diverse characteristics may influence an individual's familial relationships, social organizations, and help-seeking behavior.

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### Person-Centered and Participant-Directed Competencies

**Advance human rights and social and economic justice.**

1. Understand the forms and mechanisms of privilege, oppression, and discrimination and their impact on participants and their families.
2. Describe how privilege, oppression, and discrimination may impact access to services and supports.

**Engage in policy practice to advance social and economic well-being and to deliver effective social work services.**

1. Understand the policy history and potential future trajectory of major public programs for long-term services and supports.
2. Identify effective techniques to advocate for strengthening existing or developing new long-term services and supports.

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### Person-Centered and Participant-Directed Competencies

**Assess with individuals, families, groups, organizations, and communities.**

1. Demonstrate active listening and engagement skills in order to understand the person's approach, views, and what is important to and for them.
2. Facilitate information sharing from the person and family, agencies, organizations and communities using tools such as open-ended questions, problem solving, and motivational interviewing techniques and (when necessary) communication aids.
3. Demonstrate ability to work with the participant to identify and discuss potential benefits and risks of their options.
4. Demonstrate negotiation skills using tools such as open-ended questions, problem solving, and motivational interviewing techniques in interacting with the participant regarding the pros/cons of choices that may place the participant at considerable risk.

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## Person-Centered and Participant-Directed Competencies

Intervene with individuals, families, groups, organizations, and communities.

1. Apply a strength-based approach and build on individuals' strengths, values, preferences, and goals.
2. Discuss how family, paid caregivers, and community provide informal and formal supports.
3. Demonstrate ability to work with participants to develop support plans and individual budgets.
4. Establish capacity to provide support to the participant with employer related tasks, as needed (e.g., worker recruitment, training, discharging, etc...).

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## Connect with MCFI



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 Vice President at Milwaukee Center For Independence  
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Previous Gerianne Prom Consultant, Waukesha Memorial Hospital, Aurora Health Care  
 Education Loyola University Chicago

Send a message Endorse

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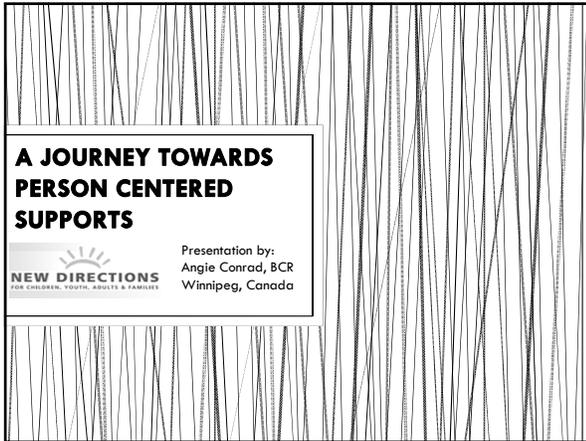
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# A7iii

## A Journey towards Person Centered Supports Angie N Conrad



**Learning Objectives:**

- Describe New Directions and our philosophy of what a Person Centered Approach is.
- Outline and discuss the organizational changes and transformation process required to become an organization that is more person centered.
- Outline and discuss the challenges and barriers to making an organizational shift to being more person centered.

**Presentation outline:**

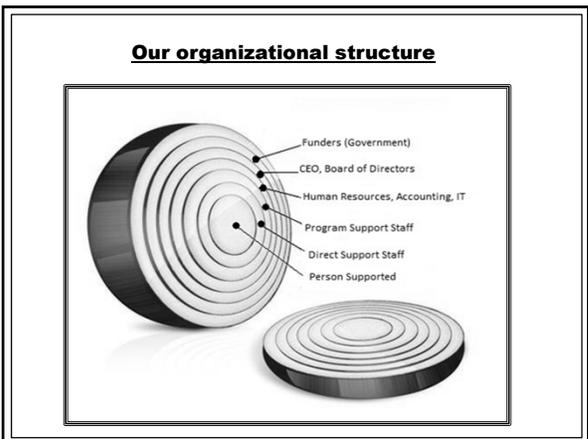
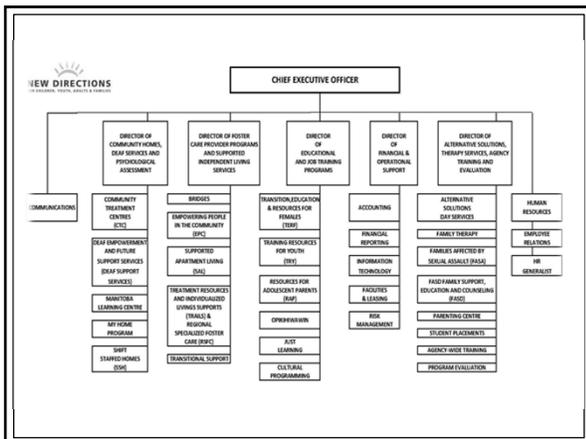
Objective: This presentation will focus on our practical plan of becoming an organization that is more person centered.

- ✓ Overview of New Directions
- ✓ Process for Change
  - ❖ Examine
  - ❖ Explore & Document
  - ❖ Support
- ✓ Barriers
- ✓ Summary
- ✓ Questions

Integrity  
Honour  
Holism  
Respect

**Strategic Goal #4:**

*Enhance individual-focused philosophy and approach that is congruent with our values of integrity, honour, holism, and respect.*



**Key Components of Person Centered Approach (PCA) from a New Directions perspective:**

- Rooted in concepts of social inclusion and citizenship.
- Rooted in a concept of empowerment.
- Rooted in a concept of allied support.
- Rooted in from a human rights perspective.

**Service Determined Supports vs Self Determined Supports**

The diagram shows a transition from rigid, mechanical 'Service Determined Supports' (represented by gears) to flexible, personalized 'Self Determined Supports'. The latter is characterized by being 'Customized', 'Self Determination', and 'Innovative', with a large arrow pointing from the former to the latter.

**Process for Change**

The diagram illustrates a person standing on a path with three diverging arrows. The process is divided into three stages:

- Examine:**
  - Organization policy and processes
- Explore & document:**
  - Histories
  - Goals
  - Dreams
  - Wants
  - Needs
- Support:**
  - Goal achievement
  - Support network building
  - Self advocacy

**Examine: Policy & Processes**

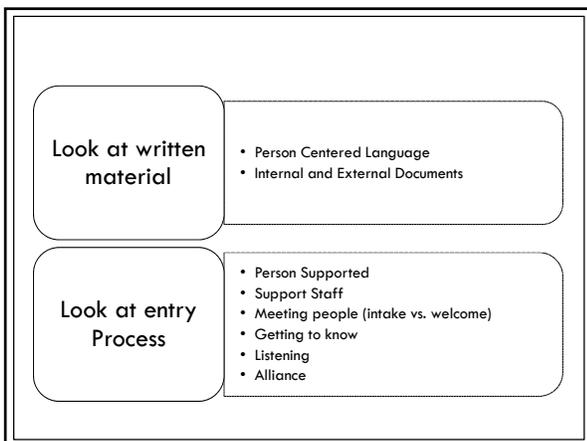
The diagram features a large diamond shape containing three curved arrows. Two boxes are connected to the diamond: 'Written material' on the right and 'Referral and Entry process' at the bottom.

**Power of Language**

A word cloud centered on the word 'client'. Other prominent words include 'medical model', 'bureaucracy', 'clinical', 'detached', 'NEGATIVE', 'non-contributor', 'impersonal', 'power imbalance', 'commodity', and 'Business distance'.

**CLIENTS → CITIZENS**

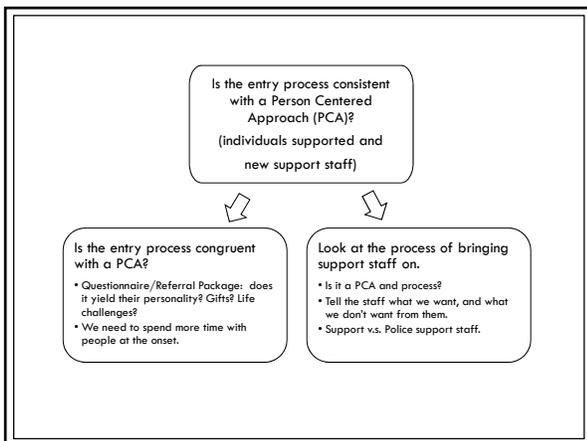
The diagram shows a transition from 'CLIENTS' to 'CITIZENS' via a double-headed arrow. Below this, a downward arrow points to 'CITIZENSHIP', which is illustrated with a photo of a person in a field and a large graphic of 'HUMAN RIGHTS' written on a banner.



**How do we do this?**

**Writing Job Descriptions**  
**DESCRIBING THE JOB**

- Duties
- Tasks
- Summary Statement
- Degree of Supervision
- Definition of Functional Verbs



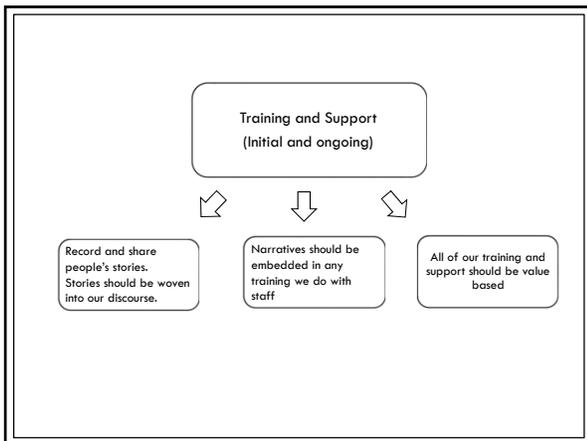
**Explore and Document**

speaker → active listener

I like ... I don't like ...

- spy films
- going for walks
- spaghetti
- coffee
- being left in front of the TV by myself
- being treated like a baby.

LIFE STORIES



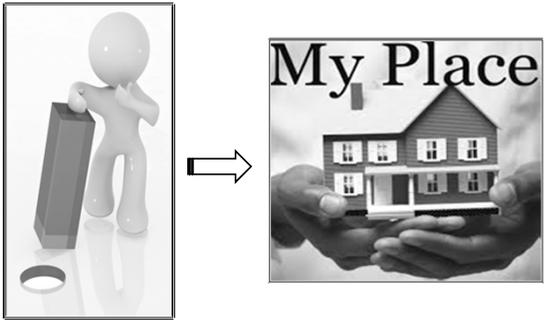
**Support**

Goal Achievement

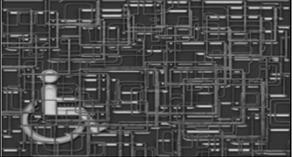
Support Network

Self Advocacy

**Shifting the focus...**



**What are some of the barriers/constraints?**



- Funding
- Existing Organizational Structure
- Receptiveness to different/alternative service models

**What are some of the barriers? (cont'd)**

- Change is not done in a vacuum. It is done in a complex environment of internal intent and external constraints.
- New Directions has to adhere to policy and practice directives of government. This does not mean planning for reliable support is impossible, but it means though that it can be challenging.
- Intentional change in complex environments requires commitment, creativity, imagination, and effort.
- New Directions understands the complexity of challenge and embraces it. The cost of not embracing it is too high and will be paid for by the individuals supported by the organization.

**In Summary...**



New Directions is shifting to being an organization that is more Person Centered by:

- ✓ Reviewing the language used throughout the organization to ensure it's person centered. This includes verbal exchanges and written use.
- ✓ Reviewing the written material used by the organization and each program to describe ourselves. We are reviewing any material pertaining to individuals supported. This includes materials within N.D., external agencies, families, and potential support providers.
- ✓ Reviewing the entry process into programs for individuals supported

- ✓ Reviewing the process to assist individuals to find "their place".
- ✓ Reviewing the training we provide for individuals supported, individuals providing support, referring agencies, and families.
- ✓ New Directions has reviewed and changed our program evaluation formats to start collecting data in order to evaluate if this shift is achieving it's desired results.




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# A8

## An International Perspective on Local Area Coordination: Making Disability Supports and Services more Personal, Local and Accountable

Eddie Bartnik, Ron Chalmers, Ralph Broad



**An International Perspective on Local Area Coordination**  
**Making Disability Supports more Personal, Local and Accountable**



**Eddie Bartnik**  
 Strategic Adviser  
 National Disability Insurance Agency

Claiming Full Citizenship International Conference  
 Vancouver, Canada  
 15 October 2015



**Presenters**

- Eddie Bartnik – National Disability Insurance Agency (Australia)
- Dr Ron Chalmers – Disability Services Commission (West Australia)
- Ralph Broad – Inclusive Neighbourhoods (UK)

**Learning objectives**

- Gain an understanding of LAC design and implementation in an international context, linked to systems reforms
- Gain an appreciation of the evidence base for LAC and critical links to program fidelity



**International perspective**

- Originally developed in Western Australia 1988 in Albany, state-wide expansion by 2000
- Successive development in some other Australian states and territories, notably Queensland, NSW, ACT and Tasmania
- National strategy in Scotland from early 2000, projects in NI, England and Wales
- New Zealand as part of New Model reforms
- National Disability Insurance Scheme (AUS) from 2013



**LAC Framework**

- Vision starts with the right question ie what's a good life rather than services needed.
- Key LAC outcomes: living a rich and fulfilling life, citizenship, family resilience and inclusive communities.
- Charter is to "build partnerships with individuals and families as they build and pursue their goals and dreams for a good life, and with local communities to strengthen their capacity to include people with disabilities as valued citizens."



**LAC Framework continued**

- **Set of 10 principles** emphasising citizenship rights and responsibilities, participation and contribution, natural authority, importance of families/friends and personal networks, information to enhance decision making, choice and control, complementary nature of services, importance of partnerships and lifelong learning.
- **LAC role** which starts with building relationships, access to information, assistance with clarification of goals, strengths and needs, advocacy support, partnerships and collaboration to build inclusive communities, using personal and community networks to develop practical solutions, accessing supports/services and direct funding.



**Quality and Safeguarding**

Some key elements

- Values and principles, "right relationship"
- Clear job design/standards
- Ratios enable a personal approach
- Careful selection of LACs, involve people
- State-wide shared values/principles, network
- Values focus induction and training
- Supervision structure, connections
- Open culture and feedback, evaluations

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### LAC as part of reforms

**Some key questions:**

- LAC design and fidelity
- LAC Implementation approach including governance and training
- LAC as an "Add On" bolted on to the current system or part of a holistic suite of reforms

**A key resource:**  
Bartnik and Chalmers : It's about more than the money – Local Area Coordination supporting people with disabilities (in Hunter and Ritchie (Eds) "Co-production and personalisation in social care ", London 2007)  
This chapter outlines the extensive and long term evaluation base for Local Area Coordination in Western Australia .Details of local and national evaluations from other states/territories and countries can be readily sourced via internet search.

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### NDIS and the NDIA (context for LAC)

The National Disability Insurance Agency (NDIA) administers the National Disability Insurance Scheme (NDIS).

The Agency's job is to:

- Deliver the NDIS
- Build community awareness of disability
- Ensure financial sustainability of the NDIS
- Develop and enhance the disability sector

The NDIA Board governs the NDIS.

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### The NDIS is the new way of delivering disability support

- Supports tailored to individual needs
- Insurance approach for sustainable costs
- Choice and control is central
- Needs driven
- Delivered in local communities
- National coverage

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### Background to the NDIS trial

2008: Commonwealth Government 2020 Summit proposes a national disability scheme	July 2011: Productivity Commission submits report to government	December 2012: Council of Australian Governments sign an intergovernmental agreement to trial the Scheme	April 2013: Bilateral agreements with trial sites signed	1 July 2014: Trial sites in ACT, Northern Territory and WA start
2010: Productivity Commission conducts enquiry into long term disability care	October 2011: Council of Australian Governments agree to the need for reform – joint taskforce develops Scheme design	March 2013: NDIS Act 2013 establishing the NDIS and NDIA passed	1 July 2013: Trial sites in Victoria, NSW, SA and Tasmania start	1 July 2015: Early transition in Nepean Blue Mountains begins

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### Three key pillars underpin NDIS design

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### How things are changing under the NDIS

Feature	Former system	NDIS
Access criteria	Varies from state to state	Nationally consistent as set out in legislation
Choice and control	Varies from state to state - most people have little say over the supports they receive	Individual has control over the type and mix of supports, delivery and how their funding is managed
Level of assistance	Capped – people may be eligible but may spend years on waiting lists	Demand driven – people with disability get the support they need, when they need it, to make progress towards their goals
Funding	Multiple programs within and across governments	Single pool of government funding administered by NDIA

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### Scheme Achievements: Quarter Four 2014–15

<p>✓ On time</p> <p><b>19,817 people</b> have become participants in the NDIS.</p> <p><b>17,303 people</b> have individualised plans, helping them change their lives by accessing the supports and services they need to live more independently and engage with their community.</p>	<p>✓ Within budget</p> <p><b>\$952.8m</b> has been committed for participant support to date.</p>	<p>✓ High satisfaction</p> <p><b>95%</b> rating their planning process as "good" or "very good".</p>
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### Trial and early transition sites are expanding

- Hunter area, New South Wales
- Nepean Blue Mountains area, New South Wales (for children and young people aged 17 years and under)
- Australian Capital Territory
- Tasmania (for people age 15-24)
- Barwon area, Victoria
- South Australia (age 13 and under on 1 July 2014)
- Perth Hills area, Western Australia
- Barkly region, Northern Territory

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### Each participant will have an individual plan

#### Facilitating a Plan

Individual Goals and Aspirations

Informal, Mainstream and Community Supports  
(provided by other systems, family, friends and community)

NDIS Funded Supports  
(reasonable and necessary)

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### National roll out of the NDIS

- The full roll out of the Scheme will commence progressively from July 2016 with full implementation by July 2019.
- Each State and Territory except Western Australia has committed to the full roll out the NDIS.
- The Commonwealth Government has signed bilateral agreements with the New South Wales and Victorian state governments. Bilateral Agreements for other jurisdictions are being negotiated.
- Each state and territory bilateral agreement will contain the details on when and how many people will be transitioned into the Scheme.
- Further information will be available to people with a disability, their families, carers, providers and the general community after these agreements are signed.

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Agency

### LAC in the context of the NDIS

- Productivity Commission identified core staffing of Scheme as including LACs and planners
- Current trials involve testing various approaches to LAC internally/externally and also combined planner and LAC role
- LAC is stream 5 of the Information Linkages and Capacity Building Policy and specifies that in addition to Scheme participants, LACs will also work with a targeted group of people at risk of entering the Scheme prematurely due to lack of support in the community
- LAC design for full Scheme is being built on the long term Australian and international evidence base applied in the context of the Scheme Service Delivery Operating Model and transition to Full Scheme
- NDIS presents enormous opportunities for LAC on a national scale as well as significant challenges related to scale and quality/consistency
- Further implementation details available late 2015

National  
**disabilityinsurance**  
Agency

### Estimated intake

It is estimated that around 460,000 Australians will be supported by the NDIS by 2020.

Year	Participants Entering the NDIS
End of trial	31,000
2016/17	120,000
2017/18	195,000
2018/19	117,000
Total	462,000



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Disability Services Commission

WA NDIS My Way

## Local Area Coordination in Western Australia: the platform for system reform

Dr Ron Chalmers  
DIRECTOR GENERAL  
Disability Services Commission of Western Australia

GOVERNMENT OF WESTERN AUSTRALIA  
Disability Services Commission

## NDIS My Way

### Local Area Coordination

- Originated in Western Australia
- 27 years of development and refinement
- Strong focus on values and principles
- Integral to the WA disability support system
- High level of consumer satisfaction
- Numerous evaluations
- State-wide coverage
- Government service

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Disability Services Commission

## NDIS My Way

**Supply driven:**  
Person has to fit the service

**Demand driven:**  
Service has to fit the person

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Disability Services Commission

## NDIS My Way

### Local Area Coordination - Success Factors

- Strong visionary leadership
- Commitment to the original vision and principles
- Locus of control with the individual/family
- Enduring relationships
- Support in the local community
- Managed within government
  - maintains coherency
  - consistent supervision and management
  - ensures commitment to vision and principles
  - Consistent approach to recruitment, induction, training

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Disability Services Commission

## NDIS My Way

WA NDIS My Way

NORTHERN TERRITORY  
WESTERN AUSTRALIA  
QUEENSLAND  
SOUTH AUSTRALIA  
NEW SOUTH WALES  
VICTORIA  
TASMANIA

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Disability Services Commission

## NDIS My Way

### Implementing the NDIS in Western Australia

- Build upon the strengths of the existing system
- Local governance and local decision making
- A focus on support rather than a focus on funding
- A relationship based support system
- Genuine choice and control
- Remote area strategies
- Minimal bureaucracy

  **NDIS My Way**

**Implementing the NDIS in Western Australia**

Integral role for **Local Area Coordinators**:

- engagement, build a relationship
- planning and funding
- linking people to supports and services
- linking people to community and mainstream services
- community development
- advocacy
- reviews and accountability

  **NDIS My Way**



  **NDIS My Way**

**Outcomes from NDIS My Way trials**

- 2,000 people now in the trial
- Average plan costs \$30,000
- 93% of plan outcomes are being achieved
- 20% of people opting for self-management
- 10% of plans require no funding
- Very high level of consumer satisfaction
- No complaints or appeals

**Local Area Coordination is the platform for NDIS My Way**

# A9i

## Toronto's Unfolding Story... Where Do We Go From Here?

Frances MacNeil, Barry Isaacs



**INDIVIDUALIZED FUNDING**

**Toronto's Unfolding Story...where do we go from here?**

**Barry Isaacs and Frances MacNeil**  
**October, 2015**



- o The Background/Context
- o Moving toward a Market Driven Service Model
- o Fee-For-Service Resource Package
- o Review of IF Models
- o Next Steps
- o Discussion

2 dsto | A Review of Individualized Funding Models 9/10/2015



### Background

- o 2011 – Passport stats were flagged and task group was formed to explore the impact for Transfer Payment Agencies
- o 2012 – Task group reported back to dsto and an ad hoc group was formed to examine the sector's preparedness for direct funding
- o 2013 – Report *Moving Towards a Market Driven Service Model*
- o 2014 – Ad hoc group develops fee-for-service resource package for TPA's
- o 2015 – Improving Quality Sub-group completes *A Review of Individualized Funding Models*

3 dsto | A Review of Individualized Funding Models 9/10/2015



### Moving Towards a Market Driven Service Model

- o The changing environment
- o What we've learned so far
- o The challenges that lie ahead
- o The opportunities of moving forward together
- o Follow-up next steps which resulted in the development of the Fee-For-Service Resource Package

4 dsto | A Review of Individualized Funding Models 9/10/2015



### Introduction & Information

- o Purpose of the resource package
- o Understanding fee-for-service
- o Leveraging funded resources
- o Pricing fee-for-service activities
- o Supporting sustainable service expansion
- o Reporting serious occurrences
- o Maintaining consumer engagement

5 dsto | A Review of Individualized Funding Models 9/10/2015



### Tools

- o Agreement templates – Agency-to-family, agency-to-agency and memorandum of understanding
- o Forms – Registration, Supplemental Info, Refund Policy, Publicity & Release
- o Activity Fee Schedule and Pricing Tool
- o Survey templates & results – family online survey and self-advocate focus group

6 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **Consumer Engagement**

- Families – 160 survey respondents
- 50% identified as in high school and 31% in rec/leisure
- Top priorities after school: employment/work opportunities, life skills training and employment training
- 92% willing to pay for activities (of those, 54% said it would dependent on cost)
- Focus group – 18 respondents

7 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **Review of IF Models**

- Using academic and grey literature and key informant interviews:
  - Gain Clarity/understanding on terms
  - Review IF approaches used in Canada, the US, UK and Australia
  - Review Experiences and Impacts
  - Inform the transition to a service environment that includes market driven models

8 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **Terms and Definitions**

- Individualized funding is an umbrella term
- Others are used to describe particular instances IF models, e.g.
  - Direct/Indirect Funding
  - Service Brokerage
  - Independent Facilitation
- Often these are understood in different ways
- All are based in principles of self-determination, choice and person centred planning

9 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **IF Across Jurisdiction**

- There are many IF programs in Canada and other countries, all share these elements:
  - Governmental determined eligibility criteria
  - Application process
  - Eligibility and needs assessment process
  - Defined list of eligible supports & services for use of funds
  - Funding limits
  - Financial means test & accountability systems (reviews/audits)
  - Mechanisms for funding allocation (person/bank, provider)
  - Development of personalized support plan
  - Mechanism for approval of personal support plan

10 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **Experience and Impact**

- Positive impacts of IF include
  - Increased service satisfaction
  - Improved quality of life
  - Waitlist reduction

11 dsto | A Review of Individualized Funding Models 9/10/2015

● ● ● **Experience and Impact**

- Concerns include:
  - Lack of adequate information on
    - the processes for accessing IF
    - how IF works with other funded disability supports
  - 'Recasting' of families as employers
    - Labour relations issues for agencies
    - Added administrative burdens/challenges
  - Low up-take of IF as a funding option

12 dsto | A Review of Individualized Funding Models 9/10/2015



## Individualized Funding: The Experiences, Barriers and Facilitators Associated With Implementing Four Pilot Initiatives in Ireland

Padraic Fleming



**INDIVIDUALIZED FUNDING: THE EXPERIENCES, BARRIERS AND FACILITATORS ASSOCIATED WITH IMPLEMENTING FOUR PILOT INITIATIVES IN IRELAND**

**Padraic Fleming B.A. M.Sc**  
SPHeRE PhD Scholar, Maynooth University

**Supervisors:**  
**Dr Sinéad McGilloway**  
Department of Psychology, Maynooth University  
**Dr. Sarah Barry**  
Health Policy and Management, Trinity College Dublin






**OVERVIEW**

- Systematic Review
- Secondary Data Analysis – Mapping 15 years of day service trends in Ireland
- Evaluation of 4 individualized funding projects
  - Document analysis and interviews
  - Participatory Workshop
- Next steps: Analysis of participatory workshop and preparations for final stage




**RESEARCH OBJECTIVES**

- Evaluate the implementation of Personal Budgets (PBs)
- Ascertain if they are feasible within the Irish context
- Determine if PBs are an appropriate mechanism for supporting people with disabilities to be independent, self-determining individuals, who are integrated into their community.
- Provide evidence for policy drivers



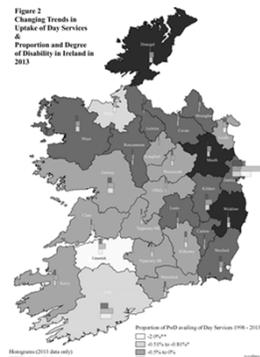

**SYSTEMATIC REVIEW**

- **Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review<sup>1</sup>**
- No systematic review that focuses on the effectiveness of personal budgets in relation to people with a disability of any form, including mental health problems.
- The review will:
  - (1) assess the effectiveness of personal budgeting interventions;
  - (2) utilise subgroup analyses to explore how effects may differ by various client and intervention parameters; and
  - (3) appraise and synthesise the experiences of key stakeholders.




**TRENDS IN DAY SERVICE USE OVER 15 YEARS IN IRELAND**

Figure 2  
Changing Trends in Usage of Day Services  
Proportion and Degree of Disability in Ireland in 2013



- Higher numbers
- Decrease in proportion to general population
- Increasing number of men availing of services
- Fewer people under the age of 35
- Emergent urban / rural divide (fewer in urban centres and increase in rural areas)
- Doubling in PCPs
- Uptake did not reflect demand




**EXPLORATORY QUALITATIVE INTERVIEWS**

- Set the scene
- Limited visibility around the individualized supports being provided in Ireland
- Funding mechanisms
- Perceptions of what's working well and where improvements could be made
  - Individuals / Advocates
  - Staff



### QUALITATIVE INTERVIEWS

- o Purposive sampling
- o 44 individuals
- o 24 interviews with 35 individuals
- o 8 secondary data video files with 9 individuals
- o 12 staff / 20 project participants / 12 advocates
- o Amounted to >71,000 words
  - Transcribed
  - Analysed using MAXQDA
    - o Critical Realist – ontological realism with constructivist / relativist epistemology<sup>3</sup>
    - o Thematic Analysis
  - >5,500 coded pieces of text
  - 200 themes

### THEMES

(6) Level 1	Stakeholders	Process	Outcomes	Systems	Organisational	Community
(46) Level 2	Advocates	Meeting Broker	Client + Outcome	Support Model	Org. Challenges	Community Spirit
(82) Level 3	Natural Supports	ID Needs / Goals	Independent Travel	Traditional	People Management	Peer Support
(54) Level 4	Family	Client activities	Bicycle / Scooter	Aware TM unfit		
(12) Level 5	Family worries	Work / Job				

### FACILITATORS & BARRIERS

- o Individual
- o Process
- o Organisational / System

### FACILITATORS - INDIVIDUAL

#### Self Image

Successful   Confident   **Adaptive**   Skilled   Leader

The challenges were huge and I think that fact that Joseph put so much energy into overcoming those challenges eh, will make it easier for other people and has possibly already made it easier for other people to do the same

### FACILITATORS - INDIVIDUAL

Empowerment   Independence   **Indo S/ Develop**   Health in   Sense of c

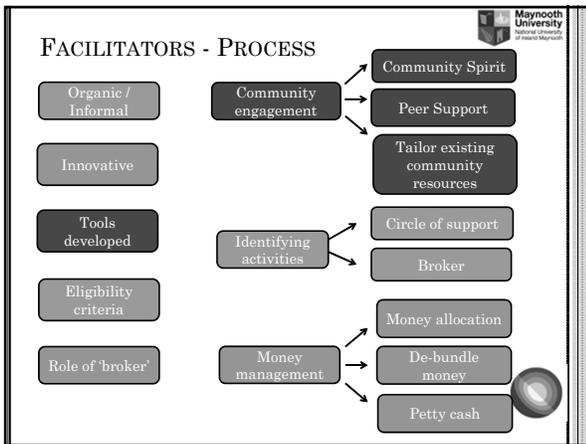
she's had such a great year of being ... out of the psychiatric ward and for her that means it's been a very good year and she knows that once that she has a schedule, a pattern to her day, she's healthy and her mental health is good

### FACILITATORS - PROCESS

Involving natural supports

I couldn't have achieved these things without my company board and circle of support. These people are motivated, conscientious and willing to assist me in gaining more autonomy in my life.

It won't be for everybody because there's quite a big input from family, you know. I'm as busy today as I was ever. But I'm busy in a positive way. I'm not just constantly fighting with somebody and that's what it was. It was just such a negative spiral, ...



### FACILITATORS – ORGANISATIONAL / SYSTEM

o Individual Funding vs. Traditional Model

**Leading the way**

... the existence of (pilot project) is a bit of a challenge to some services ... to some services it's pushing them a bit more to the individualized model...

### BARRIERS - INDIVIDUAL

Difficult to ID activities

Need Guidance

Reinforce Disabil

Protective

Disengaged

COMPLEX

She crossed a busy street with a trolley to leave it back at the shop. Now me heart was in my mouth

...parental interference and control. So that was a challenge. So right down to, let's say the individual would have liked to experience independent living, even respite, in a respite way, but the parent wouldn't let go...

...it's all Facebook and this type of Snapchats ... we have a group who can use the technology but probably don't have the where-with-all ... to be able to mind themselves ... it's a 24 hour 7 threat.

### BARRIERS – ORGANISATIONAL / SYSTEM

...see I wasn't sure what kind of, what my favourite thing to do. And then I explain, then I know what I like. Doing driving. Then I said no, I like cycling...

...that is not for the lily livered ... very very difficult, dotting the i's, crossing the t's or run into big legal problems... It's huge undertaking

Admin

People management

### BARRIERS - ORGANISATIONAL / SYSTEM

**Funding**

**De-bundle**

"The biggest single problem, and the biggest single delay has been trying to get the funding, and that comes in under a couple of headings. One is decoupling funding from a block grant..."

**WHY?**

...it still leaves the service provider with that dilemma of: "I'm running a house now with four people, it costs me almost the same amount..."

...a way of assessing funding for adults...

### BARRIERS – ORGANISATIONAL / SYSTEM

**Org. Fear**

...it seemed that making use of the PA that was already in place...

But I'm not saying we're a broker, but we are, that's really what we are. But then the danger of that is we become the service provider...

...I've seen it within the PCP process, not here, whereby people have just duplicated what's gone on six months ago, or three months ago, and that's nonsense...

 Maynooth University  
National University of Ireland Maynooth

## FINDINGS TO DATE

- o Effective for improving health and social care outcomes;
- o Feasible within the Irish context;
- o An appropriate mechanism for supporting people with disabilities to gain independence and self-determined lives, fully integrated within the community



 Maynooth University  
National University of Ireland Maynooth

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THANK YOU FOR LISTENING  
QUESTIONS?

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 SPHERE  
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# A9iii

## From Grassroots to Policy Change: The Ontario Experience with Direct Funding and Independent Facilitation

John Lord, Dave DeVidi

**FROM GRASSROOTS TO POLICY CHANGE:**  
The Ontario Experience With Direct Funding and Independent Facilitation

John Lord and David DeVidi

Claiming Full Citizenship Conference  
October 2015

Purposes:

1. To show how grassroots efforts and community development have been crucial to bringing **Direct Funding (DF)** and **Independent Facilitation (IF)** to Ontario.

Purposes Cont.

2. To show that while ‘bottom-up’ activism and ‘top-down’ policy must interact, the **drive must come from below** to ensure that policies truly reflect on-the-ground experience and lessons.

Part 1 - The Context

**1980's**

- Deinstitutionalization
- First individualized funding for families

→

**1990's**

- Parent advocacy for Direct Funding
- First brokerage/independent facilitation project

The Context: Lessons

- Governments move slowly – need to understand how to influence incremental change
- Deinstitutionalization creates the context for person-centred approaches
- Parent demands make a difference in government priorities
- Innovative approaches take time to develop and shape in implementable ways

Part 2: Advocacy and Education Set the Table for Policy Change

*Individualized Funding Coalition for Ontario*  
– key provincial group that framed DF

- Reports and research frame the ‘general position’ and values of an emerging New Story
- Provincial Symposium on IF (1998)
- Round Table on Individualized Funding (2000)

**Advocacy and Education Set the Table for Policy Change**

*Government initiates “transformation” of developmental services (2006)*

- Advocacy groups publish ‘Common Vision’ of values, principles, goals for DF and IF (2006)
- Government appoints Partnership Table with wide representation to advise on transformation

**Advocacy and Education Set the Table for Policy Change: Lessons**

***Change requires:***

- Clear Ideas: a story and a message that is understandable and feasible
- Persuasive champions who can write, present, and argue the New Story

**Policy Change: Lessons Cont.**

- Generate and maintain momentum with allies
- Don’t make enemies
  - Manage relationships with doubters and adversaries
- Seize opportunities to move from advocacy to negotiation
- Expect tension between “sticking to principle” and being “open to new ideas”
- Advocacy and education are not enough

**Part 3 - From Grass Roots to Community Groups: Affecting the Policy Agenda**

- Individualized Funding Coalition initiates Modeling Community Change and Innovation
- Strategic “seeding and supporting”
  - Leads to 6 “steering committees” for IF across province
- DF funding is increased making IF more viable
- Community groups build capacity, deepen the craft of Independent Facilitation

**From Grass Roots to Community Groups: Affecting the Policy Agenda**

- Facilitation Wellington Dufferin
  - Started as “Steering Committee”
- Obstacles to success
  - Can be local (e.g., hard feelings from advocacy days)
  - Solutions might need to be local

**Affecting the Policy Agenda Cont.**

***For us, local keys to success were:***

- Alliances with progressive service providers
- Reputation for innovation, adaptability
- Supporting and training facilitators
- Developing and maintaining relationship with government
  - Proving we can “get things done”
- Increasingly connected with similar groups across the province

Affecting the Policy Agenda Cont.

What worries *us*: Only one experienced facilitator in our regions

What worries *the government*: Only want to fund quality work in an unregulated field

Affecting the Policy Agenda Cont.

**Our solution:**

- Apprenticeship model for training facilitators; “core competencies” and evaluation process
- FWD affiliated facilitators an assurance of quality work

**The strategy:**

- Give them what they will want *before they know they want it*, so you can shape it

**The effect:**

- *Enhanced reputation*: get things done, adaptable, a partner rather than an adversary

Affecting the Policy Agenda: Lessons

- Ontario is big, diverse: solutions will vary, so community groups need to be seeded, nurtured
- Local groups will innovate, model best practice, and create conduits for government funding

Affecting the Policy Agenda: Lessons

**A challenge: getting beyond a patchwork approach**

- Need a provincial network for government negotiations and oversight role
- High level of collaboration is needed, willingness to “learn together” - balancing local innovation and need for some consistency across province
- New groups and new ideas are sure to cause tensions—need ongoing conversations on difficult questions

Part 4 - Moving Forward

- 2015-17: Independent Facilitation Demonstration Project
  - Seven local organizations, OIFN, extensive evaluation
- DF and IF now seen as connected pieces in a New Story
- Community development funds enable seeding and nurturing of community groups in other regions

Moving Forward Cont.

**Challenges:**

- Scaling up, innovating while maintaining principles
- Trying to shape government’s legitimate demands so they don’t take us off course
- Staying open to new ideas, new partners, and the next innovation



# A10

## Working Together to Reclaim Citizenship: A Story of People Labelled 'Too Challenging' or 'Too Complex' Regaining their Place in our Community

Margaret Rodgers, Leanne Burke, June Arthy, Bronwyn Moloney

This presentation will focus on a variety of initiatives in Queensland that have assisted people labelled too challenging or too complex to regain their place in their community and to direct their own support with the help of family and friends. Through the stories of two people, the presentation will describe how these different initiatives work in practice.

It will also explore the benefits gained from different organisations working together. Community Resource Unit has invested in change and leadership development across the state for over 25 years. The advocacy group, Speaking Up for You (SUFY) has called for a different response and has partnered with others to find another way. Staffing Options is a for-profit staffing agency which has responded to the needs of individuals who required a more flexible response than most organisations were willing to provide and now enables over 100 people to direct and manage their own supports. The Kalpana collective is hosted by Staffing Options and is the story of people who were 'infamous' in the system ten years ago and who are now quietly living their lives, contributing to their communities.

Session learning objectives:

Workshop participants will:

1. Hear individual stories of the way people have been supported to reclaim their place in their community.
2. Draw from these experiences the benefits of people and their families directing their own lives and their own supports, both individually and collectively.
3. Identify the benefits of negotiating for each individual situation, the roles of each party, in particular what is delegated to people who are paid to be there.
4. Compare and contrast the benefits of these models with the impact of one-size-fits-all service delivery, particularly on those considered to be challenging or complex.
5. Appreciate that it is possible for all people to direct their own support, regardless of their label.
6. Understand how different organisations can work together to create a better response to the people who challenge the system.

Ingredients List: (for note taking during the session)

1. Vision and Expectations

2. A place to start

3. Working together

4. Family business and service business

5. Creating and Reclaiming

6. Safeguarding

**B1i****Microboards and their Role in High Quality Support**

Ellen M Walker

**Learning Objectives**

By the end of this presentation, the aim is for participants to:

1. Have a deepened understanding of how Microboards can influence high quality support; and
2. Hear how microboards have maintained a stable but innovative support team.

**Introduction**

People with high support needs rarely have the opportunity to claim full citizenship. Microboards have been promoted as providing the means to seek out, provide, and enact opportunities to embrace this claim. High quality personal support is integral to success. This paper provides an update of research findings as to how microboards work to ensure the focus person has high quality personal support. An interpretive interactionist methodology was used with case study methods including interviews and document reviews followed by thematic analysis. Participants included parent-carers, members, and where possible the focus person from six Microboards in British Columbia and Western Australia.

**What we are told**

Quality support is integral to a person with high support needs having a good quality of life. A good quality of life nurtures the conditions necessary to claim full citizenship. Quality support is influenced through recruitment, induction, ongoing management and professional development for staff. Support is enhanced through having an intimate knowledge of the person for whom the service is intended, and having the capacity to develop effective professional relationships within an ethic of care.

**What we have learnt....**

Stories from research participants provide insights about how Microboards sustain a stable support team in an environment that encourages innovation while providing safeguards.

**Conclusion**

Microboards, through their collective nature, have the capacity to positively influence the quality of support available to people with high support needs. In turn, this contributes to the realization of the focus person's claim to full citizenship.

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# B2i

## Why Citizenship Matters

Simon J Duffy

### Why Citizenship Matters

Dr Simon J Duffy of The Centre for Welfare Reform



Concurrent Session B2i: 30 minute talk with Q&A  
Thursday, October 15, 2015, 3:30 pm - 5:00 pm

1. Citizenship is the most important **goal** for our work together.
2. True citizenship welcomes **difference**, creates **equality** and is inclusive of all.
3. Citizens work together to **understand** how citizenship can be opened up to everyone.
4. Our recent work has, to some degree, helped more people to **achieve** citizenship.
5. But if we take citizenship seriously then this may change **how we carry out our work**.



What are we doing



What is our goal

There are lots of good ideas and nice words that groups use to say what they think we should all be trying to achieve.

- Happiness
- Care
- Love
- Inclusion
- Empowerment
- Fulfilment
- Better Outcomes
- Increased Social Value
- Community Connections
- Greater Contribution
- Lives of Meaning
- Normalisation

But the most important goal is **citizenship**



Why

Because to be a citizen means you are part of the community that decides what its goals are.

If you are not a citizen you are outside and any goals that are set are not your goals (although they may still be set *for* you).



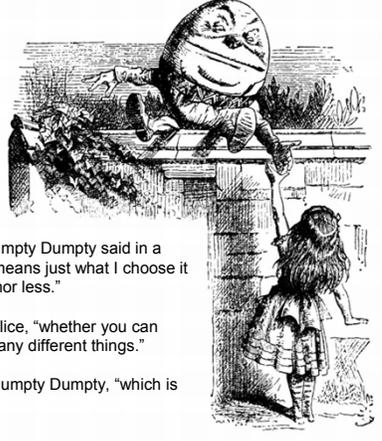
What kind of citizenship

The idea of citizenship has a long history and it has been used and abused by many different societies.





What is the true meaning of citizenship?



"When I use a word," Humpty Dumpty said in a rather scornful tone, "it means just what I choose it to mean - neither more nor less."

"The question is," said Alice, "whether you can make words mean so many different things."

"The question is," said Humpty Dumpty, "which is to be master - that's all."

**Citizenship is the best route to equality**

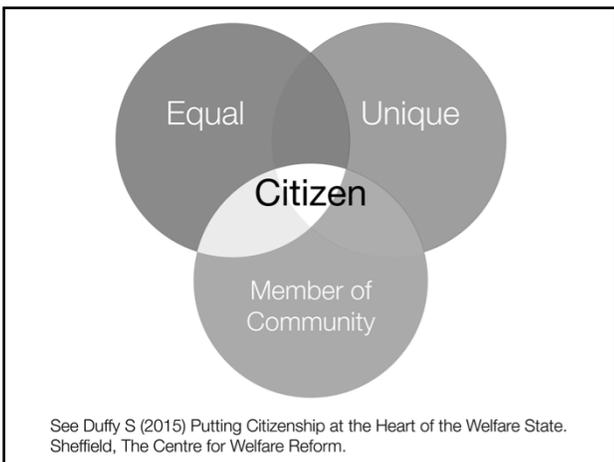
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In a community of citizens we don't all have to be the same - we can all be different and yet treat each other as equals. Equality is a status we create together - in community.



"Aristotle explains that a community is not made out of equals, but on the contrary of people who are different and unequal. The community comes into being through equalising, *isathenai*."  
[Nichomean Ethics 1133a 14]

Hannah Arendt,  
*The Promise of Politics*



"Citizenship grows when people who are different recognise they are equal and start to work together in that spirit."

---

"Citizenship dies when people abandon those who are different to injustice and retreat into passivity."

Understood correctly, citizenship enables us to be equal - and different - unique. Citizenship frees us from the idea that we must conform to a standard.

Instead we can learn to live together with respect: as free and contributing members of the community.



How can we be citizens

Citizenship is valuable.  
But it has a price. It is not enough to just call people 'citizens', rather we must work to make sure that everyone can be valued as an equal.

**Citizenship is 'Universalised' Social Role Valorisation (SRV)**

- Both pay attention to how our status is 'constructed' by society and both seek to increase status of people with intellectual disabilities. **But**
- Citizenship demands we reject social devaluation for **everyone**, rather than just avoiding placing people in devalued roles.
- Citizenship demands that we all have a **duty to act** as a citizen and to welcome others as citizens.

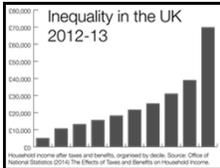
Some things are bad for citizenship.



Glamour and Fame

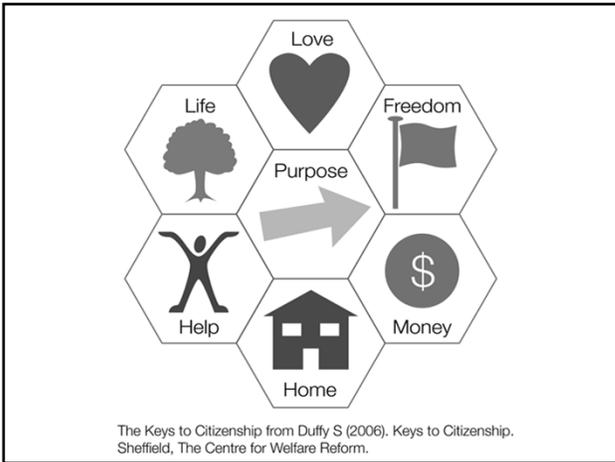


Tyranny



Income Inequality

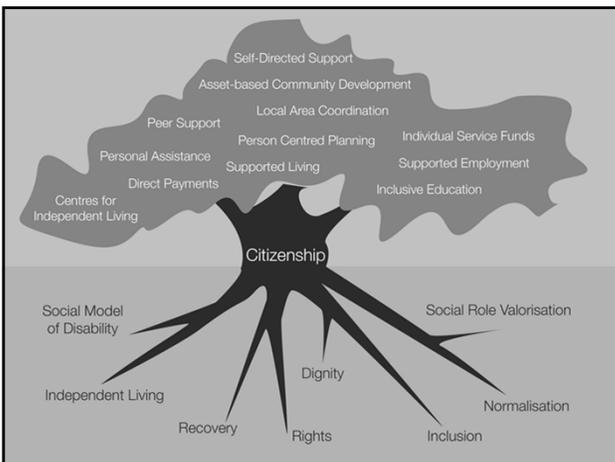
Some things are good for citizenship.

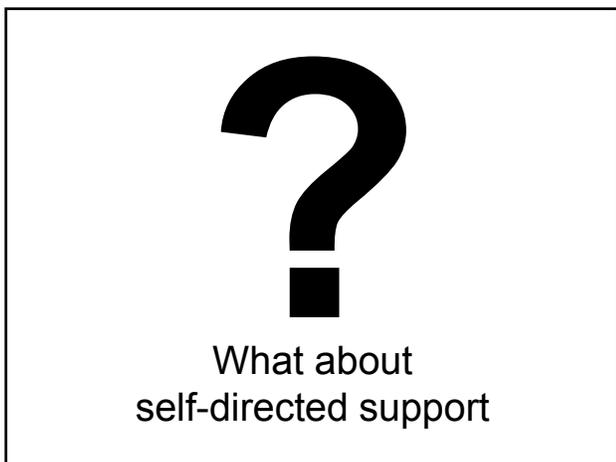


- We make citizenship real by
1. Finding our sense of **purpose**
  2. Having the **freedom** to pursue it
  3. Having enough **money** to be free
  4. Having a **home** where we belong
  5. Getting **help** from other people
  6. Making **life** in community
  7. Finding **love**

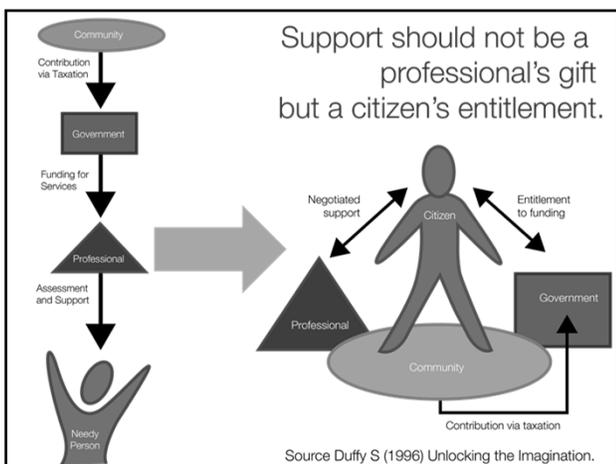
- This protects our status
1. Our life is seen to have **meaning**
  2. We are not on **someone else's** control
  3. We can **pay our way** - we're not unduly dependent
  4. We have a **stake** in the community
  5. We give others the chance to **give**
  6. We **contribute** to the community
  7. We are building the **relationships** that sustain community

This kind of citizenship is entirely practical and sustainable. It is possible to achieve the keys to citizenship for everyone. Not only does it not rely on the exclusion of others it benefits from the inclusion of all.

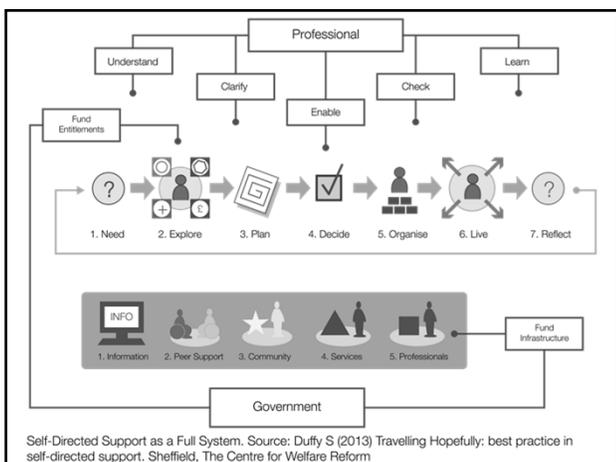




For many of us self-directed support has always been about helping people achieve citizenship.

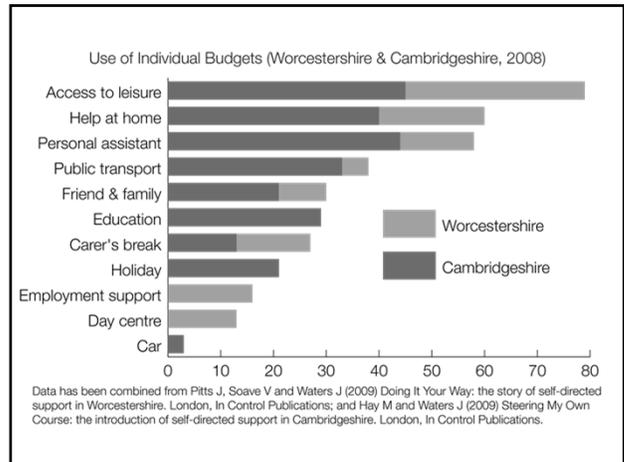


This often influences the design of different systems of self-directed support



- **Purpose** - enabling people to set their own goals
- **Freedom** - overcoming problem of mental capacity
- **Money** - moving resources from systems to citizens
- **Home** - enabling people to live where they choose
- **Help** - people directing their own support
- **Life** - increasing participation and contribution
- **Love** - strengthening families, friendships & relationships

Often research on self-directed support suggest some improvements in 'signs of citizenship'.

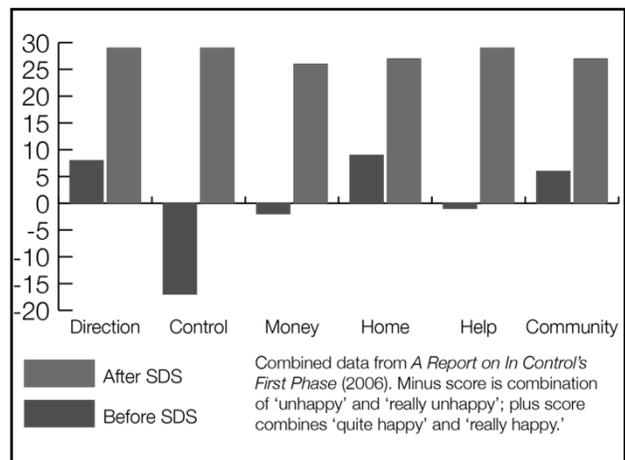


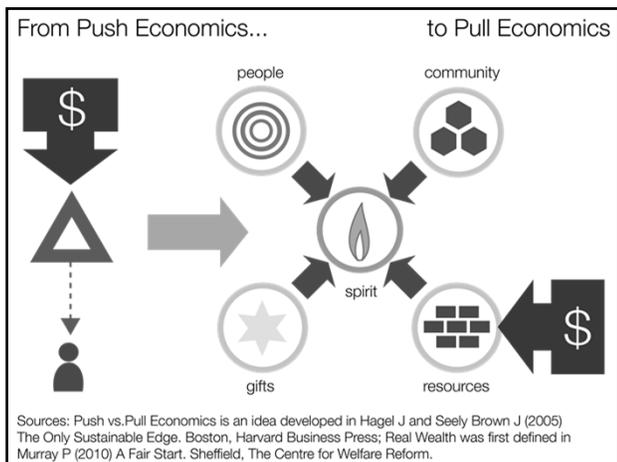
What next

Systems cannot be tricked into treating people as citizens. Self-directed support will need strong foundations if it is to be truly effective.

This means, for example

1. We must be able to **define and measure** how effective we are being in achieving citizenship.
2. We must recognise that this is about equipping people **to act as citizens**.
3. We must connect our efforts to **wider social and democratic reforms**.





People with disabilities, like many others, have had to fight for citizenship; and there is still much to be achieved. In fact people with disabilities can show people **the true meaning of citizenship**, and this raises important challenges for all societies in the decades ahead. It is time to challenge the priorities of modern society and to develop ideas that are more inclusive, empowering and creative. Citizenship is an ideal whose time has come.

But we must begin by acting as citizens ourselves.

Q & A

For more information:

- [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)
- @simonjduffy and @CforWR
- [simon@centreforwelfarereform.org](mailto:simon@centreforwelfarereform.org)
- [www.facebook.com/centreforwelfarereform](https://www.facebook.com/centreforwelfarereform)



**B2ii****Citizenship and Social Inclusion for People with Dementia: A Register Study in a Swedish Context on the Distribution of Social - Care Services**

Elzana Odzakovic, Ann-Charlotte Nedlund, Annika Taghizadeh Larsson

**Abstract:**

The issue of social inclusion has attained increasing attention in dementia research. However, the focus has mainly been on if people with dementia has equal opportunity to live as full citizens, while issues of equality within the population of people with dementia are still fairly unexplored. In Sweden, every citizen has equal right to social-care. These services are provided by the local authorities and mainly regulated in the Social Services Act. Despite a solid tradition in Sweden of saving data from social-care in databases, there is limited information on the extent and type of social-care provided for persons with dementia as well as how this provision might differ depending on individual background. The purpose of this paper is to investigate how social support is distributed for people with dementia and further to compare this distribution in an ethnicity perspective. This will be made by a statistical analysis based on data from a research database that is in progress. This study includes data from a five-year period 2008-2012 on all dementia diagnoses where every individual with an ICD diagnosis of dementia will be matched with two national registers according to country of birth, to special forms of housing, day care, and home-care services. Preliminary results will be presented on what characterizes the population with dementia with respect to country of birth and provided social-care services. Based on these results the paper will discuss matters such as social inclusion and ethnicity in relation to the provision of social-care and welfare policy.

**Learning Objectives:**

1. Share lessons learned on the implementation of self-determination, personalization, individualized funding and supported decision making
2. Promote cross national, cross cultural and cross sector dialogue
3. Foster cooperative networks across jurisdictions, sectors and interests that will continue after the conference

**Synopsis**

In Sweden, every citizen has equal right to social-care. The purpose of this paper is to investigate how social support is distributed for people with dementia and to compare this distribution in an ethnicity perspective. A statistical analysis will be presented based on data in progress.

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# B3ii

## Supported Decision Making Demonstration Project: A Collaborative Approach

Robert D Fleischer, Cathy Costanzo, Elizabeth Pell

**Supported Decision Making Demonstration Project:  
A Collaborative Approach  
and  
National Core Indicators Data to Promote Rights**



2

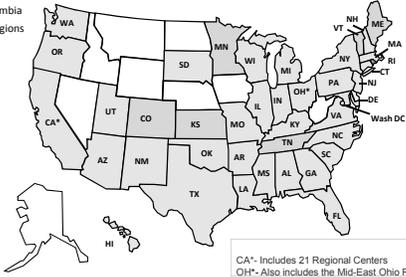
**Learn about:**

1. Different life experiences of adults without guardians compared to those under guardianship in NCI participating states
2. Supported Decision Making initiative between a public interest law firm and a shared living provider in Massachusetts
3. Independent evaluation of SDM initiative to report on lessons learned and good practices

3

**National Core Indicators (NCI)  
State Members 2014-15**

• 42 states  
• District of Columbia  
• 22 sub-state regions



CA\*- Includes 21 Regional Centers  
OH\*- Also includes the Mid-East Ohio Regional Council.

4

**Exercising Rights**

NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Rights</b>			
Can be alone with friends or visitors at home	81%	75%	71%
People ask before entering home	91%	89%	88%
Uses phone or internet without restriction	92%	90%	87%

Source: NCI-DD Adult Consumer Survey data 2013-14

5

**Exercising Choice**

NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Choice – Made decision or had some input into decision</b>			
Home	62%	46%	41%
Roommates	54%	42%	35%
Staff (day & residential)	69%	64%	60%
Daily schedule	90%	79%	77%
What to buy	93%	83%	81%

Source: NCI-DD Adult Consumer Survey data 2013-14

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**Employment**

NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Employment</b>			
Integrated employment goal in service plan	30 %	22 %	21 %
Had community paid job during past 2 weeks	19 %	13 %	12 %

Source: NCI-DD Adult Consumer Survey data 2013-14

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### Relationships

NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Relationships</b>			
Has friends who are not family or staff	78%	74%	73%
Can date without restrictions	71%	68%	58%

Source: NCI-DD Adult Consumer Survey data 2013-14

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### Personal Characteristics

NATIONAL CORE INDICATORS™	No guardianship	Limited guardianship	Full guardianship
<b>Co-occurring:</b>			
Mild level ID	49%	33%	28%
Use speech to communicate	85%	72%	65%
Live with parents or other relatives	38%	29%	33%

Source: NCI-DD Adult Consumer Survey data from 2013-14

9

### NCI Guardian Status Tracking

<u>2015 New Question</u>	<u>NCI 2013-14</u>
<p>If under guardianship, guardian's relationship to person:</p> <ul style="list-style-type: none"> <li>• Family</li> <li>• Friend</li> <li>• Employee of state or guardianship agency</li> <li>• Other</li> </ul>	<p>Adults with I/DD receiving services in NCI states:</p> <ul style="list-style-type: none"> <li>• No guardian - 50%</li> <li>• Limited guardian - 7%</li> <li>• Full guardian - 43%</li> <li>• Don't know - 2%</li> </ul>

- 10
- ### Massachusetts SDM Pilot
- Partnership between CPR & Nonotuck Resource Associates
  - Among the first SDM demonstrations in the nation
  - Individuals with I/DD enter into Agreements with supporters in areas such as health, relationships, finances, employment
    - CPR provides legal representation as necessary
    - Nonotuck care managers act as liaisons between the individual, his/her network and the community
  - Advisory Council reviews progress, offers guidance
  - Independent evaluation supported by grant from the Open Society Foundations

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### SDM Pilot Advisory Council

Representatives include:

- People using services
- Legal scholars in disability issues
- Retired judges
- Attorneys
- Medical professionals
- Directors of social service organizations



Paige and Johnathan

- 12
- ### Massachusetts SDM Pilot
- Currently 8 adults using shared living, 24 to 79 years old, with different disabilities and varying levels of support
  - Discharging guardianship for 2 participants
  - SDM networks of 2 to 10 supporters: parents, siblings, grandparents, aunts, past & current providers
  - SDM Pilot Toolkit:
    - ✓SDM Representation Agreements
    - ✓Durable Powers of Attorney
    - ✓Health Care Proxies

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### Amanda's SDM Arrangement

**Decision Support Areas:**

- Health care
- Legal
- Finances
- Home
- Personal life

**Chose 4 Supporters**



Amanda at Sandy and Eddie's wedding

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### Role of SDM Supporter

- Support person's decision-making by:
  - One-on-one conversations laying out pros and cons
  - Demonstration and role-playing
  - Lots of meetings! Lots of conversations!
- Know how person makes decisions (for example, wait 6 minutes for Amanda's response)
- Respect person's values and preferences ... and decisions

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### SDM Experience to Date

- Implementation lessons learned to date
- Types of decisions SDM used:
  - Surgery consultation
  - Medication
  - Relationship
- Receptiveness of community members

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### Resources & References

- **Massachusetts SDM Pilot:** [www.supporteddecisions.org](http://www.supporteddecisions.org)
  - ✓ Representation Agreement
  - ✓ Brochure
  - ✓ Advisory Council overview
- **National Core Indicators (NCI):** [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)
  - Webinar on outcomes by guardianship status and SDM overview: <http://www.nationalcoreindicators.org/resources/presentations/>
  - Data brief on Rights & Respect highlights differences of people with I/DD receiving services including differences by guardianship status: [www.nationalcoreindicators.org/resources/data-briefs](http://www.nationalcoreindicators.org/resources/data-briefs)
- **National Resource Center on Supported Decision Making (U.S.):** <http://supporteddecisionmaking.org/>

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### Contact Us!

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George Fleischner, CEO Nonotuck Resource Associates 425 Prospect St., Northampton, MA 01060 413-586-5256 fleischner@nonotuck.com	
Elizabeth Pell, Policy Associate Human Services Research Institute 2336 Massachusetts Ave., Cambridge, MA 02140 617-844-2307 epell@hsri.org	

## B3iii

## Shaping Up Decision Making: The Role of Active Support

Julie Beadle-Brown

## Learning Objective:

To provide participants with a basic understanding of active support and how it can be used to support people with intellectual and developmental disabilities to make decisions.

## Outline

In order to make real choices we need at least three things – we need options to choose from, knowledge and preferably experience of those options and what they involve and a way of understanding the options presented to us and to express our decision. To be motivated to make choices, we also have to have experience of having our decisions respected. This is true whether we are deciding what to have to drink, where to live or at which hospital, or even whether, to have an operation.

People with intellectual and developmental disabilities, especially those with severe and profound disabilities, often need support to make real choices. They need support to make activities, interactions and other opportunities accessible to them and to successfully participate in those opportunities (even if only for a very short period of time) in order to gain the experience necessary to make choices and the experience of having their decisions respected. They also often need support around communication – both in understanding the opportunity available to them and in showing their preference. Supporting the development and maintenance of choice-making in this way, requires a particular style of support – it requires those providing support to have what Mansell and Beadle-Brown (2012) call “an enabling relationship”, to focus on enabling and empowering people through all the opportunities available in the home and in the community, at work or school, in leisure, and in their social relationships - doing things with people, rather than doing things for or to people. This approach is known as (person-centred) active support (Jones et al., 1996; Mansell et al. 2004; Mansell and Beadle-Brown, 2012).

Active support is defined as “providing enough help to ensure successful participation in meaningful activities and relationships, so that people gain more control over their lives, gain more independence and become a more valued member of their community, irrespective of the degree of intellectual disability or the presence of additional needs, such as autism or challenging behaviour” (Mansell et al. 2004). Almost 40 years of research has shown that active support, when well implemented, brings about substantial changes in the quality of life of people with severe and profound intellectual disabilities (Stancliffe et al., 2008; Mansell et al., 2012). This includes the domain of choice and control (Beadle-Brown et al., 2012).

There are four essential components of active support:

- Every moment has potential – everything that goes on around the individual, in their home and garden, in their neighbourhood, in their wider community, is an opportunity for people to gain new experiences, improve their skills and have possibilities to make choices – whether it is what to eat when out in a restaurant or whether to peel the carrots first or the potatoes first when being supported to make dinner at home. Breaking down activities, tasks or interactions into their smaller components, identifying the parts people can do and then filling in the gaps to ensure success is an important part of this component. Activities should be real and participation should be active in order to most promote quality of life.
- Little and often – doing things in small doses is easier and allows people the possibility of gaining some experience of success without it being aversive. Taking activities at the pace of the individual being supported and allowing them to dictate the length of their engagement is important. Good presentation and communication skills are essential, as is keeping things as simple as possible. For most people the key is to reduce verbal communication (as well as possible sources of distraction and confusion) and increase the use of non-verbal communications - context, having materials visible and set up is one way but also using objects of reference, photos, symbols – whatever has been found to work best with that individual.
- Graded assistance to ensure success – everybody needs help, especially when doing things for the first time. Some people need more help or need it on an ongoing basis due to the severity of their disability. Active support is about providing the right amount of the right type of help, for that person, in that activity, at that time. If we provide too much help we will be doing things for people and people will not develop and grow in independence (however small the steps forward might be). If we provide too little help, people will not experience success and be less likely to participate next time.
- Maximising choice and control – There are times, in all our lives, when we can't choose what we do, but we do get a choice about when, where, how and for how long we do it. Active support provides the opportunity and support to shape up people's ability to make choices while engaged in meaningful activities and relationships. We often have to

support people to try new experiences “little and often” in order to give them the knowledge with which to make choices in the future. The best way to gain knowledge is to try something for yourself but with control over how and for how long you do it. So for example, if you wanted to try a new support, you would be unlikely to go and buy ten sessions at your local sports or adventure centre without first perhaps reading up about it, watching videos or going along to watch a session. However the most effective way to find out whether you think you might like it is to have a try yourself – so going along to an open day or taster session allows you to do that without too much commitment which can bring about anxiety. For some people with intellectual disability, the taster session might be holding a cloth for 2 seconds before putting it down. Overtime they may move on to washing the dishes or after several attempts, you discover that they really don't like holding the cloth but they will hold a dish brush.

By working with people to try new activities and watching their responses and their engagement in those activities, we can build a profile of their likes and dislikes based on the reality of their experiences. Support like this can both help to shape up people's ability to make choices more frequently about their day to day life but should also inform decisions that are made with respect for the “rights, wills and preferences of the person” (UN Convention on the Rights of Persons with Disabilities, Article 12). In the UK this is an important aspect of best interests decisions which should be made taking into account the individuals wishes, preferences and previous experiences and choices (Mental Capacity Act, 2005).

Key references and further resources:

Beadle-Brown, J., Hutchinson, A and Whelton, B (2012) Person-centred active support – increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disability*, 25 (4), 291-307

Beadle-Brown, J (2015) Supported Decision-making in the United Kingdom: Lessons for Future Success, *Research and Practice in Intellectual and Developmental Disabilities*, 2:1, 17-28. <http://dx.doi.org/10.1080/23297018.2015.1040995>

Jones, E., Perry, J., Lowe, K., Allen, D., Toogood, S. and Felce, D. (1996a) *Active Support: A Handbook for Planning Daily Activities and Support Arrangements for People with Learning Disabilities. Booklet 1: Overview.* Cardiff: Welsh Centre for Learning Disabilities Applied Research Unit.

Mansell, J. and Beadle-Brown, J. (2012) *Active support: enabling and empowering people with intellectual disabilities.* London: Jessica Kingsley Publishers. ISBN-10: 1849051119.

Mansell, J., Beadle-Brown, J, Ashman, B. and Ockendon, J.(2005) *Person-centred Active Support* Brighton: Pavilion Publishing

Stancliffe, R. J., Jones, E., & Mansell, J. (2008). Research in active support. *Journal of Intellectual & Developmental Disability*, 33(3), 194-195.

Promoting person-centred support and positive outcomes for people with intellectual and developmental disabilities (2014) DVD resource. Produced by Tizard Centre, United Response and Frameworks for change. <http://www.unitedresponse.org.uk/promoting-person-centred-support-and-positive-outcomes>

Person-centred support on You Tube: <https://www.youtube.com/channel/UCeeTvLnOkjRj5M6715orqdg>

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# B4i

## Using Fiscal Intermediary Services in Michigan: Self-Directing One's Services and Supports

Angela Martin, Patricia Carver

Session Description: Fiscal Intermediaries assist people with disabilities to direct their Medicaid funded community-based services and supports. Data on Fiscal Intermediary utilization is an indicator on the status of Self-Determination in a state. Michigan Partners for Freedom (MPF) is using this data to advocate for and to advance Self-Determination in Michigan.

### Learning Objectives:

1. Define the role and responsibilities of Fiscal Intermediary providers in Michigan
2. Understand the Fiscal Intermediary service data for Michigan's citizens with intellectual and developmental disabilities
3. Learn how Michigan Partners for Freedom is using Fiscal Intermediary data to advocate for and to advance Self-Determination in Michigan



Using Fiscal Intermediary Services in Michigan: Self-Directing One's Services and Supports

ANGELA  
MARTIN



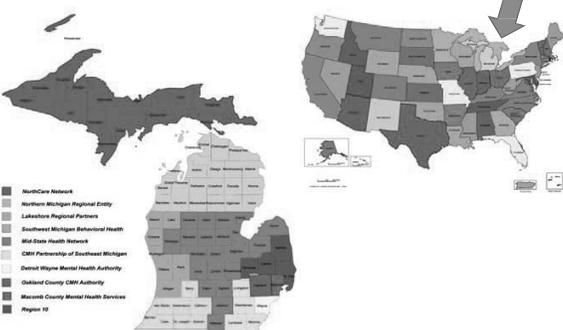
PATRICIA  
CARVER



JILL  
GERRIE



### Michigan: A State Profile



### Who is Michigan Partners for Freedom?

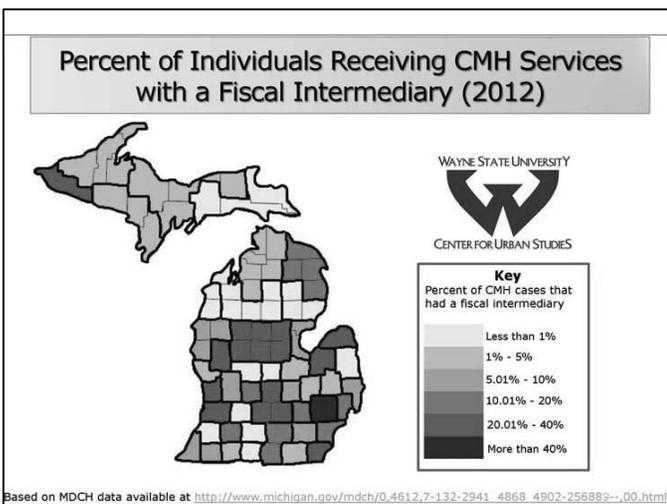
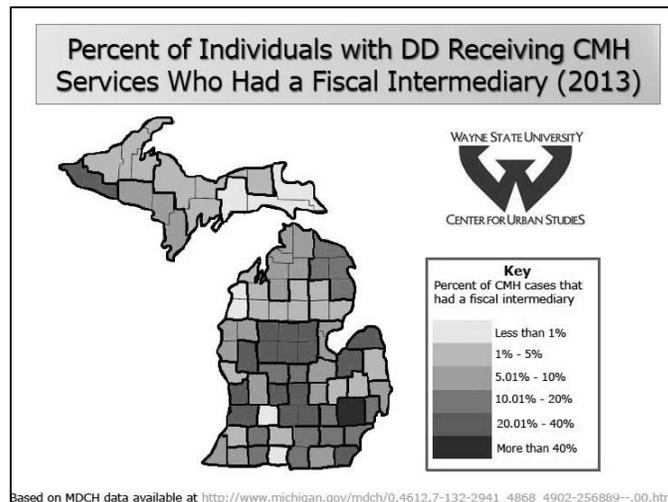
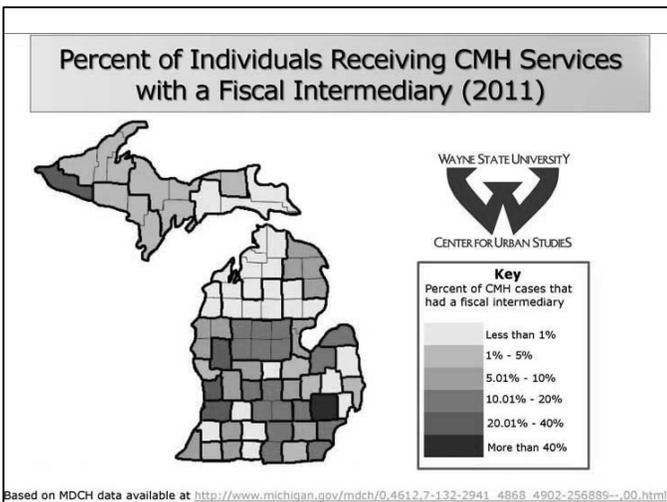



### What does the Fiscal Intermediary data tell us?

Data shows about 17% of individuals with I/DD who receive CMH services use a fiscal intermediary to manage payments for their community mental health supports.



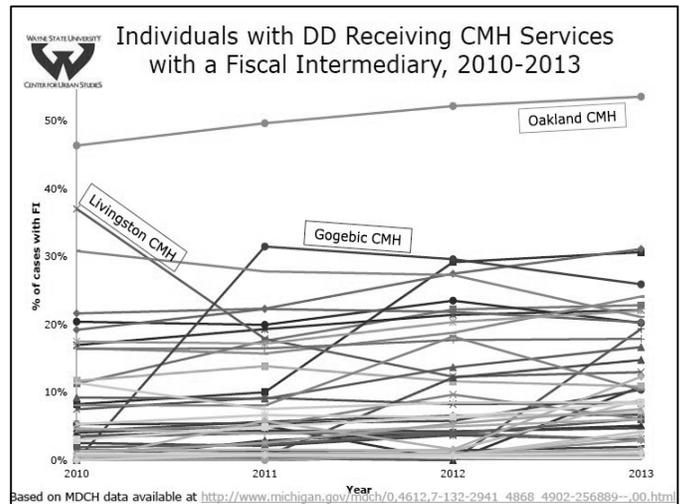
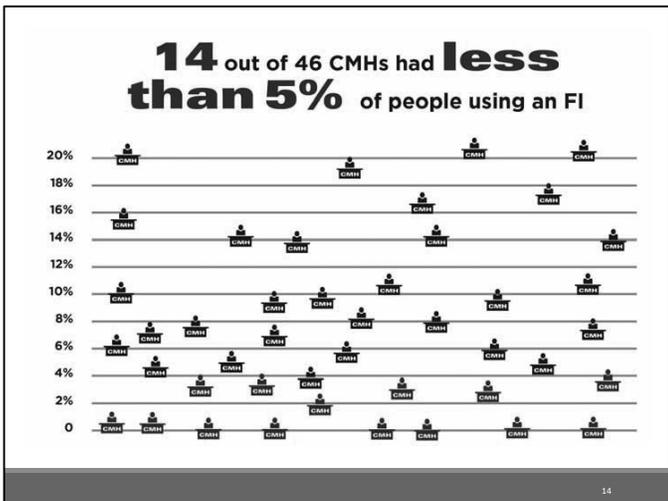
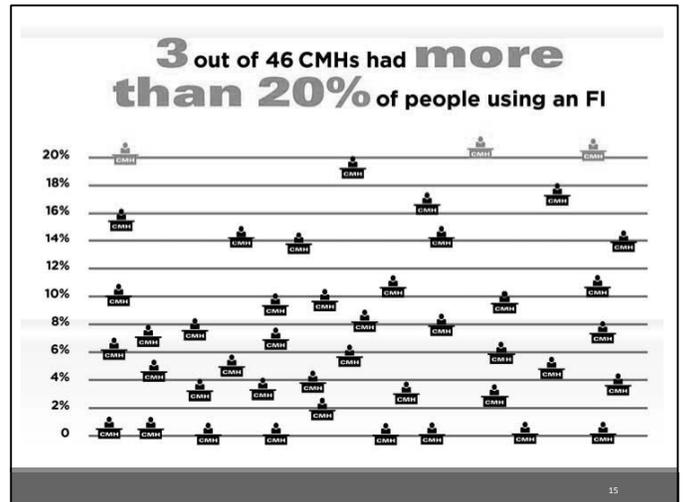
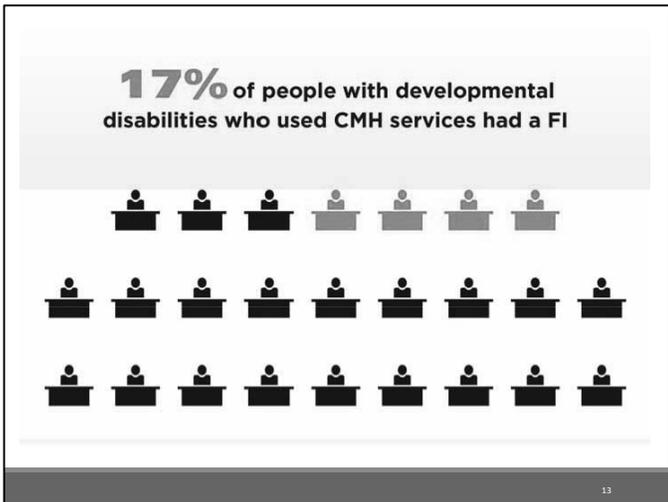




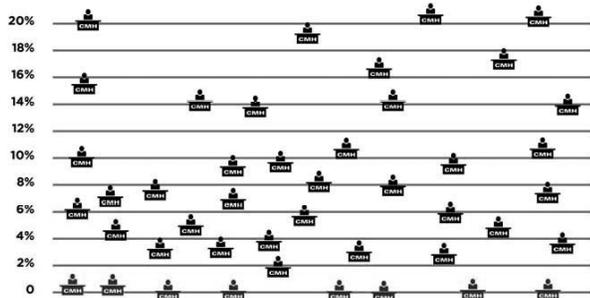
What can be learned from the data?

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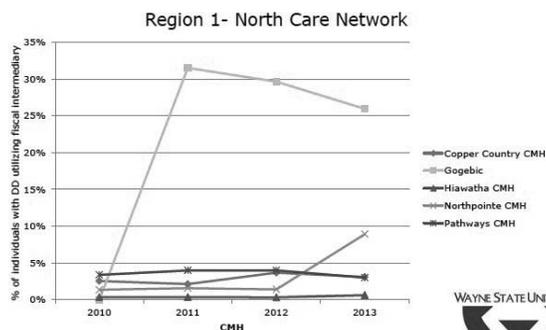


**8 out of 46 CMHs had less than 1% of people using an FI**



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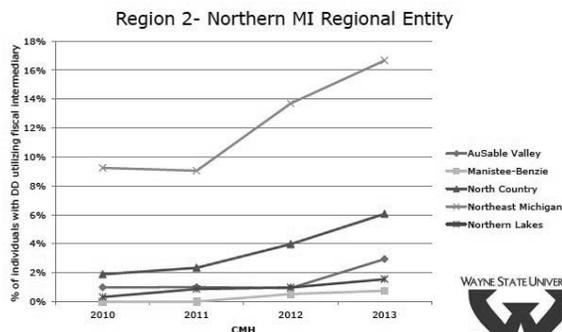
### Region 1: North Care Network



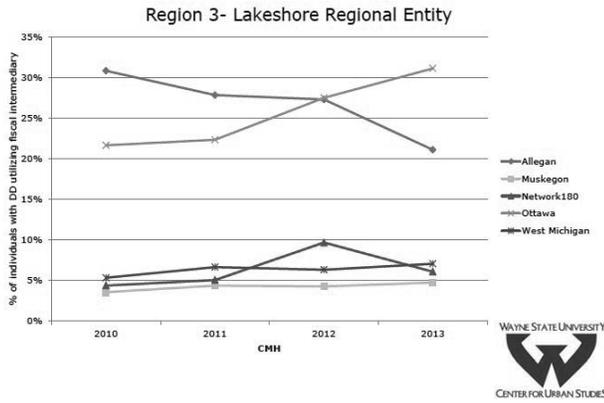
### Fiscal Intermediary Utilization in PIHP Regions



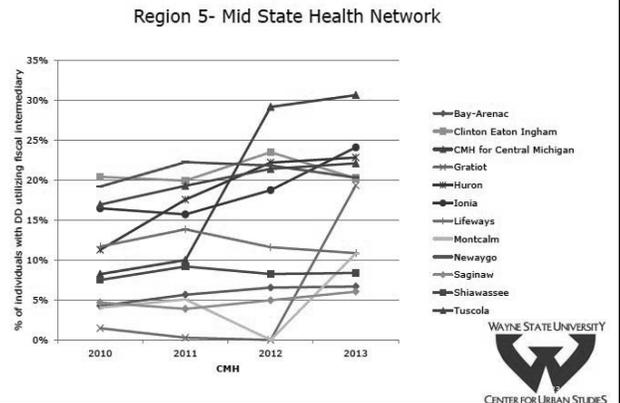
### Region 2: Northern MI Regional Entity



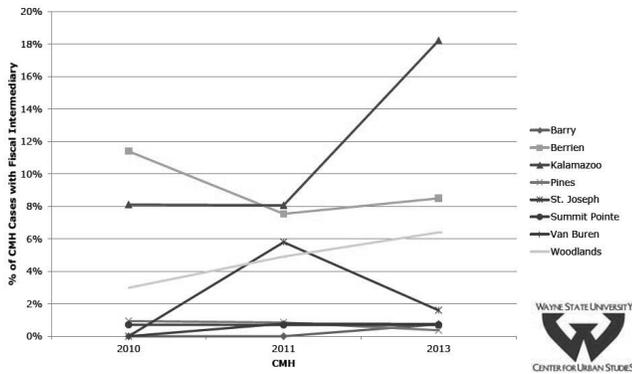
### Region 3: Lakeshore Regional Entity



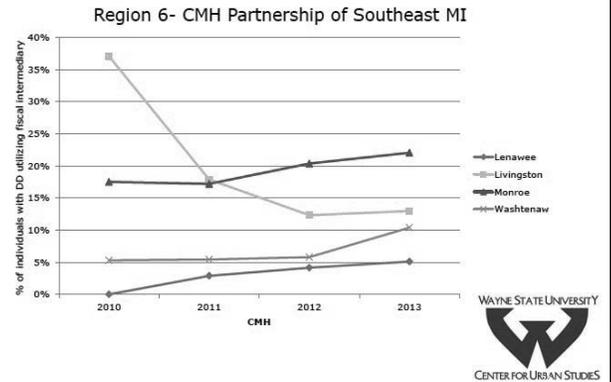
### Region 5: Mid-State Health Network



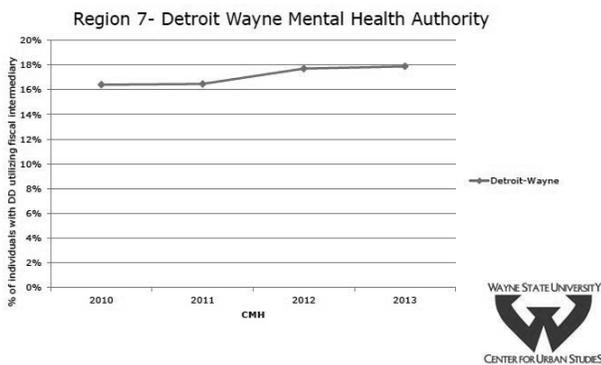
### Region 4: Southwest MI Behavioral Health



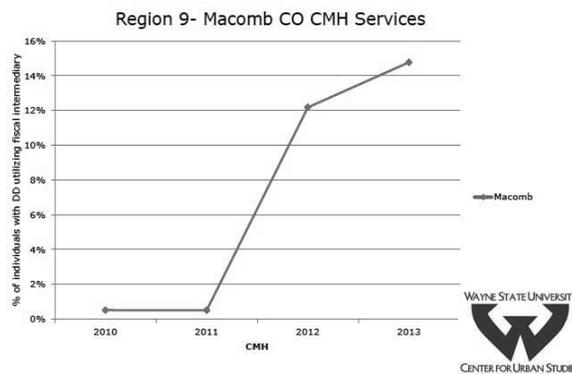
### Region 6: CMH Partnership of Southeast MI



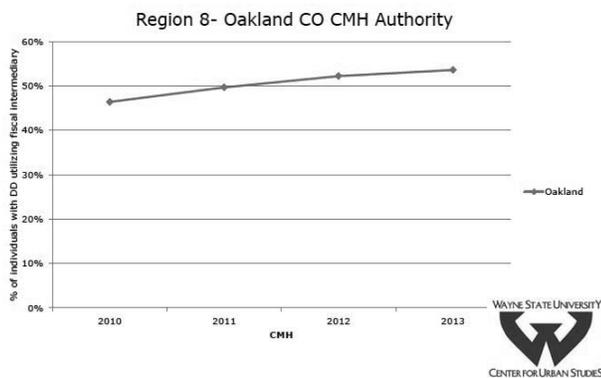
### Region 7: Detroit Wayne Mental Health Authority



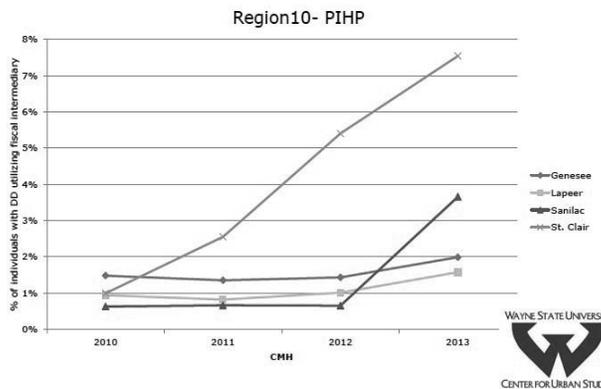
### Region 9: Macomb CO CMH Services



### Region 8: Oakland CO CMH Authority



### Region 10 PIHP





## What can be learned?

- People with disabilities: Experience of a local service provider in supporting the use of FI services
- System, Services Providers: Number of people receiving FI services
- Advocates: Communities struggling to advance the Self-Determination movement

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## Michigan Partners for Freedom

Website: <http://www.mifreedom.org/>

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Toll-free: +1 (800) 292-785, ext. 114  
Email: [jill.gerrie@arcmi.org](mailto:jill.gerrie@arcmi.org)



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# B4ii

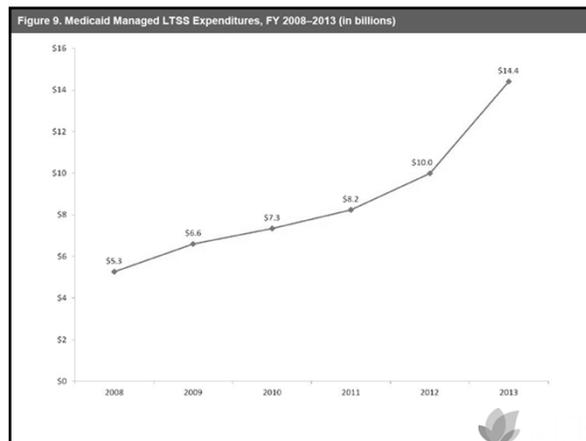
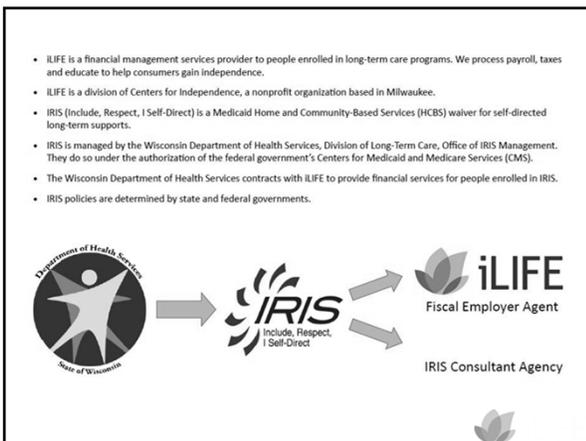
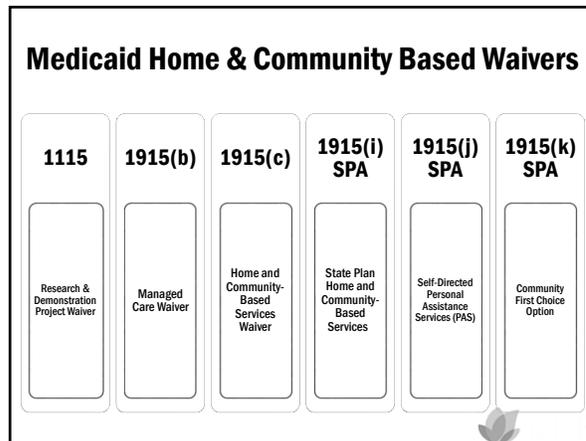
## The Participant Voice: The Strategy of Redesign and Improvement Initiatives in Self-Directed Programs

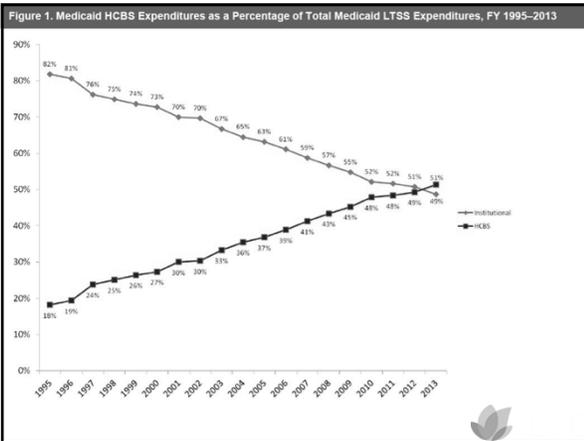
Amanda Cavanagh, Matt Queen

**The Participant Voice**  
 The Strategy of Redesign and Improvement Initiatives in Self-Directed Programs  
 Amanda Cavanagh  
 Director of Business Development



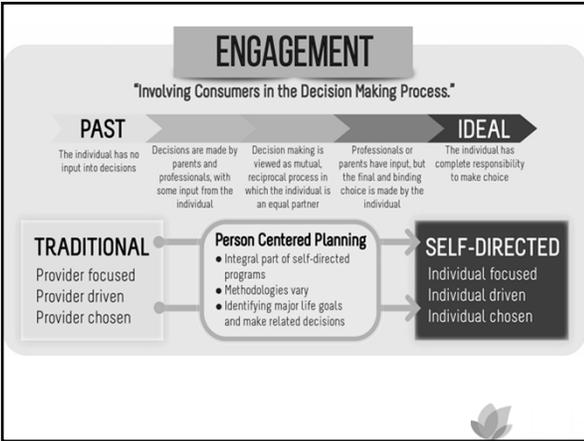

- Objectives**
- Learn how service providers can give staff an active role in their community.
  - Discuss best practice and how to enhance service excellence.
  - Explore how to control costs.
  - Engage on how to employ responsive program evaluation measures that elevate the voice of the participant.
  - Participant and caregiver feedback to guide service improvements.
  - How cultural competency impacts service excellence.
  - How to build a skilled team that can meet the needs of a diverse consumer group.





## Participant Engagement

- Listening sessions
- Surveys and feedback
- Participant Handbook



## What is a Service Excellence Plan?

- What does service excellence mean to you?
- How do you measure success?
- How does your team act as a barometer for meeting the mark?
- Who provides feedback and how do we close the loop on all participant touch points?

Get paid on time. All the time.

### Online Time Sheets

**Benefits:**

- Increases efficiency
- Controls costs
- Engages participants
- Promotes employer authority

Sign up for the iLIFE Portal

No waiting in line  
You get paid accurately and on time  
Get updates on your time report status

Get enrolled today!  
Call 888-800-5599 or email ILIFE.Portal@ILIFEms.com

## Pillars of Self-Direction

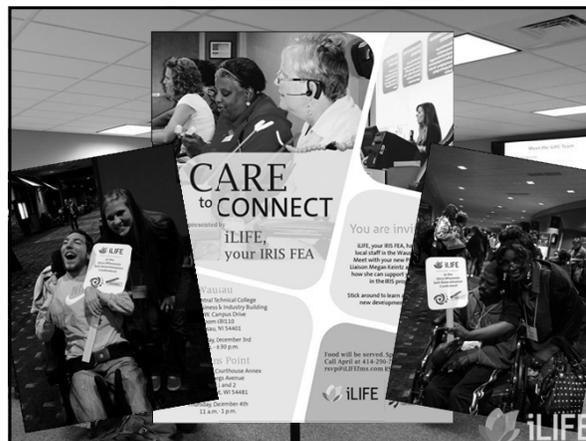
- Be educated on and understand the philosophy of participant direction.
- Provide all services with the goal of supporting participants to direct their own services.
- Have a customer service system in place that supports participants and any other authorized stakeholders to obtain information from the F/EA in a timely manner.
- Provide information in a range of formats to be accessible to individuals with a variety of disabilities, including options in foreign languages.

NATIONAL RESOURCE CENTER for PARTICIPANT-DIRECTED SERVICES

### iLIFE Participant Liaisons

Participant Liaisons are the bridge between case management and financial service delivery.

- Open communication between program stakeholders and iLIFE staff during F/EA processes.
- Provide a local presence throughout our service area.
- Have face-to-face interaction with program stakeholders.
- Better understand strengths and weaknesses of region.
- Create familiarity and positive relationship between program stakeholders and iLIFE staff.



**How to Interview an Employee**

**Interview tips:**

- Follow "The Golden Rule".
- Describe the job, responsibilities, and schedule.
- Let the person ask questions.
- Ask open-ended questions (more than a yes or no answer).
- Thank the person for their time.

Instructional materials that help people self-direct their services.

Multimedia resources for participants by participants.

Guides that allow participants to maximize their independence.

### Discussion

**The Participant Voice:**  
The Strategy of Redesign and Improvement Initiatives in Self-Directed Programs



### Connect with iLIFE

**Amanda Cavanagh**

Director of Research & Business Development @ iLIFE, LLC

Greater Milwaukee Area | Hospital & Health Care

Current iLIFE Financial Management Services

Previous Ebix, Arkadin, The Prantz Group

Education University of Colorado Boulder

Send a message

Endorse

500+ connections

amanda.cavanagh@iLIFEfms.com



### References

- "Fiscal/Employer Agent (F/EA) Core Standards." NRCPPDS, 19 Sept. 2012. Web. 28 July 2015.
- Steve Eiken, Kate Sredl, Brian Burwell, Paul Saucier. "Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013". Truven Health Analytics. Print. 30 Jun. 2015.



# B4iii

## Who Stands By Me to Make My Voice Heard?

Samantha Jenkinson

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### Learning Objectives:

1. Be able to explain the role of paid individual advocacy
2. Be able to identify the capacity building role of advocacy
3. Be able to describe how paid advocacy and self-advocacy increase self determination

### Case studies

Jonathon is a young man who moved out of home into a place of his own. After twelve months living in the community some things were not going very well. A neighbour noticed that some of his 'friends' were taking things that belonged to Jonathon, and suspected they were eating his food and taking his money. The neighbour contacted an Advocacy organisation and was asked to seek Jonathon's permission for a referral. Jonathon agreed and the advocate visited Jonathon the next day. It turned out that Jonathon's friends were intimidating and stealing from him. Jonathon also had a lot of unpaid bills because he did not know how to manage a budget. Jonathon was not talking to his parents because of a disagreement, which meant they were unaware of his situation.

An older man who is going blind gets support in his home from disability services and takes part in activities and outings at the Seniors Centre. The support person from the Centre finds out from the gentleman that he gets audio books from the Association for the Blind and really enjoys them, but it is taking them a month between when he requests a book and when he gets it.

The family of a man with an acquired brain injury want him to get housing in supported accommodation with 24/7 care. The man has memory loss, some challenging behaviour and is unsteady on his feet but able to do a lot for himself still with support. He does not want to go into a group home and vehemently lashes out whenever it is mentioned. The family are struggling to provide the support and manage the behaviour at home and feel they are getting to the end of their patience. He currently gets 20 hours a week with personal support and although his family have tried to apply for more it has been unsuccessful.

### Choose a case study and discuss:

What are the issues?

Where are the potential conflicts of interest?

Who can advocate?

How can the capacity of the person with disability be supported?

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## Who stands by me to make my voice heard?

Samantha Jenkinson  
Executive Director  
People With disabilities WA Inc



## Learning objectives

- Be able to explain the role of paid individual advocacy
- Be able to identify the capacity building role of advocacy
- Be able to describe how paid advocacy and self-advocacy increase self determination



## What is advocacy?

1. standing beside people with disability by assisting them to advocate their own interests
2. standing behind people with disability by supporting them to represent their own interests
3. standing before people with disability by representing their interests

Kevin Stone, author of the *'To Stand Beside: Advocacy for Inclusion Training Program'*.



## Why is advocacy needed?

- Some people with disability are isolated and may not have support networks, and/ or have complex needs and situations.
- Many people with disability and families lack knowledge to make a complaint or seek change



## Why is advocacy needed?

- People may lack confidence and the communication skills to assert their rights
- Many people with disability fear negative repercussions as a result of making a complaint
- People with disability are often seen as powerless and vulnerable and this becomes how we feel



## Role of the advocate

- Advocacy is speaking, acting, and writing with minimal conflict of interest on behalf of a disadvantaged person or group to promote, protect and defend their welfare and justice
  - by being on their side and no-one else's
  - being primarily concerned with their fundamental needs
  - remaining loyal and accountable to them in a way which is emphatic and vigorous and which is, or is likely to be, costly to the advocate



### Principles of advocacy

- Advocacy has a clear value base of social justice, equity and full inclusion of people with disabilities as contributing/ participating members of the community.
- Advocacy focuses on the fundamental human needs and/ or rights and interests of people with disabilities.



### Principles of advocacy

- Advocacy is on the side of the person with disability and is loyal and accountable to the person.
- Advocacy strives to be independent, autonomous and to minimise conflict of interest; it is distinct and independent from service delivery.



### Working together



### Capacity building

- Learning about rights
- Development of self-advocacy skills – how to say no, ways to say what a person wants, tools and resources
- Develop a plan of action in partnership with the person with a disability that maps out clearly defined goals
- Work through the individual advocacy plan in partnership with the person with a disability
- Development of strategies for taking effective action to address own issues, and
- Provision of mentoring and coaching as a person goes through the process



### Example

Martin, a client with intellectual and psychosocial disability received a termination notice from his disability service provider, due to complexity of his dual diagnosis. He contacted PWdWA for advocacy. Martin and the advocate developed an **action plan based on Martin's goal** to have a service provider that could understand phobias and the need for Martin to call during the weekend when under stress. The advocate researched suitable potential service providers and passed on the list to **Martin, who organised the meetings**. In preparation for the meetings Martin discussed a list of questions with the advocate. At meetings **Martin felt empowered to ask questions**, while the advocate stayed alongside and ensured that all concerns were raised. Once they met with all service providers Martin discussed his concerns with the advocate and short listed two service providers. They put together a list of pros and cons for those two service providers and **Martin made an informed decision**.



### Activity

- Choose a case study
- Identify any conflict of interest
- Identify ways to build the advocacy skills and resources of the person with disability
- Discuss









## Self-Determination: Are We There Yet?

A Brief Status Report from the US and  
Beyond

2015 International Conference on Claiming  
Full Citizenship: Self Determination,  
Personalization and Individualized Funding

October 15, 2015  
Vancouver, British Columbia

Valerie J. Bradley  
Human Services Research Institute

## Major Points

- Review of key concepts
- Brief history of self-determination in the U.S. and early results
- Review of NCI data and what it tells us about people who self-direct
- Discussion of self-determination at the state level and internationally
- Recommendations going forward

3

## What Is Self-Determination?

People plan their own lives, make their own decisions, determine how resources are spent for their supports, plan & choose their own supports (formal and informal), and take responsibility for the decisions made.

Freedom

Authority

Supports

Responsibility

4

## It is About Changing Systems...

- Shifting authority for decision making to the individual.
- Changing the way supports are funded to give people direct control over dollars.
- Changing the role of service providers, case managers and support staff.
- Putting the person into the center of the relationship between the state and provider organization.

5

## Antecedents Include...

- Family support programs
- Personal assistance programs
- Employment voucher innovations (Ticket to Work)
- Cash and counseling (1996-2013) programs



6

## The Fundamental Issues From the RWJ Evaluation

- **Technical**  
Can we figure out ways to make the structure work in a technical sense?
- **Political**  
Do we have the will to make changes to the flow of money?  
Can we abandon program (slot) driven approaches?  
Can we move from supply centered to demand centered systems?

7

### Robert Wood Johnson Demonstration Sites (1995-2001)

Arizona	New Hampshire
Connecticut	Ohio
Florida	Oregon
Hawaii	Pennsylvania
Iowa	Texas
Kansas	Utah
Maryland	Vermont
Massachusetts	Washington
Michigan	Wisconsin
Minnesota	



### RWJ Evaluation Findings

- Flexibility breeds flexibility**--A system that encourages self-determination must be flexible enough to accommodate a variety of life choices (e.g., budgeting, contracting, etc.)
- Let all flowers. . .** Self-determination requires agile procurement systems to accommodate the purchase of services and supports from a wider number of sources than typically is the case in specialized service systems.
- Self Determination is not a rehearsal** -- Leaders of successful initiatives did not treat self-determination as a "project" but rather embedded the approach throughout the system.

### RWJ Evaluation Findings

- Supporting the Supporters** -- Across the country, the ability to lead a self-determined life was significantly influenced by the availability of direct support professionals.
- Leadership Counts** -- Leadership at the state and local level and the presence of innovation and momentum within a state were key elements in the success of the self-determination initiative.
- Keep it Simple** -- Dealing with the mechanical elements of consumer budget management and employee administration can be extremely complex.

### RWJ Evaluation Findings

- Build It and They Will Come** -- To simplify the process of self-determination, it will be necessary in some states to significantly alter the "architecture" of how public agencies allocate, disperse and track funds.
- It's All Relative** -- The lesson here is that we should not confuse decision-making over the substance of one's life with decision-making over backroom operations.
- Managing Case Management** -- The nexus of self-determination is the brokerage function. It was at this point in most states/sites that the greatest stress was experienced.

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### Self-Advocates Said That Self Determination Means That. . .

- I am a person like all people: My life is my own.
- I make my own choices
- I am the boss of my own life.
- I make my decisions in my own life.



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### Self-Advocates Said They Saw Some Problems in Implementation

- There are problems with the doing
- People don't know what self determination is
- Caseworkers don't allow people to make their own decisions.
- Agencies say they believe in self-determination but then don't want to give up the money (or the power)
- Agencies don't want to get us the supports we want
- Professionals or staff not talking directly to us... talking to others instead of us.





## Measuring Self-Determination: What do NCI Data Tell Us

## WHAT IS NATIONAL CORE INDICATORS?



- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assessment of performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration

## NCI State Participation 2014-15



41 states, the District of Columbia and 22 sub-state regions

States that joined in 2013-2014  
States that joined in 2014-2015

CA\* Includes 21 Regional Centers  
OH\* Also includes the Mid-East Ohio Regional Council

## NCI is a Person-Centered Tool that Provides Information on:

- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare

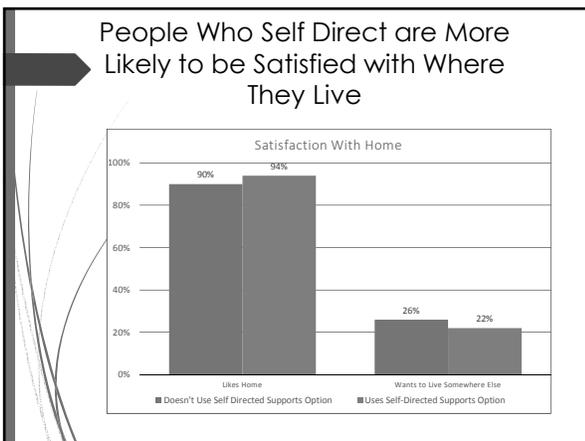
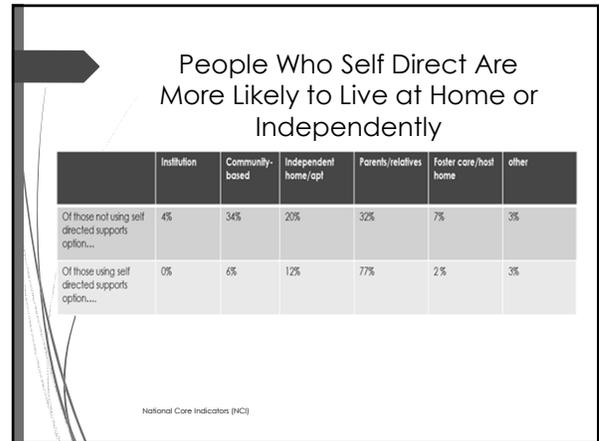
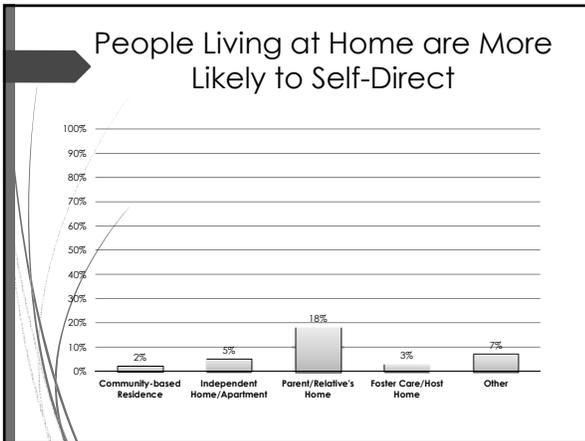
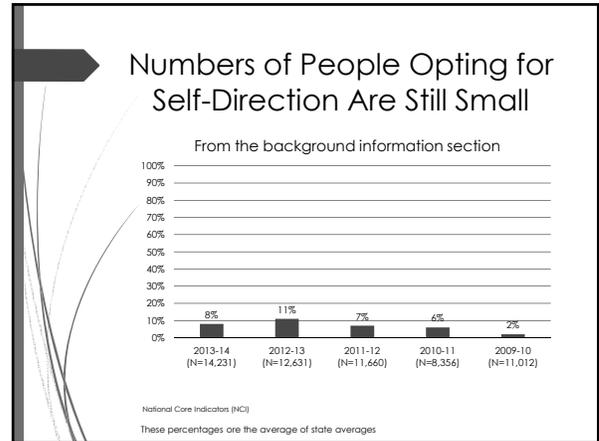
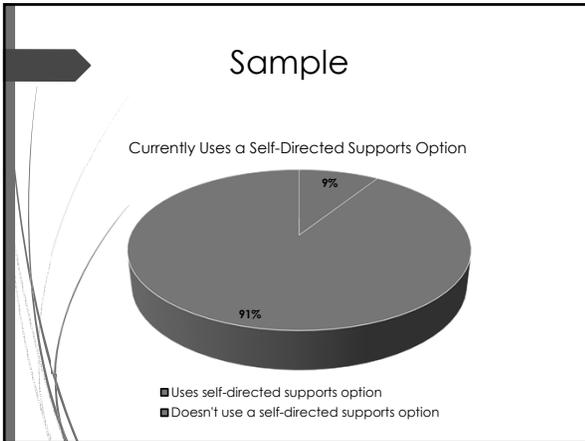
## What Are the NCI Tools?

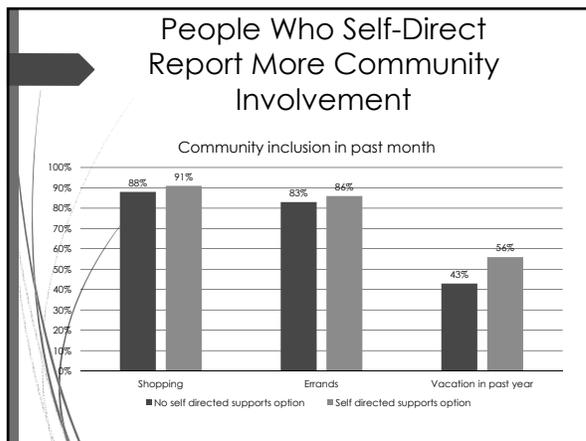
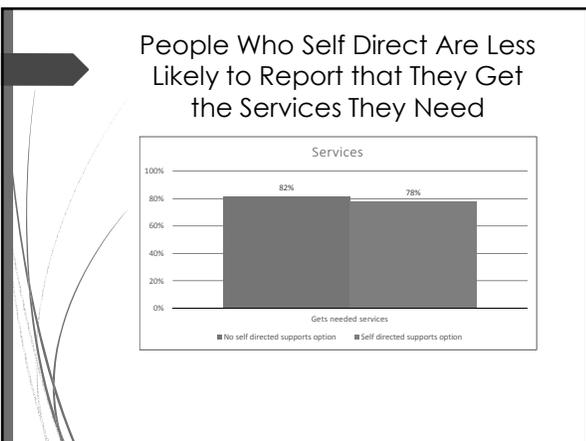
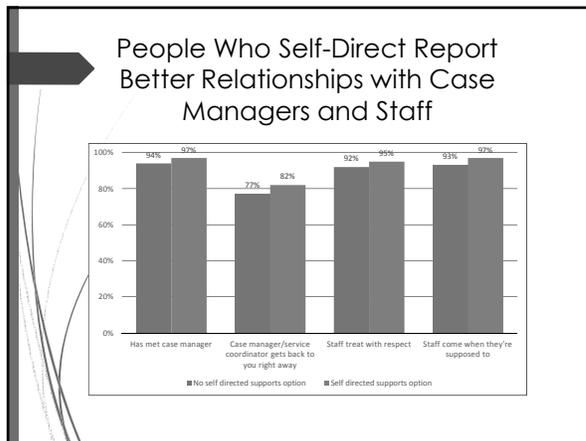
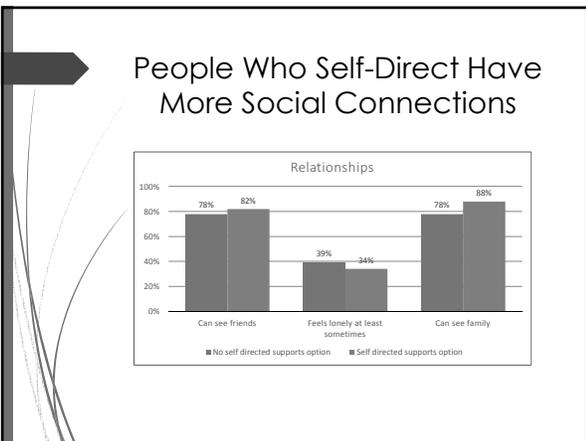
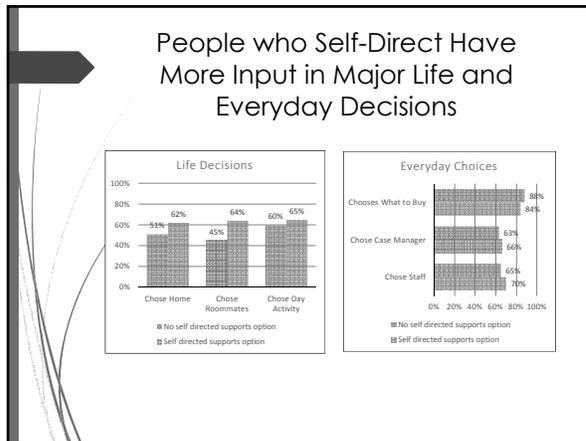
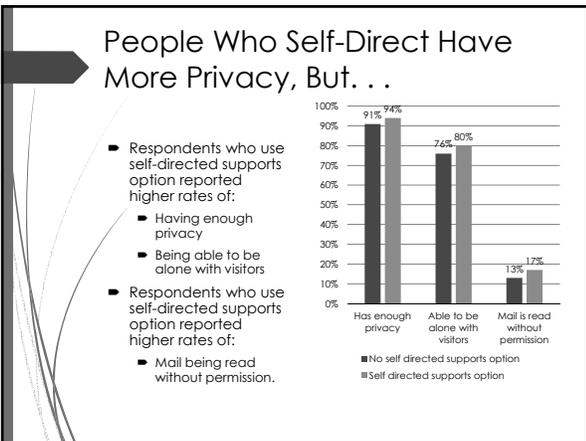
- Adult Consumer Survey**
  - In-person conversation with a sample of at least 400 adults receiving services to gather information about their experiences
  - Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys –**
  - administered by mail to a separate sample from Adult Consumer Survey
- Other NCI system level data: **Staff Stability**

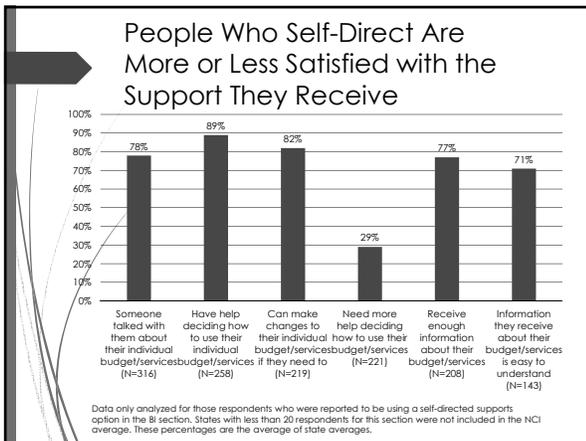
## Methods, Measures and Sample

- Findings from 2013-14 data collection cycle
- Based on Background Information Section of the survey
- Filter: Is this person currently using a self-directed supports option?
  - "Self-directed" or "participant directed" supports options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. They may hire and fire their own support workers and/or control how their budget is spent.
    - No – 13,781
    - Yes – 1,276
    - Don't Know (coded as missing)
- Total number of individuals for whom "yes" or "no" responses were entered: 15,057

Unless otherwise indicated, NCI Average=average of cases (not average of state averages)







### Self-Advocates Still Raising the Same Issues as Their Counterparts 15 Years Ago\*

- Training is needed for service coordinators so they can explain self-direction
- It is not the place of the service coordinator to decide whether self-determination is right for us
- Some service coordinators don't want to do self-determination because it's too complicated
- Need for materials in simple language about self-determination and about budgeting
- Family and other team members should not overshadow the wishes of the individual
- Need to know how to find individuals to work with us

\*Notes from a recent self-advocacy meeting in Massachusetts

### Examples of Self Determination From Other States and Internationally

- Australia
- Scotland
- U.S.

### Old System in Australia Compared to the New Individual Choice System

Current State	The NDIS
Individuals receive services from Government and non-government providers	The role of the individual is to exercise choice and control to purchase services that will best meet their needs
Funding envelope currently primarily only captures specialist disability supports services	The purchasing of services from non-specialist disability support providers will be within the scope of some reference support packages
The breadth and depth of services is determined by Government	The breadth and depth of services will be driven by market forces and their capacity for participants and suppliers to learn and evolve
A service model with heavy Government intervention	A complex service model with an evidence-based set of tailored intervention approaches that can be applied proportionately to underpin the stability and continuity of the market and ensure that there are adequate opportunities for agents within the market to learn and evolve



### Social Care Act in Scotland



- The Social Care (Self-Directed Support) (Scotland) Act 2013 is an Act of the Scottish Parliament that ensures that local authorities offer self-directed support to anyone who requires support services, including unpaid carers who require support to help them maintain their caring role.
- Covers all individuals – people with intellectual and developmental disabilities, physical disabilities, people with behavioral health challenges and elders
- **Duty to have regard to the general principles of collaboration, informed choice and involvement as part of the assessment and the provision of support** (this duty applies with respect to adults, children/families, adult carers and young carers)

### Four Options in the Act

The 2013 Act imposes a new duty on the authority to provide 4 options to all adults, children and carers eligible for support or provided with services. The options are intended to support the flexibility and creativity allowed under the social welfare and wellbeing duties relating to both adults and children.

- Option 1: A direct payment
- Option 2: Directing the available support: this option should provide greater transparency and control for the supported person without the requirement to take this support as a direct payment
- Option 3, Services arranged for the person by the authority – this is where the authority arranges any services on the person's behalf.
- Option 4, A mix of the first 3 options for different aspects of the person's support.



### States that Have Made Some Progress on Self Direction

- Wisconsin
- Oregon
- Connecticut
- Ohio
- New Jersey
- Idaho (for kids)
- Georgia has a lot of families that self-direct (but very few individuals)

### Some Tentative Lessons\*



- Do not make participants pay for support brokering out of their service budget unless all budgets include an increase to cover the costs
- Separate support brokering and case management—support brokering is a direct hands-on service focused on supporting self-direction, case management carries much broader responsibilities
- It is fine to include "traditional" services under *budget authority*—but not "true" self-direction. You cannot self-direct provider controlled service, nor can you really self-direct professionals such as nurses, PTs, etc.—they set their own treatment plans and direct their own work...

\*Suggested by Robin Cooper, National Association of State Directors of Developmental Disabilities Services

### Some Tentative Lessons

- Do not have more than two fiscal intermediaries and do not offer FI as a waiver service as you do not want freedom of choice nor multiple FIs—it should be an administrative functions – with new labor regulations, may only want one
- Provide continual education on what it means to self direct to participants, families, support brokers, administrative staff
- Make sure that self-direction is available to people with less education and income and time to master the complexities
- **Listen to self-advocates and families!!!!**

### NCI Team

- Valerie J. Bradley: [vbradley@hsri.org](mailto:vbradley@hsri.org)
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- Mary Lee Fay, NASDDDS, [MLFay@nasddds.org](mailto:MLFay@nasddds.org)
- NCI website: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

### References

- Bradley, V., Agosta, J., Smith, G., Taub, S., Ashbaugh, J., Heaviland, M. & Silver, J. (2001). The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report. Cambridge: Human Services Research Institute.
- NCI Adult Consumer Survey: 2013-14 Final Report Retrieved from: [http://www.nationalcoreindicators.org/upload/core-indicators/4\\_23\\_15\\_2013-14\\_ACS\\_508.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/4_23_15_2013-14_ACS_508.pdf)

National Core Indicators (NCI)



**Claiming Full Citizenship 2015 International Conference**

**Measuring the Impact of Self-Direction at the State and National Level**

October 15, 2015

PCG Public Partnerships  
Supporting Choice. Managing Costs.™

**Self-Direction is transformational**

- Self-direction is not a program, it is a transformation in the way individuals choose to live their life.
- It is not business as usual with minor alterations...not another service or program...but a huge transformation in the system of support and services to people with disabilities.
- It includes "attention to health and to vulnerability, learning and development, the importance of community membership. And adds to them"
  - *Tony Phillips, President, Self Advocacy Association of New York*
- "Self-direction allows my son to make personal choices about community and in-home activities as well as choosing his own staff that is a good match for his disabilities."
  - *Anonymous parent of an individual self-directing in Massachusetts*

www.publicpartnerships.com | Example PCG Public Partnerships Presentation 2

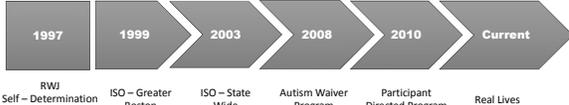
**About Public Partnerships, LLC (PPL)**

- Founded in 1999 as a privately held subsidiary of Public Consulting Group, Inc.
- Headquartered in Boston, MA
- Offices in Richmond, VA; Nashville, TN; Phoenix, AZ; Morgantown, WV; Atlanta, GA; Denver, CO and Seattle, WA
- Largest provider in U.S. of financial management and support services for Participant Self-Direction National presence
  - Operations in 25 States
  - 12 Managed Care Organizations
- Served 70,000 participants last year who employ 85,000 direct care workers
- Over \$1B in goods and services transacted annually
- Handle 100,000 customer service calls per month
- Serve all Medicaid waiver groups, all ages and veterans



www.publicpartnerships.com | Example PCG Public Partnerships Presentation 3

**PPL's History with MA DDS**

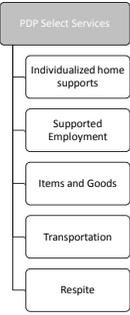


Year	Program
1997	RWJ Self – Determination Pilot
1999	ISO – Greater Boston
2003	ISO – State Wide
2008	Autism Waiver Program
2010	Participant Directed Program
Current	Real Lives

www.publicpartnerships.com | Example PCG Public Partnerships Presentation 4

**MA Participant Directed Program**

- Medicaid waiver program for adults with developmental disabilities who require a wide array of services and supports
- Over 500 Participants
- 30+ services: Flexibility allows for creative, individualized budgets
  - DDS Support Broker assists in customization of individual budgets based on needs and goals.
  - Includes home supports, employment supports, and items and goods



www.publicpartnerships.com | Example PCG Public Partnerships Presentation 5

**PPL Analysis of MA PDP Program**

FY11 – FY15

### Questions to Answer

- Question #1 – Do individuals spend their budgets?
- Question #2 – Do individuals monitor their budgets?
- Question #3 – Do individuals actively manage their budgets?

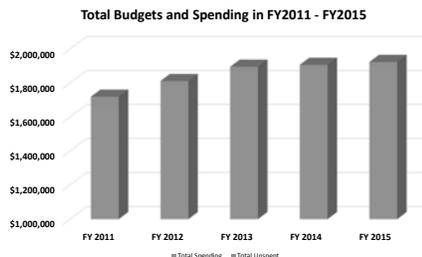
### Overview of Sample Group Used in Analysis

- Individuals who purchased services between fiscal years 2011 and 2015.
- 87 individuals were selected who made at least one purchase a year between fiscal years 2011 and 2015.
- The age range of the individuals purchasing:
  - 22 – 29 yrs. = 9
  - 30 – 39 yrs. = 39
  - 40 – 49 yrs. = 15
  - 50 – 59 yrs. = 14
  - 60 – 69 yrs. = 9
  - 70+ yrs. = 1

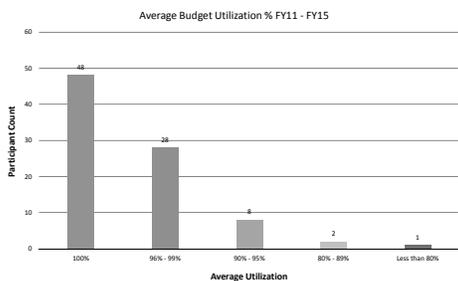
### Do individuals spend their budgets?

Are there risks of over spending or underspending?

### Total Budget Utilization



### Average Budget Utilization From FY11-FY15



### Question #1 – Do individuals spend within their budgets?

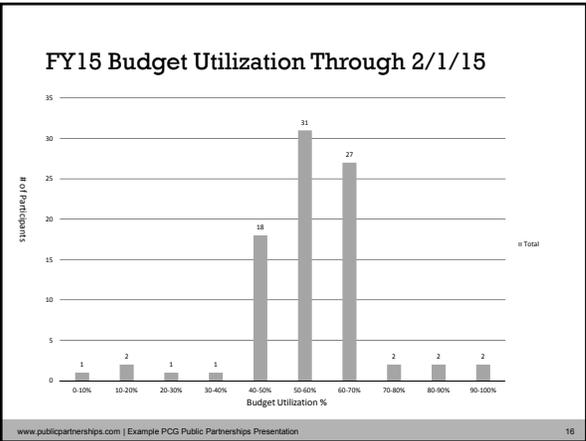
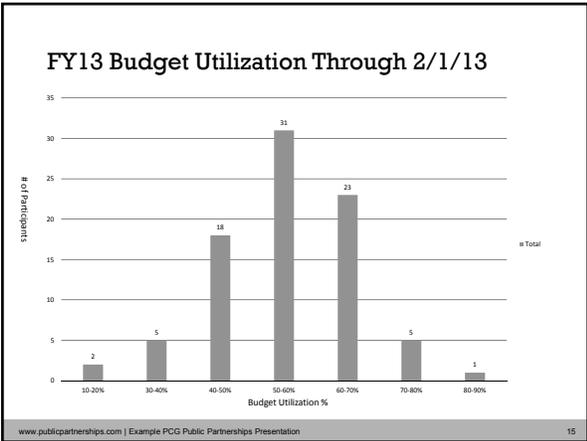
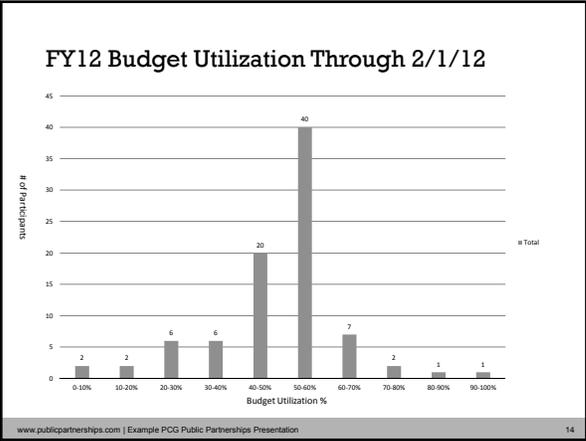
- Findings:
  - On average participants spent 98% of their budgets through FY11 - FY15
  - Only one participant overspent their budget one time from FY11- FY15
  - Only 3.4% utilized under 90% of their allotted budget from fiscal year 2011 through fiscal year 2015.
  - 55% of self-directing participants spend their entire budget each year.

Average Utilization	Participant Count
100%	48
96% - 99%	28
90% - 95%	8
80% - 89%	2
Less than 80%	1
Grand Total	87

- Individuals who self-direct tend to fully spend their budget; overspending and serious underspending is not a problem.

## Budget Utilization Throughout A Year

How does spending occur across the year?



### Question #2 - Do individuals monitor their budget?

Findings:

- If budget allocations are used evenly throughout the year we would expect about 55%-60% of the total budget used by February 1<sup>st</sup> each year.
- Using 40-70% utilization through February as evidence of budget monitoring:
  - In 2012, 67 of 87 participants were within the 40-70% utilization range.
  - In 2013, 72 of 87 participants were within the 40-70% utilization range.
  - By 2015, 76 of 87 participants were within the 40-70% utilization range.
- 82% of all participants were within 40%-70%. It appears that participants are monitoring their spending to enable them to have services as planned throughout the year.
- Over time participants monitor more effectively; up from 77% to 87%.
- This reduces disruption and service problems at year end.

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## Spending by Service

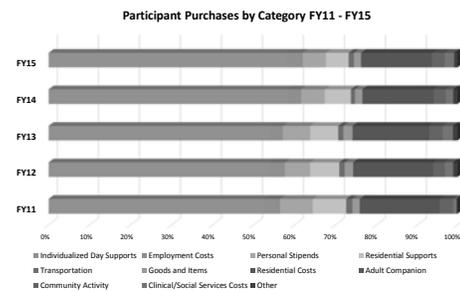
What do people purchase? Do they manage their purchases?

### Individual Purchases

PPL organized the individual purchases into major categories. The categories, along with examples of purchases within those categories are shown below.

- Clinical/social services costs
  - Case Management
  - Medical Services
  - Therapy
- Residential Supports
  - In-Home Support
- Individualized Day Supports
- Employment Costs
  - Employment Support
  - Job Development
- Adult Companion
- Goods and Items
  - Specialized Medical Equipment and Supplies
  - Home and Vehicle Modifications
  - Transitional Services
- Residential costs
  - Utilities
  - Rent
  - Moving Costs
- Personal Stipends
  - Household Bills
  - Food
  - Clothes
- Community Activity
  - Group and Individual Activity
  - Membership
- Transportation costs
  - MBTA Passes
  - Mileage
- Other
  - Volunteer Worker
  - Worker for Hire

### Individual Purchases as % of Total Spending



### Participant Purchases in FY2011- FY2015

Service Category	FY11	FY12	FY13	FY14	FY15	% Change	% Range	>/< Avg
Individualized Day Supports	\$782,535	\$914,258	\$956,067	\$1,106,616	\$1,109,298	42%	42%	above
Residential Costs	\$267,857	\$292,009	\$291,735	\$292,437	\$302,074	13%	13%	below
Personal Stipends	\$118,705	\$104,786	\$118,023	\$109,045	\$106,336	-10%	12%	below
Residential Supports	\$121,469	\$120,398	\$120,398	\$120,398	\$106,267	-13%	14%	below
Employment Costs	\$58,856	\$63,314	\$52,766	\$58,250	\$72,817	24%	38%	above
Community Activity	\$50,468	\$51,084	\$59,817	\$58,498	\$61,582	22%	22%	below
Goods and Items	\$26,838	\$35,079	\$39,181	\$33,870	\$33,614	25%	46%	above
Adult Companion	\$23,077	\$38,359	\$38,371	\$36,106	\$27,321	18%	66%	above
Transportation	\$22,613	\$22,345	\$22,247	\$19,247	\$24,400	8%	27%	same
Clinical/Social Services Costs	\$14,325	\$36,209	\$46,446	\$35,972	\$46,179	222%	224%	above
Other	\$3,440	\$18,730	\$20,640	\$20,800	\$16,320	374%	505%	above
<b>Total Spending</b>	<b>\$1,490,183</b>	<b>\$1,696,571</b>	<b>\$1,765,691</b>	<b>\$1,891,239</b>	<b>\$1,906,208</b>	<b>28%</b>		
<b>Average Spending Per Person</b>	<b>\$17,129</b>	<b>\$19,501</b>	<b>\$20,295</b>	<b>\$21,738</b>	<b>\$21,910</b>	<b>28%</b>		

### Changes in Spending FY2011-FY2015

- Total spending showed a range of 28%
- Two spending categories were substantially higher variation range than all others:
  - "Other" – range of 605%
  - "Clinical/social services" – range of 224%
- Four other categories had higher than average ranges of change:
  - Adult companions – 66%
  - Goods and Items – 46%
  - Individual Day Supports – 42%
  - Employment Cost 38%
- Three spending categories were stable with below average little change:
  - Residential cost
  - Residential support
  - Personal stipends

### Percent of Individuals Participating By Service Categories

Service Category	FY11	FY12	FY13	FY14	FY15	% Change
Individualized Day Supports	69%	70%	69%	74%	75%	6%
Personal Stipends	40%	49%	47%	43%	41%	8%
Residential Costs	32%	37%	39%	38%	38%	6%
Clinical/Social Services Costs	14%	20%	22%	20%	22%	8%
Transportation	16%	18%	16%	15%	20%	4%
Goods and Items	16%	16%	16%	15%	17%	2%
Community Activity	10%	18%	18%	17%	15%	8%
Employment Costs	15%	15%	14%	13%	13%	2%
Adult Companion	6%	6%	5%	3%	5%	3%
Residential Supports	3%	2%	2%	2%	2%	1%
Other	1%	1%	11%	1%	1%	10%

### Question #3- Do people actively manage their budgets?

Findings:

- The changes of purchases participants make annually shows an interest and ability to actively manage their budgets.
- The services purchased by individuals varies substantially every year.
  - Some services show a very wide range of change- 200% to 500%
  - Others show a range of 38% to 66%
  - Only three of 11 service categories show little change in utilization
- Every year people make changes in deciding what service categories to use.
  - Up to 10% of participants drop or add categories of services annually.

**B6****Improving Individualized Funding for End Users: An Example from British Columbia, Canada**

Zainum Bahadshah, Catriona Johnson, Jessica Humphrey, Jerry Laidlaw, Maggie Vilvang, Sylvie Zebrof

## Learning Objectives

1. Learn about the collaborative research design used to understand why take-up of Individualized Funding (IF) in BC has not been what was expected and about the effectiveness of the design
2. Hear first-hand from members of multi-stakeholder team directly involved in the work on their experiences of the research design/process
3. Learn about the qualitative research findings that surfaced through reflections guided by multi-stakeholder team with like-stakeholders across British Columbia
4. Learn about a segment of the research designed to be led and capture qualitative findings directly from individuals eligible for and receiving services through Community Living BC.

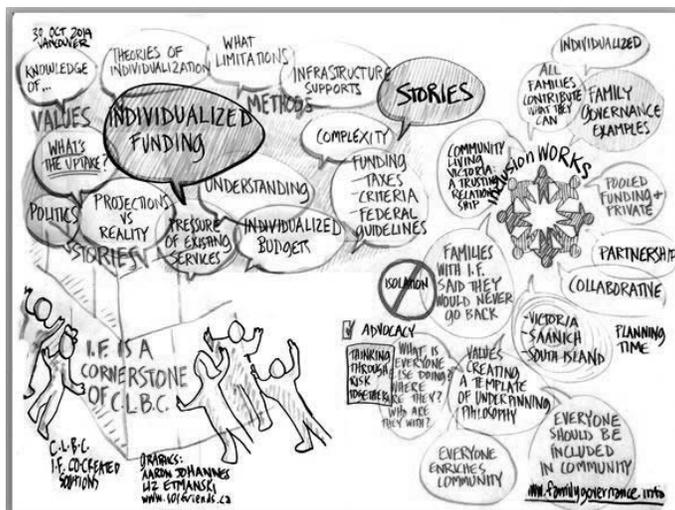
## Presentation Summary

When Community Living BC was created as a Crown Agency in 2005, a key part of its mandate was the provision of a range of funding options. As a result Individualized Funding (IF) has been a focus of the organization. Despite this focus, in 2013 the organization identified that uptake of IF had not be what it expected and launched a research project to understand why and to design solutions to increase its uptake. With a goal of understanding policy and practice from the perspective of end users at all stages, the research set out to unearth the perspectives of individuals and families, Community Living BC facilitators and administrators, and host agencies.

Using visual, auditory, and kinesthetic approaches, this presentation walks audience members through the research design and implementation process, which was participatory in nature. A multi-stakeholder team was directly involved in the work - from advisory committee to research to design of solutions – and the research findings that surfaced through guided reflections across the province of British Columbia were compelling. In particular, a self-advocate specific portion of the research highlighted the “missing voice” of self-advocates in IF and in other service models. From the research findings began a dynamic solution co-creation process and work towards answering the issues raised by stakeholders, linking IF to other continuous quality improvement efforts through CLBC.

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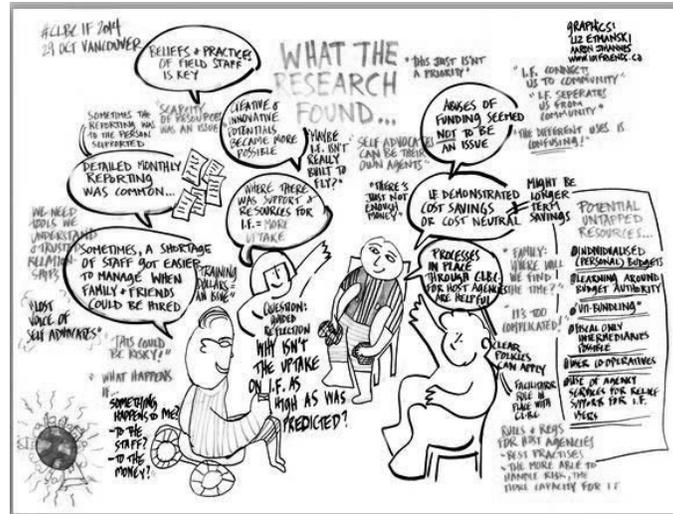


## Research Design

- Quantitative, Qualitative, Cross-Jurisdictional
- Multi-stakeholder involvement and collaboration throughout
- Research Team of 12 diverse stakeholders from across British Columbia
- Advisory Committee of diverse stakeholders knowledgeable about IF
- Qualitative research used a “Guided Reflection” approach
- Special design for reflections with self advocates

## Qualitative Research Design Guided Reflection

- Method of reflective inquiry
- Uses a “story-telling” framework
- Key patterns summarized with and by participants in the reflections.
- “Like” stakeholders reflecting with “like” stakeholders
- Special design for reflections with self advocates



## Qualitative Research Findings

### Pattern 1: Haphazard Information

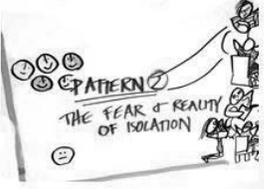
- Who You Know (*what they think*) Is How You Go
- I Can't Support Families When I'm Not Sure Myself
- Staff Bias Influences IF Uptake
- If I'd Known I Might Have Considered It
- *It's not just IF we're confused about...*
- *Self Advocates, A Missing Voice...*
- Why Haven't I Heard This Before?
- The Urban Myths...

- This pattern indicated that people chose or did not choose IF because of *how* they received information about their options as they entered services.
- People are more likely to choose something if those around them are talking about it and using it. If no one is promoting it, people won't choose it.
- Many people were confused about how the service system works and do not know what questions to ask or who to go to for information.
- CLBC staff members are not formally trained on IF. If staff are not sure how IF works or what the benefits of IF are, they may not know how to talk about it as an option.

## Qualitative Research Findings

### Pattern 2: The Fear and Reality of Isolation

- IF Was Our Only Option...
- Connection and Collaboration within Community Living is Diminishing....
- Connection To Community Is Growing...

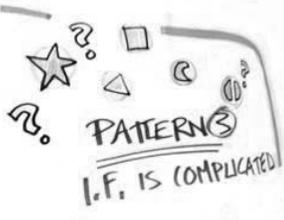


- This pattern indicated that some people chose IF because they saw it as the only option available to them, particularly for those living in more remote communities.
- Others stated that they did not choose IF because they are afraid of being isolated from CLBC and from other people who have similar experiences to them.

## Qualitative Research Findings

### Pattern 3: IF is Complicated

- Why does it have to be so hard?



- Those using direct-funded IF felt frustrated because of the amount of paperwork and reports that need to be done by both families. This was echoed by CLBC staff members who were called upon to assist families.
- Those using Host Agencies felt that IF was less complicated to administer.

### Qualitative Research Findings

#### Pattern 4: Risk vs. Safety

- What's Going To Happen To My Son Or Daughter When I'm Gone?...
- IF Is A 'Safer Option' ...
- Scarcity Of Resources Impedes Creative Risk...
- The Road Less Travelled Is Scary...

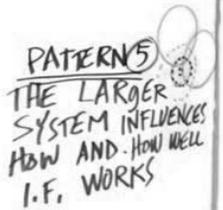


- Guided reflections found that some people felt IF is too risky in order to support their loved one while others felt it is the only option that will ensure a good life for their loved one.
- Families worried about who would manage the IF when they were gone; some indicated that this was one of the reasons they chose the Host Agency option.
- Individuals receiving services in traditional ways said it was hard to think about leaving the security of a 'community living agency' even if it meant more control.
- People talked about the community still being an unwelcoming place and that they felt safer being served by an agency, while some family members said they felt safer using IF because IF was the way to build true community and relationships for their son or daughter.

### Qualitative Research Findings

#### Pattern 5: THE LARGER SYSTEM INFLUENCES HOW AND HOW WELL IF WORKS...

- IF Was A Part Of A Bigger Plan, And Other Parts Of The Plan Changed...
- Just Not Enough Money...
- Just Not A Priority...
- Current IF Infrastructure Couldn't Handle Increased Uptake...
- Maybe IF Isn't Built To Fly...



- There was a feeling that all the parts of the Community Living system have to agree to work together to make IF a priority.

- Some people believe:
  - That too many parts of the original vision for CLBC have changed
  - There isn't enough money for IF to work for people who need full time support
  - That CLBC isn't structured/does not have the capacity for IF to be an option for more people.

### Qualitative Research Findings

**Pattern 6: THE ROLE OF IF HOST AGENCIES IS HAPHAZARD...**

- Host Agency If Isn't That Different, So Why Bother...
- Rules, Regulations And Risk For Host Agency Services



- This pattern reflected the diverse ways that Host Agencies have set up IF agreements in order to do what families want and to make the funding work. Some Host Agencies are supporting self-determination and helping individuals and families create innovative services, while in other cases families are using IF to purchase very traditional service delivery models.
- Some indicated that policies and other rules make it very difficult to be able to offer Host Agency services to individuals and their families.

### *Special Research Design*

- Modified the qualitative research so we could hear more from self advocates
- Met with a total of 30 individuals from 7 different communities around BC
- The individuals we met with were from different ages and stages in life
- Wherever possible, we tried to connect with individuals through self-advocacy groups that were not part of a contracted program





# B8i

## Shifting Towards a Person Centered System: IF and Other Initiatives

Jack Styan, Andrea Baker

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### Abstract

Community Living BC has endeavoured to shift towards a person centred system. This shift is evidenced in key initiatives that the organization has undertaken.

We will provide an overview five major initiatives that are propelling a shift towards a more person-centered system: developing a robust individualized funding framework, adopting a quality of life focus and implementing the include Me! survey, strengthening shared living residential options, promoting employment, and introducing the individual and family preference policy and contracting practices.

- Individualized Funding – overview of CLBC’s IF framework, including the range of contracting options available to individuals and families
- include Me! –overview of decisions that led to the adoption of Dr. Robert Schalock’s Quality of Life framework as a guide for person-centred practice as well as early findings and future directions
- Shared Living Residential Options – overview of the mechanisms put in place by CLBC to ensure the quality of shared living residential options (home sharing and live-in support)
- Employment – across North America a shift towards inclusive employment reflects individual’s desire to become full citizens. CLBC has undertaken a grass roots process to shift the system
- Individual and Family Preference Policy – procurement of services is often weighted towards meeting system requirements. This policy seeks to provide individuals and families with choices and power in the process of choosing a service provider within a standard contracting framework (i.e. non-IF).

The presentation will conclude with a summary of next steps and implementation challenges facing our organization and the community living sector within this province.

### Learning Objectives

1. Understand what it means to shift from system centred to person centre practice
2. Be introduced to five levers that CLBC is using to power this shift and get a sense of successes and challenges
3. Understand next steps in advancing this shift

### Synopsis

Five key initiatives are fueling CLBC’s shift from system to person-centered practice: individualized funding, individual and family preference policy, shared living residential options, employment and the quality of life framework. Join a panel of CLBC’s managers in exploring the objectives, challenges and successes of key initiatives.

### Additional Information Message

The proposed presentation is meant to be an overview of key policy and practice initiatives at CLBC, including individualized funding that are meant to promote choice, self determination, personalized services and better quality of life outcomes.

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## B8ii

## Systematizing Self-Determination: The Rationalities of Individualized Funding

Michael Bleasdale

### Abstract

The push for individualized funding as a significant challenge to the way that disability and other services have traditionally been administered has occurred over several decades, and it could be argued that it is an idea whose time has come with the progressive implementation of the NDIS in Australia. But what have been the dynamics which have made possible this change, and rendered “self-evident” to government, departments and the community at large that supports which are under the control of the individual who receives them will result in qualitatively different outcomes than those offered by traditional methods of service delivery and care? This paper explores the rationalities which underpinned both the emergence and decline of institutions, and the drive toward community living, and compares and contrasts them with those which now guide the new paradigm. It argues that the almost universal techniques of governance which require each individual to regulate themselves within our modern society have now been developed such that they are able to be applied within social service systems, no longer necessitating custodial and managerial models of control. Underpinned by strong principles of human rights it is critical to understand the limits as well as the possibilities that the new system imposes on those who will increasingly have the opportunity to self-manage their supports, and their lives, through individualized funding. Understanding these dynamics will be important to safeguard individuals within these new arrangements, and to guide advocacy into the future.

### Learning Objectives

1. Understanding the rationalities which underpin service systems, from the development of the institution up until the development of individualized funding arrangements
2. Identifying the techniques by which individuals in modern societies are effectively required to manage their lives and govern their behaviours, to ensure stability and harmony within the community
3. Understanding the dynamics which enable paradigmatic change, such as the implementation of individualized funding arrangements system wide, to better target advocacy and lobbying and so ensure continuous improvement

### Synopsis

Self-determination and individualised funding, as principles of service practice for people with disability, are not new, and have been implemented with varying degrees of success in different parts of the world over the past 40 years. They are, however, rightly viewed as “progressive”, and it is possible to view them as part of a positive continuum which started when people began to push for the closure of institutions. The principles of the UN Convention on the Rights of Persons with Disabilities provide a strong rights basis for the prominence of these principles in contemporary service delivery. But the failure to deliver real progress for people using community based services over the past 30 years forces us to ask whether or not simply adopting individualised funding approaches will actually achieve the qualitative improvement we expect of new systems like the NDIS. Understanding more fully the rationalities which drove and sustained firstly institutional care and, later, the provision of support in the community, help to identify the broader social dynamics which influence service systems, which are designed to manage groups within the population. By applying an analysis of the rationalities which exist within contemporary society, and which make possible these new, individually funded service paradigms, we can better understand what is expected of individuals to now “manage themselves”, using the supports provided, and so more clearly articulate what types of activities and interventions are likely to be more successful than others. This understanding will also assist the advocacy provided to make available to people with disability the opportunities for participation in community activities, which are not under the control of the service system.

# B8iii

## How to Let Data Help You: How to Access, Understand, and Use Nationally Recognized Data on Individuals with I/DD to Increase Self-Determination Across The United States Of America

Faythe Aiken, Josh Engler, Benjamin Miller

While most recognize the importance of self-determination for people with ID/DD, desired outcomes have been difficult to achieve. In addition, quantifying outcomes and service systems change related to self-determination has also been challenging. In this session we will look to two national datasets in the US to accomplish the following learning objectives:

1. Learn where and how to access important national outcomes data on adults with intellectual and developmental disabilities
2. Learn how to interpret the results of outcomes data from two nationally recognized public datasets
3. Gain a practical understanding of how to utilize data available for self-advocates and family advocates

About the datasets:

The Residential Information Systems Project (RISP) and The Family Information Systems Project (FISP), funded by the Administration on Intellectual and Developmental Disabilities (AIDD), collects longitudinal data on where individuals live and the supports funding they receive. These data provide a valuable glimpse of national trends on funding and how they relate to services.

National Core Indicators (NCI) is a collaboration between the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI), with the goal of implementing a systematic approach to performance and outcome measurement. Participating states gather resources and knowledge to create performance monitoring systems, develop comparable data collection strategies, and share results. NCI data provide a window on self-determination and other important outcomes of people with ID/DD receiving services. The application and synthesis of such data is often inaccessible for the general population. Presenters will invite audience participation on how to manipulate and shape data to be used to influence relevant policy decisions and share practical examples of how the data has been used by family advocate and self-advocates.

This presentation and discussion will focus on how to access, understand, and utilize nationally recognized data available for self-advocates and family advocates around outcomes such as self-determination, choice and decision making, and rights and respect. This will include self-advocates and researchers conducting hands-on training of how to find the data needed and how to interpret the results. The data discussed will be from the Family Information Systems Project (FISP) and National Core Indicators (NCI) national datasets.

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# B9i

## The Four Capitals: A New Framework to Assist Planning, Decisions, and Measuring Outcomes

Robbi Williams

### Abstract

This presentation introduces a framework to assist people with prioritising and decision-making. Called the Four Capitals, it is a central element of a model called Citizenship Support.

The presentation introduces each of the Capitals – Personal Capital, Knowledge Capital, Material Capital and Social Capital – as domains for considering a person’s life chances and how they can be used by a person to understand their circumstances, plan for the future, and make effective decisions.

The presentation describes how the material has been translated into a 7-workshop program for people living with disability and their families, and how that material has been received by hundreds of workshop participants living in South Australia and the Australian Capital Territory.

The presentation notes the material’s inclusion in the training program for South Australia’s Supported Decision Making initiative, and how it can be used not only to assist the moment a decision is made but also to help ensure the decision is enacted.

The presentation concludes by describing how the Four Capitals can be used as an outcome measure, on the basis that authentic helpfulness does not deliver a good life (because this is a matter for the person to author for themselves) but instead delivers good life chances.

### Learning Objectives

1. Learn about a new approach for thinking about life chances: gain an additional tool to use when thinking about a person’s life chances and where the issues or imperatives lie
2. Learn about a new approach for planning and decision-making: have an additional tool to use when thinking about developing a plan (and decisions) that genuinely focuses on growing life chances (not service responses)
3. Learn about a new approach for measuring outcomes: have an additional tool for thinking about outcomes and their measurement

### Synopsis

This presentation introduces participants to the Four Capitals, a life chances framework used to assist planning, decision-making and outcome measurement. This includes how the framework has been translated into a 7-workshop program for people living with disability and their families.

# B9ii

## Transition Age Youth Achieving Independence

Gerianne Prom

**Transition Age Youth  
Achieving Independence**

**Gerianne Prom**  
VP, Long Term Care Services & Supports  
Milwaukee Center for Independence




**Objectives**

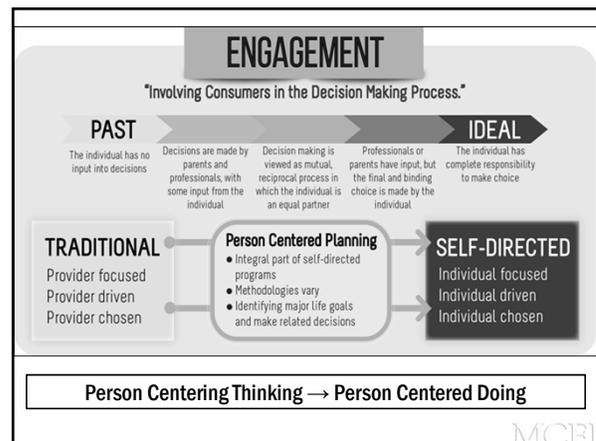
- Review the rights afforded to young people with intellectual and/or developmental disabilities at age 18.
- Renew their understanding of person-centered planning and self-determination.
- Develop skills to identify the socio-ecological factors that affect an individual's ability to self-direct.
- Gain knowledge of current best practices unique to the delivery of services for transition-age youth on the path to independent living.

MCFI

**Passage into Adulthood**

- Child to adult
- Legal adult (legal autonomy)
- High school graduation
- Exploration
- Post-secondary education
- Full-time employment
- Move from family home
- Right to vote
- Enlist in Armed Forces

MCFI



### Successful Transition: Key Outcomes

Positive Outcome	Details	Percent Reporting within 2-4 Years after High School
1 Employment	In any job, for any number of hours	41%
2 Postsecondary Education	Enrolled after high school training	35%
3 Enjoyment of Life	Answering "a lot" or "most" of the time to a survey question about how often the individual enjoys life	74%
4 Social Interactions	Answering at least weekly to a survey question about how often the individual gets together with friends outside of organized activities or groups	72%

MCRI

### Successful Transition: Key Family Characteristics

Positive Outcome	Characteristic	Impact
1 Employment	Parent expects employment	32x more likely to be employed
	High family income	7x more likely to be employed
	Completed high school	6x more likely to be employed
2 Postsecondary Education	High functional academics	3x more likely to be employed
	Parent expects employment	4x more likely to be enrolled
	High functional academics	4x more likely to be enrolled
	Parent expects postsecondary education	3x more likely to be enrolled
3 Enjoyment of Life	Medium family income	2x more likely to be enrolled
	Parent expects employment	6x more likely to enjoy life
4 Social Interactions	Completed high school	12x more likely to be social

MCRI

### Best Practices

Solutions to support success in self-directed programs

Expectation

Engagement

Exploration

MCRI

### Expectation

Clayton Marr was the second, and youngest, person with Down syndrome in New Zealand to receive his Driver's license at 19 years old in 2009.



"It's important young people with Down syndrome keep in touch with mainstream kids. One reason they achieve so much this way is because they set goals against their peers."

MCRI



Moving Forward  
Changing Expectations

MCRI

### Engagement

Dimension 1: Source of Input	Dimension 2: Degree of Risk	Dimension 3: Degree to Which Input is Binding
<ul style="list-style-type: none"> <li>The individual has complete responsibility to make choice</li> <li>Professionals or parents have input into decisions, but the final and binding choice is made by the individual</li> <li>Decision making is viewed as mutual, reciprocal process in which the individual is an equal partner</li> <li>Decisions are made by parents and professionals, with some input from the individual</li> <li>The individual has no input into decisions</li> </ul>	<ul style="list-style-type: none"> <li>The choice involves some potential for immediate risk, but little possibility of long-term harm to individual or others</li> <li>The decision involves mild risk with minimal possibility for long-lasting harm to the individual or others</li> <li>The choice results in a moderate probability for long-lasting harm to the individual or others</li> <li>The decision involves an almost certain outcome that includes person injury</li> </ul>	<ul style="list-style-type: none"> <li>Outside Input is nonbinding</li> <li>Outside Input is binding but only for a portion of the decision</li> <li>Outside Input is binding once the individual's input has been given equal weight in the development of a range of choice options</li> <li>Outside Input is binding, with the individual's input considered only if deemed advisable by others</li> <li>External individuals exert total control over the outcome</li> </ul>

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## Exploration

### Early childhood through adolescence

- Capacity building
  - Self-regulation skill development (goal setting, self-monitoring, self-reinforcement)
  - Exercising choice and decision making
  - Supported problem solving

“Adolescents will have a difficulty becoming self-determined young adults unless their early family and education experiences have laid a solid foundation upon which to build more sophisticated skills and capacities.”



## Connect with MCFI



**Gerianne Prom** 1.H

Vice President at Milwaukee Center For Independence  
Greater Milwaukee Area | Nonprofit Organization Management

Previous Gerianne Prom Consultant, Waukesha Memorial Hospital,  
Aurora Health Care

Education Loyola University Chicago

500+ connections

Send a message
Endorse

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# B9iii

## Partners for Planning; Supporting Families with Online Strategies

Susan Beayni

### Abstract

Created by Partners for Planning, the digital Resource Network is a new, dynamic, online hub designed to provide families caring for a relative with a disability, the tools, strategies, and resources that will build their capacity to create a good life and secure future for their loved ones.

As an organization committed to supporting families, we have learned that individualized funding is only one of the building blocks for creating a meaningful life. Individuals with disabilities who lead full lives typically have friends and families with the necessary creativity, skills, and knowledge to help them create a life that is uniquely their own. The primary objective of the Partners for Planning Resource Network is to help families develop their expertise in how to effectively support their loved ones in building a good life and safe, secure future. While planning requirements for individuals can vary considerably, we are confident the Partners for Planning Resource Network will enhance the resilience of families by inspiring them to utilize community resources and to consider innovative, less-traditional solutions to important issues.

Topics, or content themes, include developing supportive relationships; considering options for home; legal issues (e.g., supported decision making) and estate planning (e.g., wills, trusts); financial planning (e.g., the Registered Disability Savings Plan (RDSP)); and community participation and engagement.

The Resource Network will continually evolve as new content, resources, and webcasts are developed

This presentation will introduce this exciting initiative by demonstrating the digital interactive features.

### Biographies

Through lived experience with her 33 year old daughter Rebecca, Susan has advocated for and supported individuals and their families to plan for a good life while gathering a network to assist in implementing their plan. Susan lives in Toronto and is one of the founders of Partners for Planning.

Jeff Dobbin is one of the founders of Partners for Planning. He is a film maker and the creator of the digital resource network.

### Learning Objectives

Families and those assisting families will be able to use this digital resource to maximize their knowledge and skills to create and implement a plan for a meaningful life for their loved one.

They will be more inspired, more aware of how to plan effectively and will hear many success stories of others who are living a good life.

### Synopsis

Created by Partners for Planning, the Resource Network is a new, dynamic, online hub designed to provide families caring for a relative with a disability, the tools, strategies, and resources that will build their capacity to create a good life and secure future for their loved ones.





## PLENARY

## State of the Nations

John Lord, Eddie Bartnik, Linda Jordan, Marsha Marshall, Tom Nerney

This presentation will provide an overview of self directed approaches in New Zealand and a picture of the general direction these approaches are taking.

## Disability in New Zealand

New Zealand has a population of around 4.5million people. Of these, 1 in 6 identified as having a disability of some description in the 2013 census. This is approximately 16% of the population.

We are a multicultural country with 15% of the total population identifying as Maori, the indigenous people of New Zealand, 11.8% identifying as Asian and 7.4% as Pacific Islander. These statistics match the disability population also, with 15% of people eligible for IF identifying as Maori.

## What is happening?

There is one dominant model of self-direction in New Zealand - Individualised Funding (IF) - which has been formally running for 10 years. This programme currently has nearly 2,500 people using it, some of which use it for traditional home supports, some for respite care only and some for both respite care and traditional home supports (264 people).

There are also four demonstration projects which are aimed at testing expanded purchasing guidelines and supporting people to have more choice, control and flexibility than in the traditional IF model. Expanded flexibility is based on the following three criteria:

- The purchase must support the persons goals and aspirations
- The purchase must be a disability support and not a cost that a person without a disability would have to cover (for example, rent, power, utilities).
- The purchase must not breach government policy (for example paying immediate family members).

Together with expanded purchasing flexibility, the four models (collectively entitled "The New Model") have incorporated various versions of navigation/local area coordination, aimed at helping people to access community and natural resources to reduce reliance on funded supports and enable maximum benefit from them when they are required.

The New Model is comprised of the following independent projects which run for 3 years each – largely concurrently:

## 1. Enhanced Individualised Funding

This project is the furthest along in terms of its three year timeframe, is based on the Purchasing Guidelines above and currently has 364 (at July 31, 2015) people using it. The Ministry of Health has recently signalled that they want to revise the Purchasing Guidelines under this project to exclude the purchase of "items" (vs. services).

## 2. Enabling Good Lives

There are two cross government agency projects under this project stream. The model allows people to combine their budgets/allocation from three different funders (or any combination of the three) – the Ministry of Health, the Ministry of Social Development and the Ministry of Education. This allows people to have a personal budget with which they can purchase a range of supports across the funders portfolio areas within the Purchasing Guidelines described above. Enabling Good Lives has two geographical areas in New Zealand where the project is being demonstrated, both with limited numbers of participants and aimed at different demographic populations. Under both projects, the aim is to allow people to have a range of options and combinations of options. They can purchase supports from providers, employ their own staff, or contract with a provider to assist them to manage their budget. Both programmes are targeting 150 people each year from specifically identified demographic groups.

## 3. Choices in Community Living

This programme is aimed at facilitating choices for people currently in residential care to have more control over the budgets for their supports. The person/family work with the residential provider to facilitate a self directed approach and increased flexibility for the person to reach their self identified goals and aspirations. This often entails facilitating the person's move to independent living and/or flatting.

#### 4. Navigators, Local Area Coordinators and Connectors

A crucial part of the New Model programme, under all demonstration projects with the exception of Choices in Community Living (because it's residential), is the navigation or connection support. These services support the disabled person to bring together their existing natural supports and help build intentional community and network connections. Under the Enhanced Individualised Funding project in the Bay of Plenty, there are Local Area Coordinators who assist people to identify and access community and other natural supports. Under the Enabling Good Lives project in Christchurch, there are Navigators who do similar work. Under the Enabling Good Lives project in the Waikato, the role is a Connector. All of these roles are aimed at maximising the use of natural supports prior to identifying the need for formal funding, and ultimately reducing the reliance on formal funding. There are also pockets of experimentation with these roles that are independent of the demonstration projects. Navigators have been appointed as part of the Needs Assessment and Service Coordination teams in two other areas of the country – Otago and Lower Hutt (Wellington).

#### Supported Self Assessment

Supported Self Assessment has also been part of all the demonstration projects. This involves the introduction of a tool that allows the national assessment teams (the gatekeepers for funding allocations) to trial new ways of assessing people based on support needs as opposed to what services a person may need.

#### What did it cost?

It needs to be noted that all of the self-directed approaches as they relate to the direct support needs of people have been cost neutral. The government has invested in infrastructure to run the programmes, however the cost of direct support under these projects has been either cost neutral or cost effective. Further – the government has committed to “transformational” change to the system – and as such has attempted to take a co-design approach. This has involved disabled people, families, providers and officials.

The investment in infrastructure (programme implementation costs) has been minimal, running at approximately a million dollars per year per programme, with the exception of Enhanced Individualised Funding which has had no additional investment.

#### What's next?

There are some ongoing developments out of the demonstration projects as would be expected. These are:

- The Ministry of Health is currently reviewing the Purchasing Guidelines for Enhanced Individualised Funding.
- The combined government agencies are evaluating the roles and responsibilities of Host Providers under the Enabling Good Lives projects to expand the range of choices available to people in terms of how they purchase services.
- The funding framework for all the projects is being reviewed.
- Operational policy is being created by the Ministry of Health for Individualised Funding programmes informed by years of practise not previously formally documented.
- Frameworks are being developed on how to support families who have identified risk factors such as challenging behaviour, family dynamics or individual capability or competence to manage a budget.

Independent of the demonstration projects, other funders in New Zealand are taking up the Individualised Funding approach. This includes District Health Boards and our national insurance scheme Accident Compensation Corporation (ACC). The utility of the Individualised Funding approach is now being implemented across demographics instead of being limited to disabled people. This includes chronic illness, personal health, mental health and health of older people.



## Self-direction in New Zealand

All people have the right to make decisions about their life choices and to direct their personal support services in a manner that best meets their desires and needs.

### Disability in New Zealand:

- The dominant model of self-direction is Individualised Funding
- IF has been running for 10 years and has almost 2,500 people using it

### The "New Model"

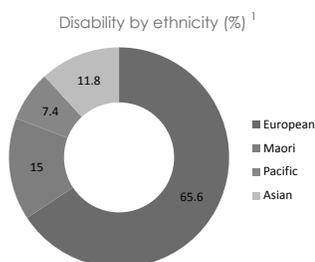
There are also four demonstration projects which are aimed at testing expanded purchasing guidelines and supporting people to have more choice, control and flexibility than in the traditional IF model. They are based on three criteria:

- The purchase must support the persons goals and aspirations
- The purchase must be a disability support and not a cost that a person without a disability would have to cover (for example, rent, power, utilities).
- The purchase must not breach government policy (for example paying immediate family members).

An integral part of the *New Model* is navigation/local area coordination, aimed at helping people to access community and natural resources to reduce reliance on funded supports.

4.5M People in New Zealand <sup>1</sup>

1 in 6 New Zealanders identify as having a disability (16%) <sup>1</sup>



Numbers by funding stream <sup>2</sup>

IF	EIF	EGL	DHBs
2334	364	91	34

<sup>1</sup> - 2013 Census, Statistics NZ  
<sup>2</sup> - Ministry of Health, New Zealand

### Enabling Good Lives

- In Christchurch and the Waikato
- Combine budgets/allocation from three different funders:
  - Ministry of Health (disability support)
  - Ministry of Social Development (Vocational & Day services)
  - Ministry of Education (special needs education support)
- People can purchase a range of supports across the funders portfolio areas within the Purchasing Guidelines
- Both Demonstration Projects are targeting 150 people each year from specifically identified demographic groups.

### Choices in Community Living

- People currently in residential care having more control over the budgets for their supports.
- The person/family work with the residential provider to facilitate a self directed approach and increased flexibility for the person.
- Often entails facilitating the person's move to independent living and/or flatting.

### Enhanced Individualised Funding

- Funded through the Ministry of Health
- Been operating for three years
- There are currently 364 people using it
- The Ministry of Health is currently reviewing the Purchasing Guidelines.

### Navigators, Local Area Coordinators and Connectors

Support the disabled person to bring together their existing natural supports and help build intentional community and network connections.

EIF: Local Area Coordinators help people to identify and access community and other natural supports.  
 EGL Christchurch: Navigators who do similar work.  
 EGL Waikato: the role is a Connector.

All of these roles are aimed at maximising the use of natural supports prior to identifying the need for formal funding, and ultimately reducing the reliance on formal funding.



## C1ii

## Self-Determining 'My Life to the Max' Based On Complex Adaptive Systems Theory

Leighton Jay, Susan D Stanford

### Abstract

This workshop builds upon the panel presentation by Perry, Walker and Stanford to further explore some learning about self-determination that has happened in the context of microboards in Western Australia. Youniverse, which is based largely in Western Australia, has consciously adopted elements of complex adaptive systems theory to understand the development of microboards and inform ways of supporting people who face complex challenges to be the architects of their own 'life to the max'. While this work has sometimes been slow, our experience is that this approach aligns better with how life really unfolds for all of us rather than the more prevalent expectations and assumptions that life will somehow unfold in linear ways (when it usually doesn't for any of us)! Having a more developed understanding of how systems work enables us to intentionally and consciously identify and build upon strengths within individuals and systems to positively influence relationships and outcomes. This experiential learning workshop will provide you with opportunities to learn (in simple terms) about complex adaptive systems and strengths-based approaches, and to see their relevance to many domains of human experience.

### Learning Objectives

1. By the end of this session, participants will be able to:
2. Identify at least three features of complex adaptive systems;
3. Explain at least three key elements of a strengths-based approach to working with others;
4. Describe how feedback loops or tipping points might apply to their life and/or the life of a person who has complex needs; and
5. Demonstrate how to apply one or more tools to benefit a person with complex needs.

### Synopsis

Life is complex and rarely unfolds as a simple linear process. In this interactive session, Leighton and Susan will use features of Complex Adaptive Systems and Strengths-based ways of working with others to assist participants to identify these patterns in their own lives and to explore how they might usefully apply them to their lives, experiences and work with people with complex, disability-related needs.

### Complex Adaptive Systems (CAS)

A forest is a CAS. So is a marine environment. So are organisations, communities, societies and families. Each one has a structure that is characterised by relationships between the parts or members. And the dominant factor determining what happens is the dynamic (or movement) in the relationships between the component parts or members.

### Strengths-based approach to working with others (SBA)

McCashen (2005) notes that aspirations, dreams & interests drive change. While our strengths and capacities fuel us to get where we want to go, it is our aspirations and dreams that provide clear direction and motivation.

### The strengths approach:

- Can underpin a process of engaging people in change. Intuitively, experientially and empirically, we know that investing in strengths (rather than deficits) is a powerful springboard for the change we seek to facilitate in ourselves and others.
- Begins with positive values and attitudes. For people with complex support needs, the strengths approach is particularly relevant and counter-cultural in its underpinning belief in each person's ability to self-direct their process of change.
- Informs encounters. The way we listen, the questions we ask and the way we offer additional resources all influence the extent to which a person becomes better placed to control and direct their change process.
- In relation to CAS, the strengths approach creates a positive feedback cycle that supports change rather than resists it. Problems are properly acknowledged and validated, and strengths are identified and highlighted in a way that changes the story about the problem. It creates positive expectations that open the way for the development of new competencies and capacities. One study suggests that for a long-term relationship (e.g. a Microboard) to survive, the ratio needs to be about five positive events to one negative event. If it's lower than that we tend to develop a negative perception of the overall experience and the relationship ultimately fails. This session will use practical examples from Australian microboards to demonstrate and explore how useful these concepts and ideas can be.



C3i

# Dementia-Friendly Communities for Care Partners: A Social Citizenship Perspective

Marjorie Silverman

**DEMENTIA-FRIENDLY COMMUNITIES  
FOR CARE PARTNERS:  
A SOCIAL CITIZENSHIP  
PERSPECTIVE**

Marjorie Silverman, PhD, University of Ottawa  
Elaine Wiersma, PhD, Lakehead University

### LEARNING OBJECTIVES

- 1) Understand why dementia-friendly communities are important from a care partner perspective.
- 2) Learn about some of the current initiatives regarding dementia-friendly communities.
- 3) Learn about a research project regarding dementia-friendly communities that is starting in Ottawa, ON.

### PRESENTATION OUTLINE

- o Goal: Advocating for the importance of care partners in dementia-friendly communities
- o Background context
- o Discussion of project: *The everyday experiences of place, space and neighbourhood of care partners of people with dementia*
- o Conceptual framework
  - Social citizenship
  - Social capital
- o Methodology
  - Mobile interviews
  - Photo elicitation

### BACKGROUND CONTEXT

- o Dementia-friendly movement in nascent stages in Canada; some provincial initiatives
- o Numerous international initiatives, including a large UK-based research project
- o Focus is often on the person with dementia rather than the care partner, despite emphasis on care in the home and community
- o More emphasis is needed on how care partners perceive and navigate the physical, social and emotional aspects of the neighbourhoods

### THE EVERYDAY EXPERIENCES OF PLACE, SPACE AND NEIGHBOURHOOD OF CARE PARTNERS

- o Research funded by the Alzheimer Society of Canada; September 2015-2018
- o Project objectives:
  - 1) Understand how home-residing care partners engage with the physical, social and emotional elements of their neighbourhood
  - 2) Encourage home-based interventions to take into account the spatial, social and symbolic context
  - 3) Contribute understanding of what would constitute a dementia-friendly neighbourhood for care partners

### CONCEPTUAL / THEORETICAL FRAMEWORK

- o Social citizenship model of dementia (Bartlett & O'Connor, 2007, 2010)  
Care partners are active social citizens who exercise agency within and beyond their caring role.
- o Social capital (Bourdieu, 2000)  
Care partners may not be able to invest in neighbourhood social capital due to lack of time, structural barriers or stigma.

### METHODOLOGY

- o 1) Mobile methods (walking or driving interviews)
- o 2) Participant driven photography and photo elicitation
- o 15 participants from urban, semi-urban and rural areas in and around Ottawa
- o Participants will be older adults who are caring for someone with dementia in the home
- o Recruitment will be conducted through the Alzheimer Society of Ottawa and Renfrew County

### EXPECTED OUTCOMES

- o 1) Provide new understanding of how care partners engage with their neighbourhoods on a daily basis
- o 2) Use the findings to support the design of an intervention tool
- o 3) Contribute to the vision of what would constitute a dementia-friendly community for care partners

### CONTACT INFORMATION

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### REFERENCES CITED IN POWER POINT

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**C3ii****Dilemmas in Care-Managing: Citizens with Dementia Encountering the Welfare-State**

Ann-Charlotte Nedlund

A key responsibility of the welfare state is to provide social support for its citizens. The individual's need for support is assessed at meetings by a care manager. Commonly, at these meetings several actors are participating besides the individual in concern and the care managers such as relatives, different professionals, e.g. nurses, occupational therapists and medical doctors. In Sweden people with dementia have their needs assessed as other citizens applying for social services even though their condition may cause strains for them to be aware of their needs as well as to formulate and to communicate them. The aim of this study is to investigate the dilemmas that care managers encounter in the assessment meetings with citizens with dementia applying for support, and further to explore how the care managers, reflect upon, discuss and handle the dilemmas they encounter.

The study is based on 19 interviews with care managers at four different municipalities in Sweden. The study shows that care managers face a range of dilemmas in the assessment meetings relating to communication, such as where people with dementia have difficulties in formulating their needs or difficulties in understanding the reason why support would be relevant for them, and relating to the various interests of the actors involved in the assessment meeting. These interests may be in conflict to others and do not always reflect the interests of the individual in concern. The study shed light on the obstacles people with dementia might have to claim their rights as citizens.

**Learning Objectives**

1. Share the experience of the care managers when citizens (in this case people with dementia) meet the welfare state, the dilemmas that care managers experience and possible solutions to those.
2. Promote dialogue between different actors such as researchers, academical disciplines, professions and the citizens themselves
3. Promote network for cooperation of research between researchers, disciplines, universities and countries

The presentation will consist of empirical findings from our interview study with care managers. We present the dilemmas that they face in their line of work and in their meetings with persons applying for social services, in other word present the experience of difficulties that care managers have in their profession and how they manage them. We also plan to present the implications that these dilemmas and solutions have on the possibilities for citizens, and more specifically people with dementia, to claim their rights as citizens and further how this affects the rights that citizens have i.e. what we call the content of citizenship.

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**C4****Self-Determination, Presumption of Capability, and Least Intrusive/  
Most Effective Responses: Perspectives on the Continuum of  
Decision Making in BC's Adult Guardianship Legislative Framework**

Leanne Dospital, Krista James, Barbara Lindsay, Faith Bodnar

1. Leanne Dospital  
 Manager, Assessment and Investigations and Health Care Decisions  
 Services to Adults  
 Public Guardian and Trustee of BC  
 AIS\_HCD@trustee.bc.ca

The following publications which reflect the continuum of autonomy to protection can be found at this link under the Adult Guardianship heading:

[http://www.trustee.bc.ca/reports-and-publications/Pages/default.aspx#Adult\\_Guardianship](http://www.trustee.bc.ca/reports-and-publications/Pages/default.aspx#Adult_Guardianship)

It's Your Choice - Personal Planning Tools

- How You Can Help
- Consent to Health Care
- Protecting Adults from Abuse, Neglect and Self Neglect
- Options to Consider
- Assessment and Investigation Services
- A Guide to the Certificate of Incapability Process under the Adult Guardianship Act
- Information for Temporary Substitute Decision Makers Authorized by the PGT
- Decision Tree: Assisting an Adult Who is Abused, Neglected or Self Neglecting

2. Barbara Lindsay, LLB.  
 Director of Advocacy & Education  
 Alzheimer Society of B.C.  
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Freda's Story: [http://www.alzheimer.ca/bc/~media/Files/bc/Advocacy-and-education/Personal-planning/2015-02-13%20Fredas\\_Story\\_Online.pdf](http://www.alzheimer.ca/bc/~media/Files/bc/Advocacy-and-education/Personal-planning/2015-02-13%20Fredas_Story_Online.pdf)

Cam & Sally's Story and Getting Your Affairs in Order: <http://www.alzheimer.ca/bc/~media/Files/bc/Advocacy-and-education/Personal-planning/2012-11-15%20Cam%20and%20Sally%20Story.pdf>

- I have dementia
- Caring for someone

Dementia Friendly Communities Resources -

- <http://www.alzheimer.ca/en/bc/About-dementia/Dementia-friendly%20communities>
- <http://www.alzheimer.ca/en/bc/Feature-stories/Take-action-and-become-a-Dementia-Friend-today>
- <http://www.alzheimer.ca/en/bc/Feature-stories/BC-Legislature-first-in-Canada-to-receive-dementia-education>
- <http://www.alzheimer.ca/en/bc/Feature-stories/New-Westminster-and-Valemount-set-to-become-dementia-friendly>

3. Faith Bodnar  
 Executive Director  
 Inclusion BC  
 fbodnar@inclusionbc.org

Supported Decision Making – Are You Ready – all people are competent to make decisions within the framework of UN-CRPD and the Canadian Charter of Rights and Freedoms. This biggest obstacles are the experiences and values we have that limit our capacity and competency in supporting people to make their own decisions:

- Models of Support
- Disability and Competency - Competency of the Person versus Competency of Process
- Canadian Charter of Rights and Freedoms, UNCRPD
- Right to Disability Supports
- Values and Principles of Supported Decision Making
- Risks
  
- <http://www.inclusionbc.org/about-us/social-policy-positions>
- [https://www.youtube.com/watch?v=bA\\_D5Qd1mg](https://www.youtube.com/watch?v=bA_D5Qd1mg)
- <http://www.bcsaf.org/>

4. Krista James  
 National Director  
 Canadian Centre for Elder Law  
 kristajamesbcli@gmail.com

Understanding the Lived Experience of Supported Decision Making in Canada - <http://www.bcli.org/project/understanding-lived-experience-supported-decision-making>

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## C5i

## Individualized Funding in New Zealand: A Purist Approach

Marsha Marshall

This presentation will provide an overview of Individualised Funding in New Zealand, and the purist approach being applied.

## Learning Objectives:

1. Gain awareness of Individualised Funding in New Zealand, how it is implemented, and what a purist approach looks like.
2. Understand the transformation IF has on people's lives, in their own words.
3. Be able to use the model as a tangible and real example.
4. Be inspired to take action where models of support are not empowering for people.

## Disability in New Zealand

New Zealand has a population of around 4.5million people. Of these, 1 in 6 identified as having a disability of some description in the 2013 census. This is approximately 16% of the population.

We are a multicultural country with 15% of the total population identifying as Maori, the indigenous people of New Zealand, 11.8% identifying as Asian and 7.4% as Pacific Islander. These statistics match the disability population also, with 15% of people eligible for IF identifying as Maori.

Individualised Funding is the predominant form of self direction currently in use in New Zealand and by far the most widespread, with nearly 2,500 people using it across the nation. Individualised Funding has largely been pioneered by Disability Support Services, a branch of the NZ Ministry of Health, which fund services for people with disabilities under 65 years of age. Of the nearly 10,000 Ministry of Health funded people eligible for IF, 23% of them currently using it, 75% of these are with Manawanui. In terms of ethnicity, 18% of our clients identify as Maori..

Although IF has predominantly been funded through Disability Support Services, increasingly, other parts of the health and disability system are taking it up. In particular the District Health Boards who fund primary through to tertiary level personal health, mental health and health of older people. There are also various models being trialled across the country to improve the initiative and improve overall choice, control and flexibility for people. These demonstration projects are much smaller scale, with approximately 500 additional people participating. All models being implemented currently with the exception of one are community based and take a purist approach to the provision of choice.

## A purist approach

Manawanui is New Zealand's expert Individualised Funding Host provider, and are involved in all the models of self direction being implemented in New Zealand, except one (which is residential). All the models we implement take a purist approach where all decision making belongs to the person with the funding. They can design and direct all aspects of the delivery of their own supports, within the particular funder's guidelines. Manawanui do not employ our client's staff, nor do we engage in decision making related to purchases, unless support for this is requested by the client. We act as a bureaucratic buffer, and facilitate the administrative component of the clients support environment.

This purist model has underpinned the transformational outcomes for people, and the success of the programme in New Zealand.

## Implementing the model

In terms of implementation, IF in New Zealand is one of the only initiatives in recent times to be cost neutral (or as our research indicates – cost saving over time) and scalability of the programme is based on taking the purist and "hands off" approach. We aim to support people to build their own capability and capacity to become independent, and attempt not to interfere, unless people request specific support. We take the approach that we will do as much or little as possible in the context of supporting independence. Our interface with people is at the beginning of the journey, with the intent of them needing us less and less over time.

Fundamental to empowering people to be self directed is the absolute requirement for a paradigm and power shift – people must have control over money and decision making. Also critical is acceptance of a degree of risk. The values and



## C5ii

## Shared Management: A Partnership That Builds Capacity between People, Families and Support Providers

Kate Fulton

### Learning Objectives

- To share the model of Shared Management including the principles, features and practice
- To share and understand the benefits and outcomes for people, families and providers of a shared managed approach
- To explore some of the potential economic benefits from Shared Management
- To explore what it takes for an organisation to develop effective shared management.

### Summary of the Session

Shared Management has its beginnings in WA in the 1990's when individualised funding first became available to people with disabilities. Its growing success is based on people, families and Support Organisations working together to develop an approach that honours everyone's contribution and has the flexibility to move and develop as people's lives change and develop. It has a deep appreciation for sharing the responsibility and management of supports, building people's own capacity in a way that has personalised back up.

Recent trial site data in Australia suggests that the number of participants choosing Self Management (Direct Payments) in the NDIA trial sites is low. In contrast the number choosing Self Management in Western Australia is significantly higher. We believe this is based on a solid history of people, families, providers and funders working together using an approach called Shared Management.

Shared Management provides a mechanism for people to direct, control, manage and monitor their support, in a way that makes sense to them and their changing lifestyle. It is not about people 'having to' manage all aspects of their funding and supports. It's about people being able to take on the level of responsibility and control that they want for each aspect of their support.

Confusion over perceived conflicts of interest are in danger of reducing this option to people and families.

*'Shared Management honors my freedom to be a part of the thinking, designing, developing and problem solving – to be recognized as having a big part to play, after all (no agency or manager) knows me, like me!' - Justin, Western Australia*

Although the initiative began in partnership with people with disabilities and their families, it is now being developed alongside Elders and people who experience mental ill health.

Shared Management essentially offers an honest and transparent mechanism to:

- Understand and participate in the range of tasks involved in designing, planning, setting up and managing a support approach.

and

- Define a partnership agreement between people, families and the Support Organisation about who is responsible for each task in the short and long term.

*'I manage everything, I manage my budget and my team – I set the rate of pay, I am their employer – I have kept my support team for years – it works well for us' - Brian*

Further information about Shared Management can be found at Western Australia Individualised Services (WAiS)  
<http://waindividualisedservices.org.au>

References included in the presentation; The National Disability Insurance Scheme - <http://www.ndis.gov.au/about-us>  
 The Centre for Welfare Reform - <http://www.centreforwelfareform.org>

## C5iii

**Life is Good In the Company of Friends - An Innovative Model**

Patti Chiappetta, Laurie Miller

## Life is Good in the Company of Friends – An Innovative Model

“We do not accomplish anything in this world alone.....whatever happens is the result of the whole tapestry of one’s life and all the weaving of individual threads from one to another that creates something beautiful.” (Sandra Day O’Connor)

Welcome to a great life, In the Company of Friends (ICOF). ICOF is not the same as an agency or formal residential setting – it is different, on purpose.

In the early 1990’s, shortly after Manitoba’s “Welcome Home Project” and challenges to the Mental Health Act, a group of like-minded people came together (self-advocates, families, community living groups, community members, government representatives). They believed there was a better way to support people with intellectual challenges based on a belief in: relationships, inclusion, community participation, self-determination and individualized funding.

In 1993 In the Company of Friends was launched as a pilot project. In 1996 ICOF was assessed and approved as a Supported Living Option in the province of Manitoba.

**Imagine the Possibilities!**

ICOF is a funding model offered throughout Manitoba to adults who are eligible for Manitoba government’s Department of Family Services - Community Living disABILITY services. ICOF is designed for individuals who prefer to self-direct and self-manage day to day living with the support of family and friends. This option ensures that design, responsibility and management of daily living is in the hands of each individual, in the company of his/her friends.

**Building Community!**

Individuals receive their monthly funds directly from the Family Services. With this money, they (the participant/the employer) hire their own staff, manage their finances, pay their bills, decide where to live and work!

The principle of supported decision making is central to this self-managed lifestyle option. A Support Network, chosen by the individual, is the structure that makes this happen. Most importantly the support network members have a relationship with the individual (the employer). The network may assist with functional roles and respects and listens to the employer’s voice in making decisions.

**The Story Continues.....**

In the late 1990’s discussions began about who would be best to administer and support this model (government, agency or community) for the long term.

In August 2000 – LIFE was born.

Innovative LIFE Options Inc. is a non-profit organization contracted by Manitoba Family Services. LIFE is designed to offer resources, training, advice and guidance to each person who chooses In the Company of Friends.

**Develop Novel and Unconventional Approaches.....Be CREATIVE and INNOVATIVE!!**

- Options for Services – provides alternatives for those who want to self-direct but do not want to or cannot do task themselves; helps contend with network burn out
- Options for Learning – new ways to teach
- Accountability – financial coordinator ensures that accountability is attained in the least intrusive way.
- ICOF is flexible as well as portable
- Collaboration and partnerships – (individual, family, friends, community and government) to create a good life
- ICOF is UNIQUE – no cookie cutters allowed
- ICOF is innovative and challenges us to think outside the box!

# C6i

## Transformational Change: Implementing the National Disability Insurance Scheme in Western Australia

Ron F Chalmers



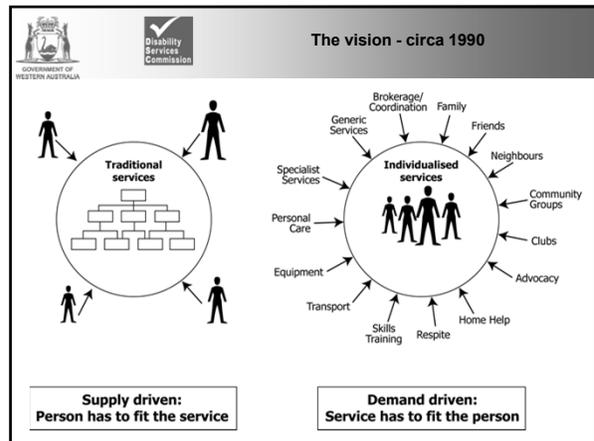
### Transformational Change

Implementing the National Disability Insurance Scheme (NDIS) in Western Australia



### LEARNING OBJECTIVES

- Share the challenge of being part of national system reform without compromising the positive features of an existing system
- Gain an appreciation of the challenges associated with implementing a national entitlement based support scheme




**During the 1990's we saw the start of major system reform.**

- Local Area Coordination
- Individualised funding
- Self-management
- Individualised accommodation
- Innovative, community based supports
- Informal supports



**By 2010 the support system in Western Australia had developed and matured:**

- Strong relationship-based support system
- Local decision making
- Remote area strategies (suits WA context)
- Partnership between Government and non-government services
- Sustained growth in government funding (6-7% per annum)

**National Investment (projections)**

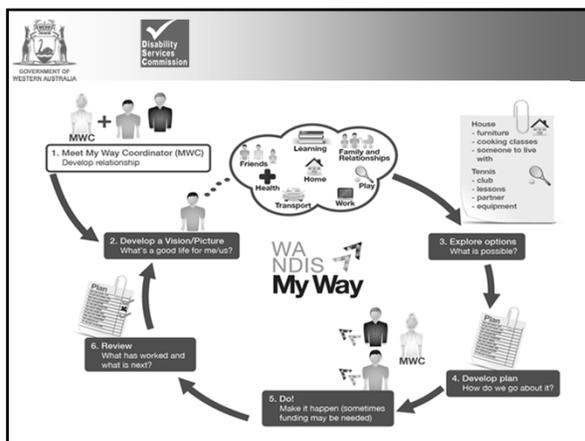
- \$22+ billion per annum
- 450,000 eligible people
- Western Australia: \$2 billion (50:50 Commonwealth and State)
- Political investment
- High community expectations

**NDIS – key features**

- National consistency in eligibility
- Portability across the nation
- Certainty of support over a person's lifetime
- Reasonable and necessary supports
- Choice and control by the individual/family
- Individualised planning
- Early intervention
- Long term projection of cost of support based on actuarial analysis

**Implementing the NDIS in Western Australia**

- Relationships and minimal bureaucracy
- Local decision making
- Integral role for Local Area Coordinators
- Strong focus on informal networks and community based supports
- Genuine choice and control
- Sector development planning and development
- Flexible pricing
- Payments in advance to service providers



**NDIS My Way**

The map shows the geographical focus of the NDIS My Way trials in Western Australia, specifically the Cockburn-Kwinana area and the Lower South West region.

**Outcomes (so far) from NDIS My Way trials**

- 2,000 people now in the trial
- Average plan costs \$30,000
- 93% of plan outcomes are being achieved
- 20% of people opting for self-management
- 10% of plans require no funding
- Very high level of consumer satisfaction
- No complaints or appeals

## C6ii

## Implementation of the National Disability Insurance Scheme in the Perth Hills Trial Site in Western Australia

Marita Walker

### Learning Outcomes

1. An awareness of the characteristics of the Perth Hills Trial Site and the activities undertaken in the first year of the two year trial period.
2. An appreciation of the steps involved for individuals and families entering the Scheme, developing a Plan and putting it into place.
3. A perspective of the challenges and opportunities for Providers in the Trial Site.
4. A snapshot of the results at the end of year one.

### Synopsis

The Perth Hills Trial Site is located in the outer eastern suburbs of the metropolitan area. As the name suggests it includes suburbs in the Hills of the Darling Range as well the City of Swan local government area at the bottom of range. The demographics vary from low to high socio economic areas, suburban to rural with representation of indigenous and culturally and linguistic diverse populations that are typical for metropolitan WA. Historical patterns of residential facilities have resulted in a reasonably high level of shared accommodation services. The Productivity Commission report projected up to 4,300 participants for the site.

The National Disability Insurance Agency established an office in Midland, the main service centre, which opened just before the trial began in July 2014. Trial Site staff have been recruited progressively through the first year. The main activities involve the transition into the scheme of individuals already known and receiving supports from programs funded by state and commonwealth governments and those who are "new" who meet the access criteria but have not had funded supports. The gradual intake over the 8 quarters of the two year trial is prescribed in the Bilateral Agreement signed by the Commonwealth and WA Government.

### Participant and Family Experience

The first contact with the Scheme in Trial usually occurs through a phone call to the individual and family to invite entry to the scheme and completion of the Access Request Kit. This information is required to confirm age and residency and for those who are "new" evidence of level of functional impairment is needed to make an access decision. Assistance is available from NDIA staff, providers and peer groups to complete the forms. People can also "walk in" to initiate their own transition.

The next step is an opportunity to attend a Pre Planning workshop. Initially these were conducted by a local peer group called Valued Lives on behalf of NDIA. More recently these have been held on a weekly basis at the office facilitated by Planning and Support Coordinators.

Within the NDIS legislation the description of a person's aspirations and goals is the Participant Statement which is the first part of the Plan which is wholly theirs to own. The second part of the plan outlines the informal, community and mainstream supports and the "reasonable and necessary" funded supports to achieve their goals. The individual Plan is developed through a meeting/s between the Planning and Support Coordinators and the individual and family and other people they have invited. Often this will be a key worker from the current service provider. During and after the meeting/s information will be gathered from a range of sources to enable the supports to be determined and written up in the Plan. The draft Plan is provided to the individual and family for their agreement before the formal approval by the appropriate delegate at the Trial Site. Part of the development of the plan is the participant /family deciding on the extent to which they wish to directly manage the funding within their plan. Whichever option they decide on the money is allocated directly to them for them to use with service provider/s they choose in flexible ways that are described in the plan. Plan supports are considered under the headings of Core, Capacity Building and Capital. The focus on early investment as part of the Insurance pillar of the Scheme to build capacity and therefore better outcomes and reduced long term costs is proving to be a huge benefit for many people.

Plan implementation is the next step and one which has resulted in challenges for all involved. For some it is a matter of the current provider being advised by the participant/family, a service agreement negotiated and the provider claiming through the NDIA portal for payment of services. When there are new services to be chosen this may be done independently or assistance may be provided as part of the plan for either short term or over a longer period.

The presentation will include an individual story.



# C6iii

## Campaign for a National Disability Insurance Scheme. A Successful Change to Social Policy?

Samantha Jenkinson

### Campaign for a National Disability Insurance Scheme A successful change to social policy in Australia?

Samantha Jenkinson



### Learning Objectives

1. Identify how people with disabilities can be involved and engaged in campaigns
2. Identify the challenges and competing interests when bringing together service providers, family carers and people with disabilities around self determination
3. Identify challenges and strategies in putting vision into practice

### The Cause

#### What do people want?

- . Certainty of funding, more funding, sustainable funding – meeting unmet need
- . Individualised and personalised approaches, choice, self-directed services - people with disability and their families and carers in control of their lives and supports – a paradigm shift
- . National consistency

### Stakeholders

- . People with disability
- . Families and Carers
- . Service providers
- . Building the alliance of the three key stakeholders
- . Involvement of the national advisory council and advocacy groups



### The Campaign



#### What is needed?

- . A clear message
- . Defining the target audience
- . Testing assumptions
- . Setting goals for the campaign
- . Getting the right skills
- . Showing a united stand

### The Campaign



#### How do we do it?

- . Real stories - people's lived experience
- . Web based, social media, grassroots
- . Rallies at key points
- . Key spokespeople and celebrities
- . 'Disabiliteas' – capturing the broader community
- . Real people lobbying politicians at key times
- . Bi-partisan focus

**MAKE IT REAL**  
NDIS 2012

## The Campaign



**MAKE IT REAL**  
NDIS 2012

## The Campaign



**MAKE IT REAL**  
NDIS 2012

## The Campaign



## Policy Environment

- Self-directed, consumer empowerment and service user led models
- UNCPRD signed
- National Disability Strategy developed but weak implementation plan
- Global Financial Crisis fallout and austerity measures
- Disability low profile – othering of disability
- Growing community resentment of perceived government over spending

## Politics

- Tensions between alliance groups – who is the campaign for and who is running it? Who paid?
- What is the role of the campaign vs the role of the sector?
- State vs Federal – a national scheme or a federated national scheme? How to keep local relevance?
- Party politics – is there real commitment from both sides? Is there the same understanding?

## Current Scheme

- Legislated in 2013
- Principles in Act highlight rights, choice, control and participation of people with disabilities
- Trial sites in every state in Australia with rollout expected in 2016
- Learning organisation
- Tension on funding, insurance model and participation by people with disability at a policy level

### Current Scheme

PWDA Citizens Jury Scorecard

- NDIS improved participation in the community and independence
- NDIS provides high levels of choice and control to participants – to set their own goals and choose their preferred service
- The person-centred approach was seen to be working
- Reports of increased self-esteem

### Current Scheme

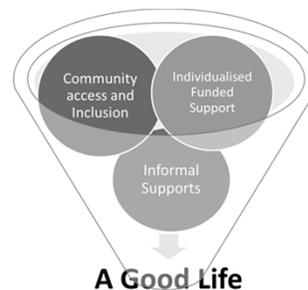
PWDA Citizens Jury Scorecard

- Planning – people need more information, preparation, advocacy, and better training for the planners themselves
- Services being stopped before changeover to NDIS
- Better communication and accessible information and customer service
- Mechanisms for real participant feedback need to be built in to the system

### Future Challenges

- . Politics – getting in the way of a focus on people
- . Keeping the story relevant and in public eye – taxpayers money and outcomes
- . Having a responsive scheme willing to change - getting a scheme vs getting the right scheme.
- . When is community development going to happen?
- . Housing and Employment
- . Who is being listened to and responded to?

### Future Challenges



### References and Further Information

- . Every Australian Counts Campaign <http://www.everyaustraliancounts.com.au/>
- . Ramp up: A nice hot cup of mediocritea by Kate Larsen <http://www.abc.net.au/rampup/articles/2012/10/15/3610533.htm>
- . National Disability Insurance Scheme <http://www.ndis.gov.au/>
- . NDIS Citizens Jury Scorecard Project by PWDA <http://www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html>

### Questions



**Thank you  
Samantha  
Jenkinson**

# Understanding Families' Experiences of Self-Direction: Learnings from Queensland Families

Lesley Chenoweth

Griffith UNIVERSITY MENZIES HEALTH INSTITUTE QUEENSLAND

## Understanding Families' Experiences of Self-Direction: Learnings from Queensland Families

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### Context

- Australia – currently rolling out National Disability Insurance Scheme (from State based programs)
  - Individualised funding / self direction
  - Choice & control
  - Commenced trial sites July 2013
  - Now present in all states and territories except Qld
- Queensland – no trial site.
  - Roll out planned July 2016
  - Launch site to be announced for earlier

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### Queensland & self direction

<p><u>Government managed</u></p> <ul style="list-style-type: none"> <li>▪ State government pilot of direct funding – 2011           <ul style="list-style-type: none"> <li>» Children and families</li> <li>» Young people with ABI</li> </ul> </li> <li>▪ Your Life Your Choice - 2012</li> </ul>	<p><u>Non-government</u></p> <ul style="list-style-type: none"> <li>▪ Government funding administered by community orgs</li> <li>▪ Innovative community organisations offered direct funding/self direction in various “versions”</li> <li>▪ Family governed/ family centred</li> </ul>
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### Queensland & self direction

- A wide range of family experiences in self direction
  - » no knowledge of self-direction
  - » others who have been managing funding for their son or daughter for up to 15 years.
  - » Some families relatively new under YLYC
- Many Qld families have significant experience in self direction / direct funding (estimated 1000+ families)
- Many factors are at play in supporting or inhibiting family participation in self-direction and direct payment schemes
- What could be learned from these experiences as we head into the NDIS?

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### The studies

1. **Self Direction and people with an intellectual disability** (Crozier & Muenchberger, )
2. **User Experiences of Self-Direction** (Chenoweth, Crozier, Reese, & Dorsett )
3. **Your Life Your Choice – Quality Health Check** (Crozier & Muenchberger)

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### 1. Study 1 Self Direction & people with intellectual disability

**First aim:** Identify perspectives of people with an intellectual disability and their families with **no experience** of self direction to explore

- (1) current experiences with services
- (2) aspirations to self-direct
- (3) core skills required to self-direct

**Second aim:** To develop an appropriate skills package or tool/s to respond to those findings.

**Third aim:** To explore staff understandings of current service practices and concepts in terms of self-direction and service coordination for people with a disability and their families.

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### Study 1 - Findings

- **Families:** happy to hand most if not all aspects of service over if they had input into the decision making and planning and had the capacity to change providers in the future. BUT greater choice and involvement was a clear aspiration.
- **People** with an intellectual disability expressed a very low level of interest and motivation to engage about their service experiences let alone take a more active role in the coordination of them.

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### Study 1 - Findings

- **Staff** identified barriers to increased involvement for families and clients:
  - » service culture that focuses on deficits;
  - » capacities of the staff in terms of time, resources and skills to engage people;
  - » personal attributes of people with disabilities and families (e.g. lack of interest & desire, not understanding what it is, limited knowledge of entitlements and levels of involvement, lack of confidence and assertiveness, limited family resources, personal impacts of ill health and aging and prior negative experiences with services);
  - » power imbalances within services;
  - » being presented with limited options

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### Study 1 - Findings

- Staff (23%) noted organisational incongruence in aspiring to self-direction practices but incurring (unspecified) difficulty with proper implementation.
- We found that it was not skills that families needed, they needed tools around decision making
- We also found that people with intellectual disabilities needed skills in self-determination particularly in terms of how services work, who to go to for support and assistance and being empowered to do so.

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### Study 2 - User Experiences of Self-Direction

**Aim:** document the experiences of people who have been self-directing prior to Your Life Your Choice in Queensland, as well articulate the missing evidence on self-direction (people's experiences) within the broader national disability insurance scheme

Qualitative study – in depth interviews with persons and families with **significant experience** in self direction

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### Study 2 - Findings

Although there are complexities with self-directing the prior wounding experiences of life and service systems are somewhat addressed through a self-directing paradigm, although they can also be impactful.

THEME 1: A good life an ordinary life more achievable when self-directing

THEME 2: A lifetime of wounding and service provider failures

THEME 3: Creating a new more personalised culture under Self-direction

THEME 4: Systems and self-direction - different burdens but worth it

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### Study 3 Your Life Your Choice (Crozier & Muenchberger)

- **Aim 1:** To develop a snap shot understanding of Your Life Your Choice participants who have moved from a traditional models of service delivery (or are new to services) to Your Life Your Choice through **two quarters** of payments.
- **Aim 2:** To develop an understanding of the experiences of Host Providers.
- Focus groups & interviews (participants & host providers)
- Survey

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**Study 3 –Findings (Preliminary)**

- Data are still being analysed

**Themes**

- The journey toward Your Life Your Choice
- Experiences of Your Life Your Choice
- Operating Your Life Your Choice

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**Learning**

- Majority of families aspired to or wanted more control and choice
- Given appropriate support and tools, families can and do self manage (to varying degrees)
- People with intellectual disability need skills and support in self direction but can participate in decision making
- Attitudes of staff and organisations crucial in providing supportive cultures for self direction
- Experienced self managers have a depth of knowledge and skills
- Much trial and error learning
- Can be demanding on time and responsibility
- But "worth the trade off" i.e. do not want to revert to agency control

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**Learning**

- Approaches on long term self managers are very individualised for their situation
- Longstanding self-directed arrangements appeared to have developed a firm foundation of **trust** between the paid workers and families and/or the person with disabilities.
- Some long standing family members concerned about future when they can no longer do this – other family members not interested
- Preparation is crucial – readiness
- Practical support – e.g. financial management, recruitment, staff supervision etc

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# C7ii

## Models of Family- and Person-Directed Respite in Canada: A Cross-National Comparative Analyses

Paula S Hutchinson, Catharine Shanahan

**PROFILES OF  
FAMILY- AND PERSON-DIRECTED RESPITE IN CANADA**

**Canadian Respite Network**  
**Paula Hutchinson, Dalhousie University**  
**Catharine Shanahan, Family Respite Services of Windsor**

**LEARNING OBJECTIVES**

1. Define respite and its importance to full citizenship.
2. Introduce the Canadian Respite Network and survey goals.
3. Describe variations in respite services across Canada.
4. Detail the types of respite services that promote full citizenship.
5. Develop a fuller understanding of the types of respite supports available across Canada to enable us to create federal policy ensuring adequate supports for individuals and their families.

**Why is Respite Important?**

Parents said they had an urgent need for respite support but it had to meet the needs of their children/adult children. If it didn't then it wasn't a break (Hutchinson et al, 2010).

Respite services should be a way to achieve equity!

**Respite promotes Full Citizenship**

- Re-define respite as a support for individuals to participate in the community (Full Citizenship) vs. a need for families to have a break.

Provides equitable opportunities to:

- Participate in activities that everyone has a right to participate in.
- Give families a similar quality of life to other families

- Not a Break from life, but a Change in quality of life!

**Canadian Respite Network**

Network formed as result of the International Short Break Conference held in Toronto, Ontario in 2012.

Canadian respite service providers came together to share knowledge and resources.  
<https://www.facebook.com/canadianrespienetwork>

Access to respite varies based on the capacity of service providers, funding, and geography (Hutchinson et al., 2010) but how does it vary across Canada?

**Method: Survey Design**

Survey Questionnaire

- Network members formulated questions
  - structured- and open-ended questions
- Respondents were contacted through members' contacts and community (note: no Canadian directory of respite service providers).

Advantages: standardized questions – everyone answers the same questions  
 Limitations: self-reporting and possibly bias recall



C7iii

Family Vision as a Force for Inclusion: The Role of IF Funding

E Anne Hughson, Bruce Uditsky

**Family Vision as a Force for Inclusion: The Role of Individualized Funding Mechanism**

**Presenters:**  
**E. Anne Hughson**  
**Bruce Uditsky**

**Learning Objectives:**

- Identify what's at stake for families and individuals who wish to stay on the normative pathway in contrast to what is at stake for policy makers, funders, staff and community members.
- Determine whether policy trends that favor IF options could affect the perceptions of disability, personal values, perceptions about community connections, and professional practices.
- Identify whether funding mechanism actually influence/constrain the power of vision, the limits of traditional community service programs and community connections.

**Inclusion Alberta's Involvement with Individualized Funding**

The emergence of individualized funding for adults with developmental disabilities close to 30 years ago:

**Families experience with:**

- unresponsive service providers
- poor life outcomes, perpetual clienthood, confused agency values (e.g., personal choice; care and safety; inclusion )
- difficulty finding services and supports for individuals with complex needs
- lack of individualization & personalization by service providers
- negative view of role of families in the lives of adults

**Inclusion Alberta's Involvement with Individualized Funding**

The emergence of individualized funding close to 30 years ago:

**Families desire to:**

- be heard & engaged
- have the importance of families valued
- see a meaningful life realized
- have their family members known and understood as a person, not a client of services
- address loneliness
- escape bureaucratic entrapment of agencies
- know what was happening (what were the plans, who would be working when, doing what)

**Inclusion Alberta's Involvement with Individualized Funding**

- Inclusion Alberta has played an instrumental role in the development of individualized funding since its inception in Alberta – extensive individual and systems advocacy required for it to work effectively
- Contracted by government in the 1990's to conduct a provincial review and evaluation of Individualized Funding – found that IF was not realizing its promise.
- The strengths and limitations of IF need to be understood by all stakeholders and accurately communicated

**Common Misperceptions of IF**

- Consumer is a powerful role
- Funds drive the market, create choice
- Believing there is "marketplace"
- Funding (\$) is power, liberates from the yoke of services
- Changing the culture and practice of human services is easy
- Planning is person centered and creative
- Plans can be implemented – the expertise, knowledge, means and talent exist

**Common Misperceptions of IF**

- Values are universal, understood and shared
- Quality, consistent and sufficient staff are readily available
- Everyone has the capacity to: facilitate inclusion; enable membership and belonging; secure and sustain employment; recruit, train, manage, direct, and employ staff; account; plan; create; innovate; negotiate; determine needs and supports; adapt to changes; etc., etc.
- Everything should be individually funded – this equals individualization

**IF History in Alberta**

- Rapid growth in utilization
- At one point, there was more IF in Alberta than anywhere else in the country
- IF mechanism was the only way to get new money into community services
- Led to large growth in number of spaces and new service providers
- Service providers and families then said ‘why bother with IF; we’re buying the same thing as before’
- IF was almost lost completely – went from many thousands of users to a few hundred
- There was (and is) no agreed definition or measure of a good life

**What was Needed for Renewal Of IF Mechanism in Alberta**

- Focus on values, vision, dreams, aspirations, pathways, possibilities, opportunities
- Facilitating inclusion is an art form – it requires talent, critical thinking, reflective practice
- Needs independent community governed infrastructure and resources for individuals/families – so the benefits of IF can be better realized and more equitably distributed

**When asked, families said:**

We want a virtual and/or actual family resource center, directed by families and specific to IF, as the best means of ensuring needed and relevant resources would be offered.

The desired features of a resource centre include:

- Provision of mentorship through experienced families
- Values based workshops & seminars for families and their staff, with topics to be determined by families
- Assistance in visioning, effective planning and implementing plans
- Support to effectively recruit and sustain staff
- Current & accurate information on legal, financial, and government policies and practices

**Resource Centre**

The desired features of a resource centre would include:

- Pooling of staff to improve staffing retention
- Assistance for families in being responsible employers (e.g., labor standards, managing accounts, etc.)
- Centrally located and accessible (parking, transit, LRT)
- Available to families at hours convenient to them
- Assistance in determining if FMS is a feasible choice

The Centre has influenced the development of a centre in Australia.

**Resources Offered by the Center:**

- Visioning, planning, implementation and follow-up with individual families
- Information and education related to visioning, planning, community inclusion, staffing and all matters related to IF
- Family mentors and support/training for mentors
- Administrative and technical support for families, including registry for finding staff

### Website

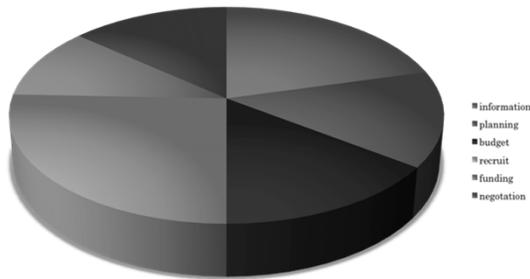
- <http://fmsresourcecentre.Inclusion Alberta.org>
- Resource Categories
  - Recruiting, Hiring and Managing Support Workers
  - Building Communities
  - Individualized Funding Articles
  - Creating a Good Life
  - What is FMS
- Employer Tips of the Month
- Available to families across the province and globally

### Who is Using the Resource Centre?

In December 2014, a file audit was completed of the 300 families who had accessed the Resource Centre.

- The following pie chart indicates the types of services accessed:

**File Audit**  
Resource Centre Supports



### Who Accesses the Resource Centre?

- Families
  - Transitioning from childhood services
  - Inquiring about IF
  - Aging
  - Of individuals with complex needs
  - Transitioning from agencies
  - Having challenges with IF, wanting better outcomes, needing to find staff, seeking training for staff, etc.

### Outcomes

The Resource Centre tracks individual outcomes in the areas of:

- Having a real home
- Gaining employment
- Continuing education
- Community inclusion
- Health and well-being

Tracking process - records maintained online through Inclusion Alberta's database

Close collaboration with government funder and many community partnerships

### Concluding Remarks

For individuals and families the stakes amount to the difference between a full and meaningful life or one bound by government dictates, limited program options and the constraints of congregated human service provision.

Being able to envision what an inclusive life looks like is absolutely essential – in contrast to what is offered by programs and services.

It is counter cultural to 'see' what an inclusive life looks like.

Requires the people who facilitate visioning to have the capacity to see what 'it' is and take action !!

## Age 7

Abused, Neglected, Developmental Disabilities,  
 7 Foster Homes,  
 Oppositional Defiance Disorder  
 Reactive Attachment Disorder  
 Violent, Post Traumatic Stress Disorder  
 Health Challenges,  
 Segregated Early Childhood,  
 Segregated Classroom  
**UNADOPTABLE**

What are the expectations for  
 his life and who decides?



## Video Clip



Married July 11, 2013

## Concluding Remarks

An IF mechanism can support an inclusive life for those with the vision and capacity to capitalize on as a resource, but

this requires an independent, comprehensive family driven, values based resource 'centre'.

# C8

## International Examples of Self Determination, Personalisation and Individualised Funding in a Mental Health Context

Eddie Bartnik, Nick Dixon, Gerry Naughtin



Claiming Full Citizenship Conference  
Vancouver, 15-17<sup>th</sup> October 2015

**Personalisation and People Powered Health in Stockport**

Nick Dixon  
Commissioner, Stockport MBC, England



### Background



Stockport based in England's North West in Greater Manchester

Large Town, Population 292,000

Local Municipality

Specialist Mental Health provided by Pennine Care NHS Trust



### Mental Health System- Background

- Delivered by statutory and voluntary services working in relative isolation
- Criteria tightening
- Little focus on outcomes and recovery or prevention
- Risk averse practice dominated
- People referred on and through- or get stuck, get ejected, fall between
- Delivered primarily in 'service land', excluded, detached

### Over time.....



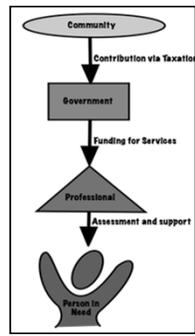
- **Values** Based Awareness, 2002
- **Recovery** of a life, irrespective of the illness, 2003
- **Social Inclusion**- hopes and aspirations made possible, 2005
- **Personalisation**- choice and control, 2009
- **Outcomes** based commissioning, 2010
- **People Powered Health** and Coproduction, 2012
- **Collaboration** and redefined relationships, 2013
- **Social Action**- People Powered Places, 2015

### Times are changing

Power with clinicians	Co-production-power shared
<ul style="list-style-type: none"> <li>• Traditional interactions</li> <li>• Expert knowledge creates behaviour change</li> <li>• Goals are set by the clinician and success is measured by compliance with them</li> <li>• Decisions are made by the clinician.</li> </ul>	<ul style="list-style-type: none"> <li>• Collaborative interactions</li> <li>• Person is supported in defining their own goals. Success is measured by attaining those goals</li> <li>• Meaningful choice and control</li> <li>• Decisions are made as a service user-clinician partnership</li> <li>• Use the assets in the system</li> </ul>

### Professional gift model

acknowledge Simon Duffy Centre for Welfare Reform



- The underlying system of power: 'we know best'.
- Professionals and commissioners work out what you need.
- They buy things they think will help.
- You have to slot in.
- You feel you should be grateful.
- We have not rethought **power**

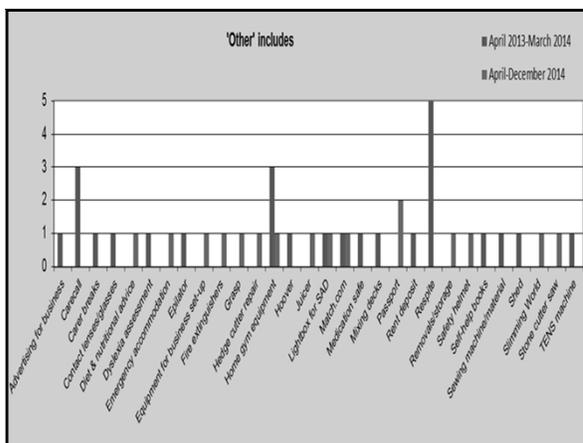
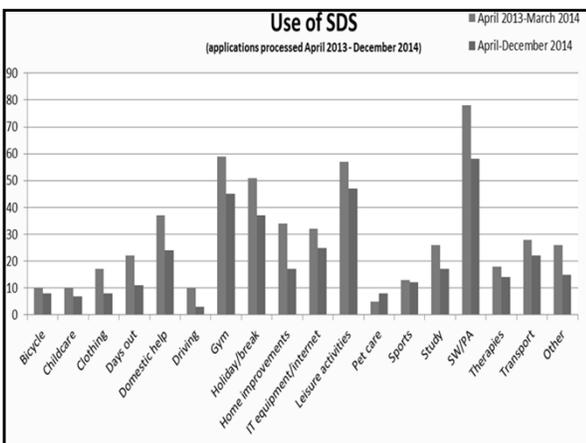
### Citizenship Model

acknowledge Simon Duffy  
Centre for Welfare Reform

- Citizen at the centre
- Services negotiated
- Entitlements defined
- Community fully engaged
- **Outcomes improved**

### Personalisation in Social Care

- Launched in 2009- giving people control over their own recovery
- Now embedded as core offer- 587 people (218 current)
- Average budget per person £3.1k
- Average spend per person £2.7k
- Budget stabilised at around £600k
- Just 3 renewed into a 6<sup>th</sup> year
- Offering meaningful choice



### Some of the risks

- The 'professionalising' of personalisation
- Power in the system remains with the professionals
- Personal budgets used to support a 'maintenance' approach
- Limited and reducing budget, new demand
- Recovery and self management not prioritised
- Unwise choices and consequences

### Kar's Story

<http://play.buto.tv/bnKdb>

Kar's journey towards Recovery  
my self directed support plan

**Some key messages**

- Gather evidence , **narratives win hearts and minds**
- People usually know what works for them
- Avoid focus on ‘the what’ , do focus on ‘the why’
- Small amounts of funding can transform lives
- Resilience to mental ill-health can be found in unexpected places
- Offer choice of brokerage – aspirational support planning is key
- **Locate personalisation in a recovery context**
- Encourage independence and self management
- Connect people to community based circles of support
- Grow community capacity and social action- people helping people

**Health  
for people....  
by people...  
with people**



[www.nesta.org.uk/health-lab](http://www.nesta.org.uk/health-lab)

**Cashable Savings and Benefits**

- Fewer people in expensive services for shorter periods- **demonstrated**
- Improved productivity for clinicians in primary and secondary care- **demonstrated**
- Sustained outcomes and social returns- **demonstrated**
- Reduced use of personal budgets- **demonstrated**
- Capacity built in communities- **demonstrated**



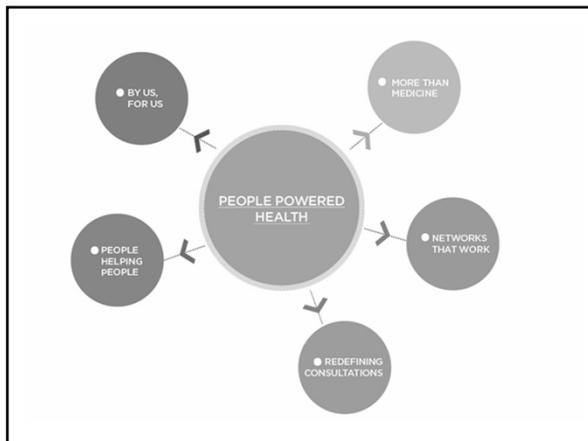
**What is People Powered Health?**

A set of principles...

- **A health and social care system that mobilises people** and recognises their assets, strengths and abilities, not just their needs
- **An ability to live well with long-term conditions powered by a partnership** between individuals, carers and frontline professionals
- **A system that organises care around the individual** in ways that blur the boundaries between health, public health, social care, and community and voluntary organisations

...underpinned by practical, outcome-focussed, interventions

- New forms of consultation
- Support for self-management
- Social prescribing
- Peer support and time banking
- Coaching, mentoring and buddying
- Health trainers and navigators
- Co-designed pathways
- Self-directed support
- Personal health budgets
- Integrated care through collaboratives, partnerships and alliances



**The Asset of Peers**

- Tap into the power of peers- one area of growth still open to commissioners
- All Together Positive, User Led Organisation <http://www.alltogetherpositive.org/>
- Peer brokerage, Peer evaluation  
Peer reviewing of personal budgets
- ‘People Helping People: Peer Support that changes lives’ <http://www.nesta.org.uk/project/people-powered-health>

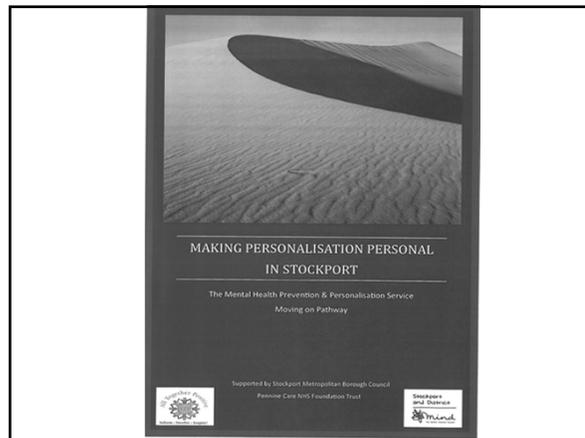


## Personal Health Budgets

The case of Kazz:

“...I would like to extend my utmost thanks to ATP for all their understanding and patience....you have made (me) less fearful and that is the greatest gift anyone could receive. Thank you to everyone involved in giving me hope of freedom to live, not just exist, and have the chance to help others learn new arts and feel they are not alone too. God bless you all as you truly are heaven sent for the gift of changing my existence which is now LIFE....”

The cost? Less than £500



## Summary

- Culture change is critical
- Seek to give hope, through hope comes resilience
- Personalisation must fit within a whole system approach
- Address what matters, not ‘what is the matter’
- Gather evidence and build a compelling case
- Capture and share stories
- Enable people to grow and thrive
- Connect, Take Notice, Learn, Be Active, Give
- “Recovery for me is knowing that when I die I have contributed something”

## Any questions....

- Nick Dixon 07866999540  
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- Kar Rowson  
[kar.rowson@gmail.com](mailto:kar.rowson@gmail.com)




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Supporting mental health recovery

## Improving client choice and engagement for people with psycho-social disabilities due to mental ill-health

Dr Gerry Naughtin PhD.

Chief Executive, Mind Australia and member of the Independent Advisory Council to the National Disability Insurance Agency

[mindaustralia.org.au](http://mindaustralia.org.au)



Supporting mental health recovery

## Two innovative Australian examples of improving client choice and engagement

- Mind Australia is a leading mental health NGO that works with people with psycho-social disabilities associated with persistent mental ill-health.
- Presentation will discuss how two initiatives are deepening understandings of client self determination in Australia.
- **Example 1:** Mind Recovery College - a learning and educational approach to improving client choice and control.
- **Example 2:** Research Project: People Making Choices - the support needs of people with a psychosocial disability.



Supporting mental health recovery

## Mind Recovery College

- Mind Australia has developed a Recovery College to strengthen consumers access to information and education about recovery.
- Approach adopted has built on the strengths and weaknesses of approaches developed in North America and United Kingdom.
- Features:
  - A place where real people with real life experiences share what works for good mental health.
  - Teachers who have learned from their own first-hand experiences of mental distress.
  - Our Recovery College offers a very different experience to anything participants have encountered in mental health services before. At the Mind Recovery College you get to be a student, learning real-life skills for a better life.



Supporting mental health recovery

## Who is the Mind Recovery College for

- The College is for anyone who wants to learn more about mental health, with a focus on what we learn from experience rather than the textbook.
- Most of our students are people seeking their own mental wellbeing who are keen to hear what works for other people.
- We also have a number of students who support loved ones experiencing mental distress, as well as some mental health professionals who wish to enrich their work.



Supporting mental health recovery

## Research Project: People making choices

- Qualitative study of 41 participants asked participants what they wanted in terms of services and supports, how they would make these decisions and what if anything would assist them to do this.
- Study undertaken in Barwon region in Victoria, one of the NDIS trial sites.




Supporting mental health recovery

## Definition of psychosocial disability

*“A mental health issue that affects people’s daily activities such as **socialising or interacting with others in a social setting, learning or self-care, or their capacity to fully participate in society.**”*

(Australian National Mental Health Consumer and Carer Forum, 2011)

### Participants

- 41 people participated
- All self-identified as having a psychosocial disability
- All were unemployed or underemployed
- 90% on disability pension
- Most were lonely or socially isolated
- Majority lived alone or in supported housing
- Aged between 26 and 65
- 24 male and 17 female

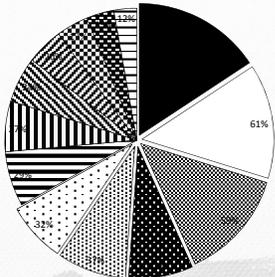



### Methodology

- 14 prompt cards developed to assist participants to think about their goals and ideas about a “good life”.
- From these, participants were asked to select their top five goals.
- Participants were given 10 seeds (which represented 100% of a funding package) and asked to spread them across their goals.



### Prioritisation of 14 good life domains (N= 41)



Domain	Percentage
Health	12.0%
Economic	12.0%
Social connection	12.0%
Housing	12.0%
Support Person	12.0%
Personal life	61.0%
Self	12.0%
Passions and interests	12.0%
Recreation and leisure	12.0%
Family	12.0%
Empowerment	12.0%
Cultural	12.0%
Living skills	12.0%



### Key supports identified

- Access to a good doctor, psychiatrist or counsellor.
- Good support person.
- Peer and consumer support groups where people could openly share their experience and find environments of support and guidance.
- Financial support including support to access low cost medical and dental care.
- Information and advice to make good health decisions relating to physical exercise, medication, controlling drug and alcohol consumption.



### Supports for health

- Peer support
- Treatment options
- Integrated health treatment
- Doctors and medication
- Dental treatment
- Psychologist, counselling and psychotherapy
- Financial support to subsidise health care
- Group based activities
- Personal carer
- Prevention strategies

*“Right medication, professional mental and medical help to alleviate symptoms, reduce cholesterol, reduce weight, have a healthy life, live long, prosper and do stuff.” (Participant)*



### Supports of economic security

- Training and skills development
- Employment Assistance
- Financial support and stability

*“I was thinking of getting a mentor and support worker through [CMHSS] but that was more for the economic sort of thing to help me...I was thinking of getting them to help with budgeting, getting budgeting up to scratch so I can save money and actually pay off my debts and such. So some sort of economic support would be good.” (Participant)*











## D1i

## Citizenship as Practice: Handling Communication Problems in Encounters between Persons with Dementia and Social Workers

Johannes H Österholm, Lars-Christer Hydén

What it means to be a citizen and a person with dementia is an under-theorized and under-researched area within dementia research. Bartlett and O'Connor point out that "the preferred frame of reference in the dementia care literature is invariably personhood" (2007, p. 109). In searching for an alternative they note that in social science research on citizenship there has been a shift from recognizing rights and responsibilities toward "the practice of citizenship", as "something individuals achieve for themselves, through the power dynamics of everyday talk and practice". Bartlett and O'Connor (2007) suggest that citizenship as practice could be used as a framework for further research in the area of dementia practice and research.

In Sweden, entitlement to support is assessed by a representative for the care agency in an assessment process. Central to this process is the assessment meeting where information about different kinds of support is given, and where the clients' entitlement to support is assessed. In an assessment meeting with a representative of the agency, the person with dementia must negotiate his/her needs and wishes in terms of the agency's possibilities. In this sense these meetings are examples of what is called "institutional conversations" (Agar, 1985). They are conversations in which "lay persons pursue various practical goals", while at the same time being "the central medium through which the daily working activities of many professionals and organizational representatives are conducted" (Drew & Heritage, 1992, p. 3). This is accomplished by the way the conversation is organized: it is the professional who steers the conversation, and sequences of question-and-answer dominate (Drew & Heritage, 1992; Hydén & Mishler, 1999). This also implies a standard organization of the encounters into a specific order of phases (Agar, 1985; Jokinen, Juhila & Suoninen, 2001), together with a "hidden" agenda that might cause asymmetry in the conversations, as lay persons rarely are aware of the agenda (Hydén & Mishler, 1999).

Dementia decreases the capacity to communicate and/or comprehend information (WHO, 1990), to find words in conversations (Hashimoto et al., 2004), or it can cause a decline in verbal fluency (Rousseaux et al., 2010). This has an effect on the ability of the person with dementia to engage in conversations with others (Lindholm, 2010). It might therefore be extra problematic for clients who are diagnosed with dementia to participate and present their needs and wishes for support in the assessment process, and thereby to practice their citizenship.

In the Swedish Social Service Act (2001:453) there is no legal support for letting persons' opinions other than those of the formal client (i.e. the person with dementia) govern decisions. Instead, the act recognizes the importance of listening to and respecting the clients' wishes (Klemme Nielsen, 2012). Assessment meetings could consequently be seen as examples of institutional conversations where persons with dementia practice their citizenship "through the power dynamics of everyday talk and practice" (Bartlett & O'Connor, 2007, p. 109); they present their needs and wishes and invoke certain social rights.

In this study encounters between social workers and persons with dementia were analyzed as examples of citizenship as practice. The purpose of the study was to investigate if and how persons with dementia were able to take part in negotiations for formal support. An additional purpose was to see if there are any communicative problems occurred in these meetings and if so, how they are manifested and how they affect the dynamics of the encounter.

The transcripts used for analysis were from eleven assessment meetings conducted in Sweden, in which the formal applicant was a person with dementia.

The findings suggest that the actual degree of participation of persons with dementia in assessment meetings varies. Communication problems occurred in all 11 assessment meetings. Some of the most common communicative problems affecting the ability of the persons with dementia had to do with finding words, and with understanding and making use of information presented during the assessment meeting. Other problems included keeping up with and talking about the same topic as the other participants, remembering previous happenings or experiences, and being able to negotiate accounts or descriptions of things that were contested by their relatives. The persons with dementia also quite often tended to repeat previous turns (either their own or some other participant's) when they were irrelevant.

For those persons with dementia making contributions to the ongoing conversations at the same levels as the other participants, there was an attempt at mutual understanding. For those making fewer contributions, the other interlocutors took over the initiative and thus affected the practice of citizenship by persons with dementia in a negative way.

In conclusion, the practice of citizenship is situation-based and varies depending on all participants. When the person with

dementia is able to participate in the conversation, social workers can facilitate for them to overcome communication problems by giving them more time and signaling acceptance. If the person with dementia has great problems in participating, the other participants can find different strategies to at least involve her or him in the conversation

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# D1iii

## Citizenship in Action: Examining the Lived Experiences of Citizens with Dementia Who Campaign For Social Change

Ruth Bartlett

Health  
Sciences

UNIVERSITY OF  
Southampton

**Citizenship in Action: examining the lived experiences of citizens with dementia who campaign for social change**

Dr Ruth Bartlett  
Friday Oct 16 2015 | Claiming Full  
Citizenship, Vancouver.

### methods

- qualitative/ethnographic
- diary-interview method
  - pre -diary group/individual interview
  - diary [circa one month]
  - post -diary individual interview
- participant observation of participants 'in action'
- Data were analysed manually using a combination of content and narrative analysis techniques



Photo copyright Ruth Bartlett

Bartlett, R. (2013) Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research*, 23, 11, pp. 1717 - 1726. doi: 10.1177/1099726112462240

### sample

- 16 in total
- 11 men
- 5 women
- ranged in age from 53 – 74 years (m64 years)
- all had a dementia diagnosis
- lived in England or Scotland - white European
- different occupational background
- all engaged in some kind of activism

### Campaigning (re) locates a person within the realm of work



*Modern notions of citizenship are constructed around work and 'doing' (Isin and Turner, 2007).*

the advantage I've got – with being a patient – you can say what you think and it doesn't matter does it because they can't do anything to you. They can't sack me can they, you see, you're not working for anybody'.

Edward likened his diagnosis of dementia to a 'flak jacket' – it protected him.

the diagnosis gave him the freedom to speak candidly

He said:

'you can just say, to hell with it, take me for who I am'.



*Rather than feeling embarrassed by a social faux pas (Goffman, 1959) – the dementia excused it.*





## D3i

## Standing Alongside People as they Change

Judith McGill, Maureen Emmons

## Learning Objectives:

1. Consider how change occurs for individuals and their families
2. Grapple with the role of Independent Facilitators in the change process

As a provincial, independent facilitation organization in Ontario, Families for a Secure Future is dedicated to serving adults with developmental disabilities and supporting them to become more engaged in directing their lives, making choices and taking up full citizenship in the community.

Our vision focuses on supporting people within the context of their family/friends to develop a unique plan for moving forward and creating a meaningful life for themselves. This plan evolves over time, out of intentional conversations that help them to clarify their vision as well as explore what it will take to really make it happen. Many of the people we support have chosen to secure individualized funding in order to build an ordinary life where they can contribute their gifts within a community context and among others.

As independent facilitators and planners of any kind, we can lose our way if we want to be seen as the instrument of change. Especially if we want to be seen as the person whose task it is to bring about change—set the course, define the goals—draw forth the vision/dream of what is possible. We lose our way if we judge our worth by the changes we are privileged to witness and be part of. We are lost if we insist on change. We cannot insist that people change—so that there is something to write about in the second quarter report.

Change does not operate that way.

Change is grueling. It takes initiative. It takes deliberate action. It requires something of us on a daily basis.

It entails pushing past our fears and engaging our will. Moving forward.

Even making little changes, requires tremendous effort the kind of effort that is sustained over time. We all know that change is hard won and that there is always the risk that we revert back to the way it was before.

As independent facilitators and planners, the system may want us to sell change—bring about change—work for change—enumerate certain changes, but we must resist the temptation to expect change. Change is a conscious decision to take a risk, to leave something behind and step into something new. It often means stepping into a new role/embracing a new identity or way of being in the world. For that to happen, for that to be rewarding and worthwhile something new needs to be activated not only within ourselves but also among the persons that love and care about us.

For years, I worked within the People First movement. I witnessed some tremendous changes in people's lives over time—transformative changes. I experienced it as ripening into change, that when people were inwardly prepared to act differently they did so. When their will got activated—they acted. This was sometimes with the support of others and sometimes alone. It was sometimes with other's blessings and sometimes against all odds. In fact, change seemed to be about taking a stand for oneself, standing up for something. It was for some a form of resistance. For this change to be possible inwardly, they needed to be emboldened, inspired by others. They needed to be witness to change, and have people who acted as models for change. They needed someone, at least one person that believed in them wholeheartedly.

I came away from the People First movement believing that we need to be careful to honour this process of "ripening into change" and not try to push or cajole people into change for the sake of change. We cannot change on behalf of another, it takes them to "will it" to happen. They must decide to act differently and willfully for themselves.

Those who take up the work of Facilitation and Planning need to be aware of the careful balance between expecting change and supporting change.

We need to be a “stand for change” and assist people to:

- declare what they need and want,
- state what has become unmanageable in their lives,
- consider various directions and possibilities,
- think differently and act boldly with courage,
- choose consciously to pursue a different storyline about what is possible in their lives.

We need to be a stand for others to remain open to discovering something new about themselves and finding their unique voice.

At the same time, we need to recognize that change has its own time. That people need many opportunities for trying change on, exploring the new situation, the new role, the new relationship, to see if it “fits” with who they believe themselves to be. People need help with scenario building at first and then support as they and their loved ones need to experiment with what the consequences to change are and whether they will be able to sustain it.

I have found that one of the most important things people need is time to practice the change in behavior or the change in role- to try it on, try it on for size. They need support for adjusting their lives while they are working toward the new possibility.

As “story beings”, we need to carefully construct a new story about ourselves over time, in such a way that we feel transformed from the inside out, so that we own the new story.

We need to recognize that personal change requires us to consider others, engage others. My change always necessitates that those around me change, adapt, reorder their pictures of what is possible, and ultimately stretch their imagination of who I am. I need people to be there for me when I stumble or if I fall. For me to sustain change I need to know that people are behind me, that they have my back. Each of us asks the same questions when we take on change. Who will be there for me? Where is the safe place for me to fall back into? Who believes in me?

When we formed Families for a Secure Future, we worked on the premise that for individuals to take on and fully embrace change, their families would also need to change. Their families would also need to embrace and take part in that change. We believed from the outset that the wellbeing of the individuals and their families/loved ones were intricately and intimately linked.

For this reason, we create Family Groups so that parents and siblings can come together to learn and grow with one another over time. So that family members in joining together can listen to one another, co-inspire one another and hold the impulse for positive change among each another. At the same time as supporting the parents and siblings to gather so that they can imagine differently we actively support the person to gather key people in their life so that there is an intentional context for supported decision making and for helping them consider stepping into change, so that there is a “place” for change.

As an organization, we understood from the outset that there is a kind of reciprocity in change. As you change, I also change. For change to be sustainable it needs to arise out of relationship, trusting relationships, where we know each other's stories and how the story has evolved over time. The kind of relationships where we tenderly hold each other's dreams and vulnerabilities while choosing to act differently. For this to be possible, independent facilitators need to acknowledge who is it that is really taking the risk to bring about change and who bears the consequences of the change. We also need to ask who defines the pace and the nature of change?

As independent facilitators, we have the privilege to stand alongside people as they change, the change that they have willfully chosen.

We bear witness to these changes. We see how these changes bring about changes in everyone who is woven into that persons' life.

We help people adjust to the newfound expectations and demands brought about by these changes and help them to consider their next steps day by day. This takes a great deal of humility on our part, to be present to this kind of ripening, ripening into change.

Standing Alongside People as they Change.

Copyright Judith McGill, Executive Director of Families for a Secure Future, Ontario, Canada [www.familiesforasecurefuture.ca](http://www.familiesforasecurefuture.ca)

Adapted from the conference report, Reflections on Common Threads: Approaches and Contexts for Planning Everyday Lives. A conference sponsored by The Ontario Independent Facilitation Network in partnership with The Individualized Funding Coalition for Ontario, April 2014

# D3ii

## Citizen-Centered Leadership: Everyone is Born 'In'

Carol Blessing, Niki Stevenson, Joanie Parker

Claiming Full Citizenship

Citizen-Centered Leadership  
*Everyone is Born IN*

16 October 2015  
The Hyatt Regency, Vancouver, BC



Cornell University  
ILR School  
Employment and Disability Institute



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*weeks*

CAN CHANGE  
*the World*

"My experience of this course has been life changing."  
Chris H., UK

[WWW.CCLDS.ORG](http://WWW.CCLDS.ORG)

### Objectives

- Understand and apply a universal concept of citizenship as a means to promoting equal access to community
- Explore the gap that exists between what we say and what we do in the name of "person-directed" support
- Understand the role person-driven work plays in resource allocation leading to valued outcomes



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### CCLD Learning Partners

- Carol Blessing – Cornell University, New York
- Joanie Parker – Heritage Christian Services, New York
- Niki Stevenson – Extend-A-Family, Ontario
- Sheldon Schwitek – Mr. Sheldon Consulting, Michigan



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### Unable to Join Us Today (but with us in spirit)



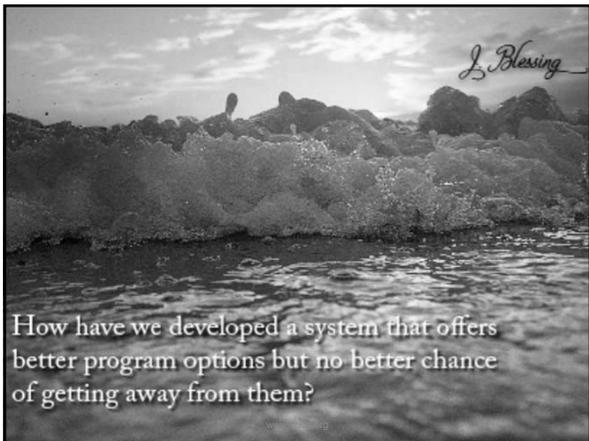
Chris Herbert  
The Hesley Group, UK



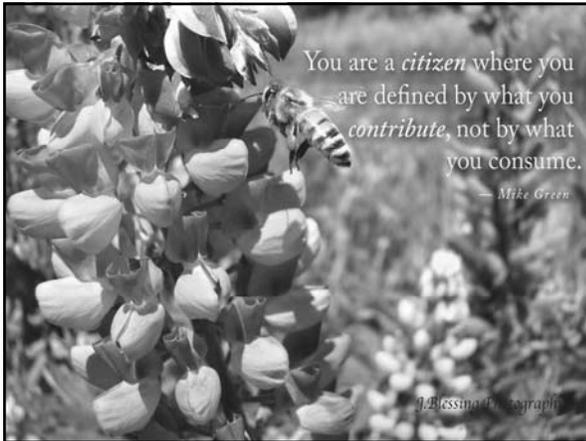
Reva Guimont  
Exceptional Parents, CA



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How have we developed a system that offers better program options but no better chance of getting away from them?



### 3 Ideals of Citizenship

- All people are created equal – that means everyone has a higher purpose that they are entitled to reach for
- There is equal opportunity to reach for this purpose
- There is responsibility to contribute, to give back to the good of society

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### Easy 3-Step Process for Brainstorming Contributions of Citizenship

1. Discover and Name the Gifts
2. Explore and Identify places where the gift will be well-received/welcome
3. Imagine and Find the valued social roles that are shaped by the gift

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### Name the Gifts

 hospitality	 advocacy	 conservation
 compassion	 curiosity	 fellowship
 leadership	 creativity	 networking

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**Closing the Gap**

What We Do 

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The space of freedom

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What We Say 

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**Tell the Truth** – Seth Godin

We don't know what you see. We have no idea what you are thinking. We need your contribution, your vision, your truth.

Yes, for a long time, for most of your life, we demanded you ask for instructions and that you comply.

We're ready now, though. Ready for you to show up and to lead us. Ready for your contribution. We are ready for you to tell us your truth.

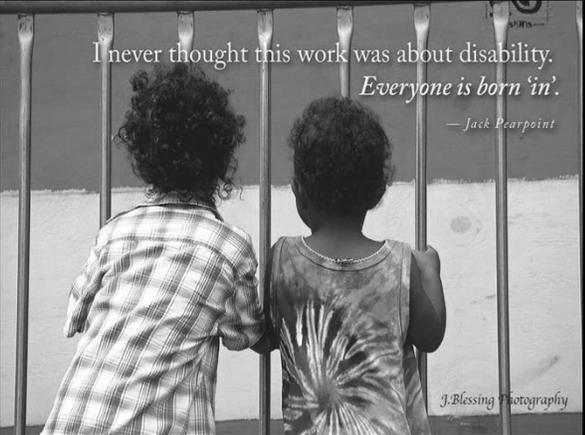
Not *the* truth, but *your* truth, the truth of the world as you see it and as you wish it to be.

From *What to Do When It's Your Turn (and it's always your turn)* [www.yourturn.link](http://www.yourturn.link)

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Cornell University 2015

I never thought this work was about disability.  
*Everyone is born 'in'.*  
— Jack Pearpoint



J. Blessing Photography

**Resources**

- Asset-Based Community Development. [www.abcdinstitute.org](http://www.abcdinstitute.org)
- Citizen-Centered Leadership International Community of Practice. [www.clds.org](http://www.clds.org)
- Community Activators. [www.communityactivators.com](http://www.communityactivators.com)
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- O'Brien, J., & Blessing, C. (2011). *Conversations on Citizenship & Person-Centered Work*. Toronto: Inclusion Press

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# D3iii

## Building a Movement to Advance Self-Determination: Michigan Partners for Freedom Local Leaders

Patricia Carver, Angela Martin

Building A Movement 1

### Building a Movement to Advance Self-Determination: Michigan Partners for Freedom Local Leaders

Learning Objectives:

1. Define the role and responsibilities of Michigan Partners for Freedom Local Leaders
2. Acquire tools and resources to build knowledge about Self-Determination
3. Learn about Michigan's Self-Determination Policy and its technical assistance guidelines for the state disability service system



Building Statewide Demand For Self-Determination

Pat Carver  
COMMUNITY DRIVE

Angela Martin  
Michigan Developmental Disabilities Council



Building A Movement 2

### Michigan Partners for Freedom

A grassroots coalition of people with disabilities, family members, advocates, service providers, Community Mental Health organizations, and allies partnering to build statewide demand for Self-Determination.





Building A Movement 3

### Principles

**F**REEDOM  
**A**UTHORITY  
**S**UPPORT  
**R**ESPONSIBILITY  
**C**ONFIRMATION

- 1: **Freedom** to craft a meaningful life in the community
- 2: **Authority** over a targeted amount of dollars
- 3: **Support** to organize resources in ways that are life-enhancing and meaningful to the individual with a disability
- 4: **Responsibility** for the wise use of public dollars and recognition of the contribution individuals with disabilities make to their communities
- 5: **Confirmation** of the important leadership that individuals with disabilities and their families must play in a newly re-designed system and support for the self-advocacy movement

Michigan Partners for Freedom [mifreedom.com](http://mifreedom.com)  
Michigan Self-Determination Peers Project

Building A Movement 4

### Where are the Local Leaders?



Local leaders are located in:

- Alpena
- Bay/Alcona
- Berrien
- Clare
- Genesee
- Kalamazoo
- Kent
- Lenawee
- Manistee-Denbie
- Oakland
- Ottawa
- Washtenaw
- Wayne

Building A Movement 5

### Local Leader Outreach

**HOW?**

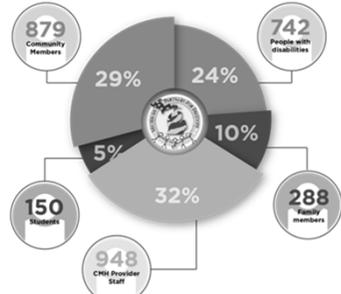
- Inform people about the tools of Self-Determination
- Educate people that they can arrange supports with the tools of Self-Determination
- Sharing stories about Self-Determination
- Making the community aware of Self-Determination

**WHO?**

- Individuals and Families who use CMH services and supports
- Student with disabilities and their families
- People in your local community
- Policymakers
- Community leaders
- Advocacy & community organizations

Building A Movement 6

### Michigan Partners for Freedom: people reached in 2014



Category	Count	Percentage
Community Members	879	29%
People with disabilities	742	24%
Students	150	5%
CMH Provider Staff	948	32%
Family members	288	10%



# D4i

## Effective Advocacy: Can We Talk to Each Other About Hard Topics?

David DeVidi

Effective Advocacy  
Can we talk to each other about hard topics?

DAVID DEVIDI  
PRESIDENT, FACILITATION WELLINGTON DUFFERIN  
CHAIR, DEPARTMENT OF PHILOSOPHY, UNIVERSITY OF WATERLOO

What's the problem?

Academic Version (as described by Heath)

- ▶ If a member of an oppressed group stakes out a position, reasonable people "in the middle" do not voice their disagreement because *they do not want to appear unsympathetic*.
- ▶ So the only criticism you hear comes from
  - ▶ People who say you're "insufficiently radical"
  - ▶ Unreasonable and unsympathetic people

What's the problem?

Consequences

- ▶ Positions and rhetoric become more radical over time
- ▶ All critics are perceived as being unreasonable or ill-motivated
  - ▶ Shaming, silencing, demonizing of critics
  - ▶ Example: 85% of Canadians, including 85% of severely disabled Canadians, support assisted suicide, given safeguards.
    - ▶ Response of activists is often a version of: supporters of assisted suicide "don't value disabled lives"
    - ▶ Are 85% of Canadians (including disabled Canadians) really this evil in their heart-of-hearts?

Why is that a problem for advocacy?

- ▶ People are often not going to tell you when they are skeptical about what you're selling
  - ▶ This includes people who control resources
- ▶ Often our rhetoric is persuasive *only to the people who are already convinced*

Step 1: Recognize the job to be done

- ▶ Remember that you have to convince your **actual audience**, not an ideal audience and not people already on side
- ▶ **Shaming** isn't the same as persuading
  - ▶ It might shut someone up, but it doesn't get her helping the cause
- ▶ Not everyone who doesn't agree yet is a bad person, so don't use rhetoric that is going to offend

Step 2: what are your reasons?

- ▶ We're often bad at this (but so are most people).
- ▶ Requires asking *hard, potentially offensive* questions:
- ▶ Examples:
  - ▶ Lots of people who think hard about these things believe that "full membership in the moral community" requires certain cognitive abilities that it's not obvious that everyone has
  - ▶ Many ordinary citizens don't understand why someone who doesn't show any sign of understanding the issues of the day should vote in elections.

We in this room think they're obviously wrong. But *they* don't think it's obvious at all. How many of us can provide strong answers to the question "why?" that don't amount to "because it's obvious"?

## Step 2: what are your reasons?

- ▶ We're only going to get the answers we need by taking these questions seriously and formulating plausible responses
- ▶ This requires disagreement, explicit discussion of other views
- ▶ We don't have much practice at this
- ▶ There will be disagreement about answers. (Not every remark can "build on" the last thing somebody said).
  - ▶ Disagreement ≠ Disrespect
- ▶ People who do raise hard questions often are treated with suspicion ... 'Are you really on our side?'

## Additional concerns when discussing issues to do with vulnerable people

- ▶ It's all very well to deal with harsh-seeming claims in the abstract, but it's hard to keep your cool when it hits close to home.
- ▶ Eva Feder Kittay---professional philosopher: "imagine being the mother ... and reading statements such as ... [examples above]"
- ▶ "Nothing about me without me"--- but
  - ▶ Do limits to understanding mean this is *nothing but* telling people that others believe things that might hurt their feelings?
  - ▶ If professional philosophers can't separate feelings from these topics, is it fair to expect it from people who have experience of being marginalized, picked on, not taken seriously?

## We need to have discussions anyway

- ▶ Kittay again: vulnerable people, those who know them best, are in a position to know things the rest of us don't
  - ▶ This isn't *magic*, mostly just *location and familiarity*
- ▶ If we advocate for autonomy, we need to ensure that the people we advocate for help drive the bus---it's part of meaning what we say

## The Challenge

- ▶ How to have the discussions productively?
  - ▶ *Take it slow*
  - ▶ *Plain language*---a lesson many academics could stand to follow
  - ▶ *Teach the lesson*: "I wouldn't bother to argue with you if I didn't respect you"
- ▶ *My fellow citizens*: people I respect enough that when I disagree with them I think it's worth trying to change their minds

## References:

- ▶ Joseph Heath, "The problem of 'me' studies," blog post from May 30, 2015, <http://induecourse.ca/the-problem-of-me-studies/>
- ▶ "Most (84%) Canadians Believe a Doctor Should be Able to Assist Someone Who is Terminally Ill and Suffering Unbearably to End Their Life," <http://www.ipsos-na.com/news-polls/pressrelease.aspx?id=6626>
- ▶ Eva Feder Kittay, "The Personal is Philosophical is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battleground," in *Cognitive Disability and its Challenge to Moral Philosophy*, Wiley-Blackwell, 2010, pp. 393-413



## Enabling Good Lives Partnership, Outcomes and Lessons

Marsha Marshall, CEO, Manawanui

Richard Buchanan, Manager, Enabling Good Lives,  
Christchurch



## Overview

- \* Roles and perspectives
- \* Successes
- \* Challenges
  - \* Host perspective
  - \* Funding perspective
- \* Your thoughts



## Roles and Perspectives

- \* Host Provider role and perspective
- \* Funding role and perspective



## Successes

- \* Real life stories
  - \* Ryan
  - \* Prue



## Ryan




## Prue

[Prue's story/](#)





## D4iii

## The Potential of Family Group Conferencing for Older Adults: The Results of a Multiple Case Study

Rosalie N Metze

### Learning objectives

1. Learn about the principles and working methods concerning the decision-making model Family Group Conferencing;
2. Gain insight in critical factors which increase the probability of positive or negative outcomes of Family Group Conferencing for older adults;
3. Learn about the influence of feeling and framing rules (Hochschild, 2008) and changing citizenship regimes (Tonkens, 2012) on the use and impact of FGC in general.

### Summary

Family Group Conferencing (FGC) is a decision-making model, mostly used in Child Care, in which individuals and their social networks make their own plan. A Dutch action group of older women thought this model might also be helpful for older adults, and initiated the implementation and monitoring of FGC in elderly care. In 2010-2012, we worked together with them and the Dutch FGC foundation to implement and study FGC for older adults.

During the implementation period, eight older adults went through the FGC process, and we were able to study their experiences. We conducted a total of 28 interviews: with each older adult (before and after the FGC), with social network members and with social workers, and we found some critical factors which seemed to determine the FGC outcomes. We divide these factors into 1) personal factors and 2) societal factors.

We start with the personal factors, determined by characteristics of the older adult him- or herself, and by the social network involved. If one or more social contacts were willing and able to interfere with compassion (Verkerk, 2001; MacKenzie, 2008) and respect for the older adults' needs and wishes (Barvosa-Carter, 2007), this seemed to have a crucial positive influence on the outcomes of the FGC. Contrastingly, if the issues were complex, partly caused by members of the social network, and related to generational poverty, they were difficult to solve with the help of a FGC. Social contacts appeared to be either unwilling or unable to offer the necessary support, and the older adults seemed to be unwilling or unable to take control of their lives. In such cases, a more extensive process of empowerment and deliberation seems to be necessary for the social network to obtain the skills to successfully take responsibility for their own problems and solutions.

To understand the influence of societal structures on FGC for older adults, we used Arlie Hochschild's theory on feeling and framing rules, and Evelien Tonkens' application of citizenship regimes to Hochschild's theory. In short, Hochschild (2008) considers emotions to be connected to the context in which people are living. People unconsciously match their emotions with what is clinically, morally, socially and contextually expected of them, which Hochschild sees as (unwritten) 'feeling rules'. Although many feeling rules are universal, the more subtle rules are determined by the way people look at the world, which Hochschild calls 'framing rules'. She distinguishes the moral, the pragmatic and the historical framework. Tonkens (2012) has supplemented Hochschild's theory with a dynamic contextual component, to better understand conflicts between feeling and framing rules and reality in a changing social context. She introduces the concept of 'citizenship regimes', which she defines as: 'The institutional arrangements, rules and understandings, and power relations that guide and shape current policy decisions, state expenditures, framing rules, feeling rules and claims-making by citizens' (2012: 201). The three main citizenship regimes which succeeded each other in the Netherlands in recent decades are 1) the community regime, 2) the welfare-recipient regime, and 3) the active citizenship regime (Tonkens, 2012). The community regime assumes that communities, and mainly the women, must provide for their needy members. In the welfare-recipient regime the focus is on professional help, and receiving professional care is seen as a right. In the active citizenship regime, which currently dominates in many Western societies, citizens are expected to arrange their own care by combining what they can do themselves with the capacities of their social network, possibly assisted by formal services.

When analysing our eight cases along the lines of these theoretical concepts, we found various conflicts between care expectations of the stakeholders, which were based on different feeling and framing rules. These conflicts are summed up in Table 1.



# D5i

## Individualized Funding in New Zealand: A Study of Financial Impact and Potential Cost Savings

Adrian Field

### Learning objectives

- To explore the profile of people using IF in New Zealand
- To explore the overall pattern of costs over time for IF in New Zealand
- To explore the costs of IF compared to non-IF use, for comparable groups of users
- To discuss implications of these findings

### Introduction

This presentation provides an exploratory quantitative analysis of the cost patterns of Individualised Funding (IF) in New Zealand. Individualised Funding is a means by which disability support funding is allocated directly to disabled individuals. IF offers families more choice and control over how to meet the needs of their personal circumstances, and offers the potential to develop their lives in a way that is self-directed rather than prescribed.

The focus of this study is on the established model of IF operating in New Zealand, which is funded within the Home and Community Support Services (HCSS) portfolio. Enhanced IF, currently being trialled in some parts of New Zealand, is excluded from this study.

The following questions are the focus of this study:

1. What are the characteristics of IF users compared to people in non-IF situations?
2. How has funding for IF changed over time, and how does this compare with non-IF spending?
3. To what extent does IF contain disability services costs compared to non-IF situations?

### Data sources

This report is substantially based on a detailed analysis of entries in the Ministry of Health's Socrates database, and validated against records from the client management system of Manawanui InCharge (MIC). The Socrates database offers an extensive record of interactions between disabled people and disability support services, and the allocated expenditure to meet people's needs; it is not however designed for this type of analysis and the records required considerable filtering and recalibrating to enable this analysis to occur. In addition, the estimated costs were derived from applying an allocation/spend ratio of 85%; this is a conservative assumption and MIC's own data indicates a ratio of 81%, therefore the actual costs may be lower than the estimated costs.

A key challenge of this research was identifying comparable groups of IF users and non-IF users, given the variation in levels of need within support package allocation categories. The research has focused on a core group of complex users with high levels of HCSS allocations.

These findings should therefore be seen as indicative and exploratory, and are best viewed as a means of assessing cost management, rather than specifying the actual costs themselves.

### Findings

#### People using IF

- IF users tend to be younger than people in non-IF situations, and have more complex care needs.

#### Costs of IF

- Use of IF has increased markedly over the five years from 2009 to 2014. The increased uptake of IF has resulted in an increase in total IF spending from \$10 million in 2009/10, to \$39 million in 2013/14.
- Total non-IF HCSS spending has fluctuated over this time, ranging between \$88 million to \$98 million.
- IF costs per user (in the school leaver to 65 years age group, which was the focus of this study) declined from 2009/10 to 2013/14, from \$28,035 per annum to \$20,212; a decline of 28%. This was driven by the growth in IF spend being lower than the growth in IF users. This may indicate some degree of controlling costs.



Figures 1&2: Indexed average allocations – HCSS only (school leavers to 65 years)

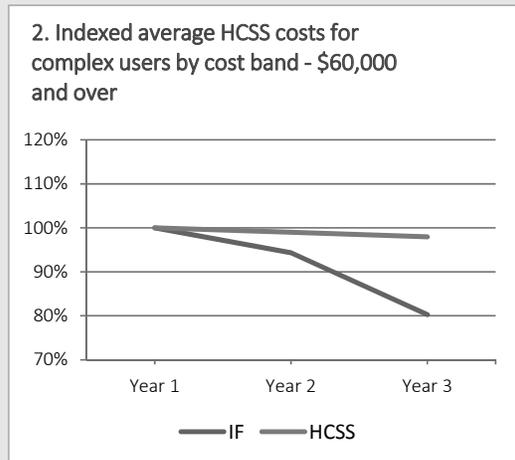
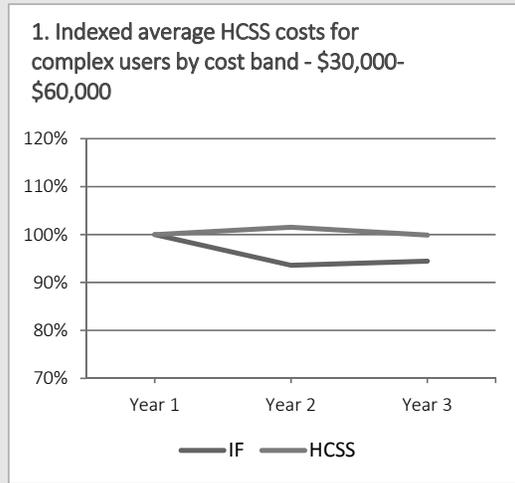
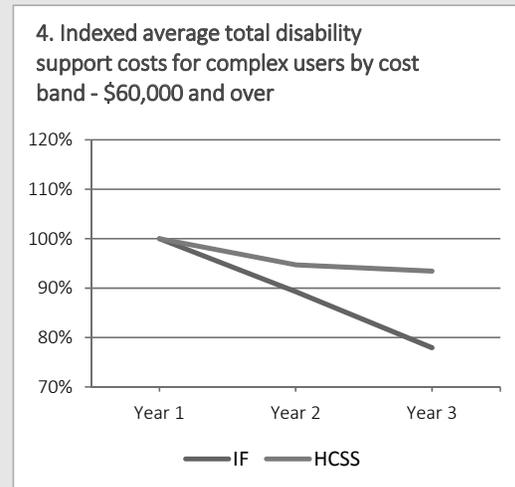
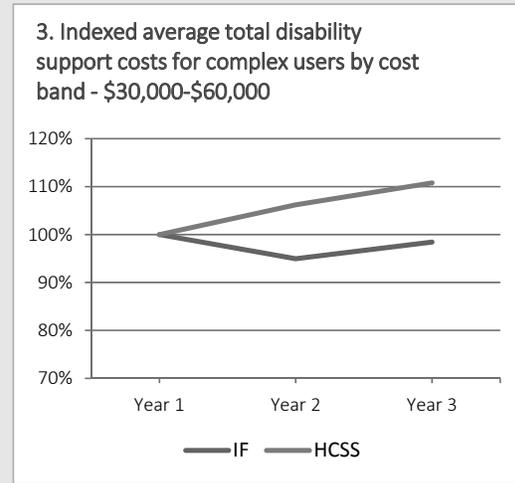
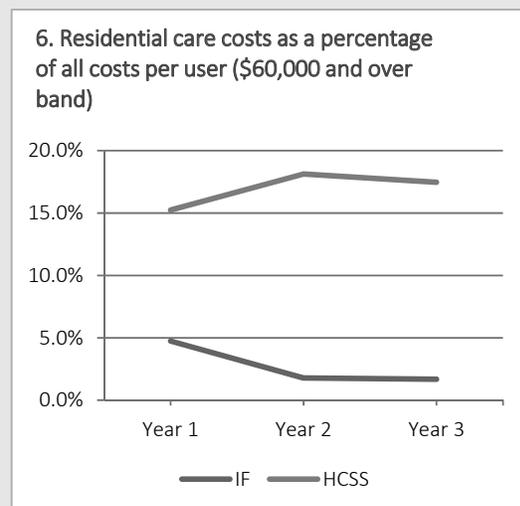
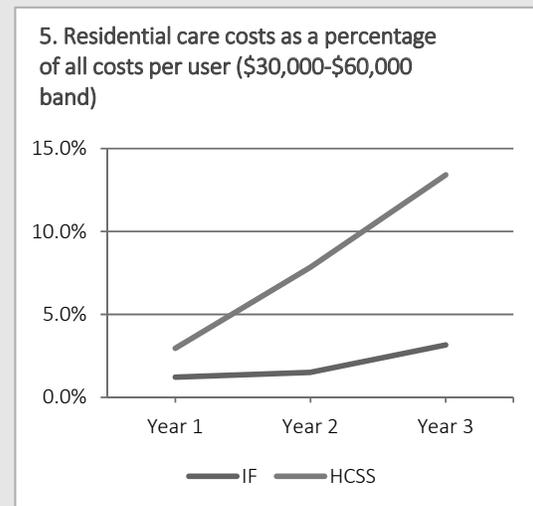


Figure 3&4: Indexed average allocations – total disability support (school leavers to 65 years)



Figures 5&6: Residential care costs as a percentage of all costs per user



# D5ii

## Peer Supports and Self-Managed Funding: Developing Local Peer Networks Across Australia

Robbi Williams

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### Abstract

Australia has commenced a major social reform in disability funding and support, at the heart of which is Individualised Funding. Among other sector developments in support of this change, the Australian Government has commissioned an initiative to develop local peer support networks across Australia, coordinated by an independent not-for-profit agency.

This presentation examines progress in the first year of the initiative, in particular the extent a Communities of Practice model, supplemented by a body of online information resources, can contribute to the momentum for peer support networks.

This work is anchored on methodological elements taken from Participative Action Research.

Critically, the work examines the early impact of local peer support networks on people's decisions about Individualised Funding, including the extent of take-up of self-managed funding options be it individually or family governed, or through third party mechanisms such as user-led organisations or microboards.

The work also examines how the nature of peer support networks might change depending on whether people are living in metropolitan, rural or remote areas.

Given the overall goal of creating momentum leading to a 1000 peer support networks across Australia, this presentation examines early findings on the interplay between a formal coordinated approach and local grassroots development.

### Learning Objectives

With the goal of supporting participants to consider the extent of their own practice/involvement in peer support networks, conference participants will learn about what happened in the first year of an initiative to build a nationwide network of peer support networks. This will include what elements of community development best supported the emergence and sustainability of peer support networks, the extent to which nationally coordinated communities of practice helped same, and the extent to which peer support networks developed in these ways can help people with their decisions about Individualised Funding, including taking up self-management options.

### Synopsis

This presentation talks about work building peer support networks across Australia. The project helps different communities (called Communities of Practice) talk and learn from each other's stories. The project gave information to help people talk about their decisions. The presenters talk about what happened and if people said it helped them.

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# D5iii

## Establishing Individualized Support Budgets for People with Intellectual and Other Developmental Disabilities

John Agosta, Jami Petner-Arrey, Alena M Vazquez



Human Services Research Institute

### Establishing Individualized Support Budgets for People with Intellectual & Other Developmental Disabilities

Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding  
2015 International Conference

October 15 - October 17

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Establishing Individualized Supports Budgets 2

### Today's Agenda

- What We Believe & the Challenges Ahead
- Typical Scope of Work
  - General approach
  - Primary Tasks Timeline
- Focus on Primary Tasks
- Questions & Discussion



Establishing Individualized Supports Budgets 3

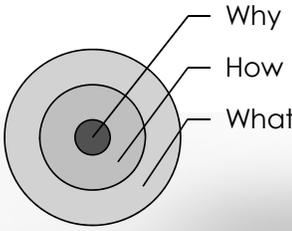
### What We Believe

One question to ask...

Why are we doing this?

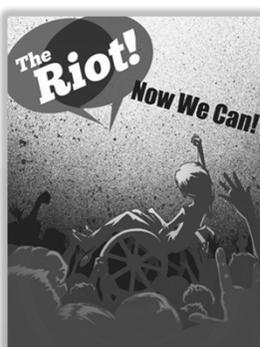



Establishing Individualized Supports Budgets 4





Establishing Individualized Supports Budgets 5



### Framing: The BIG IDEA

We believe that people with intellectual & developmental disabilities have the **right** to live, love, work, play, and pursue their life aspirations just as others do in their community **with** the support they need.



Establishing Individualized Supports Budgets 6

### Framing: Secondary Themes

Integration, Shared responsibility, Fair Jobs, Contribution, Community, Sustainability, Personal responsibility, Mutual support, Accountability

A person-centered & community-oriented approach to deliver services for people with IDD emphasizes:

- People with IDD be in **charge** of their lives as much as possible.
- People with IDD have opportunities to use resources in ways that **enhance** their lives & help them **participate** in their communities.
- **Shared** responsibility for the wise use of public dollars & the **contribution** that people with IDD & their families can make.
- The system is managed in a way that is efficient & fair to **everyone**.

Establishing Individualized Supports Budgets 7

### Framing: Issues to Resolve

<b>Wait List</b>	<b>Risk aversion &amp; need for creativity</b>	<b>"Meaningful Life"</b>
<b>Medicalization of services</b>	<b>Employment</b>	<b>Self-direction, or not</b>
<b>Paperwork &amp; regulatory burdens</b>	<b>Peer support</b>	<b>Supports budgets</b>
	<b>Family members as staff</b>	<b>Reimbursement rates</b>

Establishing Individualized Supports Budgets 8

### State of the Field: A Lot to Consider

Enduring demands: community integration & self direction

Fiscal pressures

Increasing demand for services

Workforce factors

The way things are

→ **Policy Decisions**

Establishing Individualized Supports Budgets 9

### We Face a **Big** Problem...

**Increasing Service Demand**

**Wait List**

**Resources**

Establishing Individualized Supports Budgets 10

### Reliance on Founding Systems: A Living Museum

Can this be efficient?

Group Homes, Family Support, Apartments, Public Institutions, Supported Work, ICFs-DD, Day Habilitation, Customized Employment, Sheltered Work, Token Economies, IEP, ISP, IHP, IWRP, IFSP, IPP, Supported Living, Self-determination

1956... 1962... 1972 ... 1976... 1983... 1987... 1992... 1997... 2004... 2008... 2015

Establishing Individualized Supports Budgets 12

**Rebecca Cokley**  
Executive Director  
US National Council on Disability

*"Thank you for everything that you've done, for all the services that there are, but what you built, we don't want."*

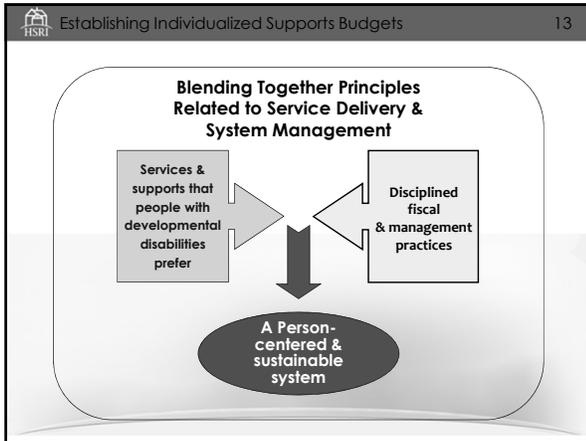
Establishing Individualized Supports Budgets 13

### What To Do???

We can't stay on this spot →

**RETHINK**

We need to rethink what we do – affirm our values but resolutely search for value



Establishing Individualized Supports Budgets 14

### The General Approach

- The general approach
- Supports Intensity Scale
- Assessment Levels
- Building Supports Budgets
- Looking Things Over

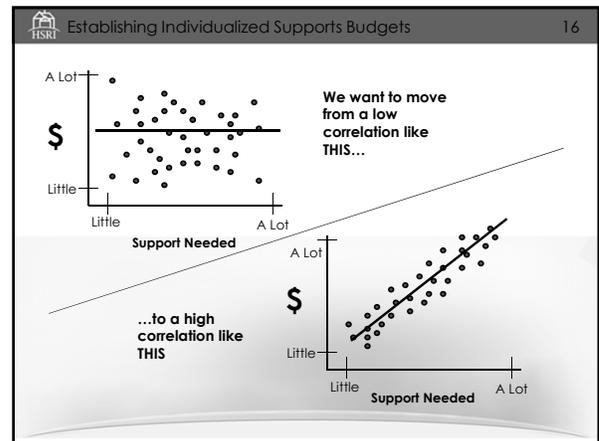
Establishing Individualized Supports Budgets 15

### General Approach

**An assessment** is used to assist with establishing individualized budgets. This also provides a way for policy makers to make fiscal choices that are **fair & predictable**, but also makes the **best use** of available money that's consistent with driving system **principles**.

**Allocating resources** to people based on their assessed level of need. Each person receives **what they need**.

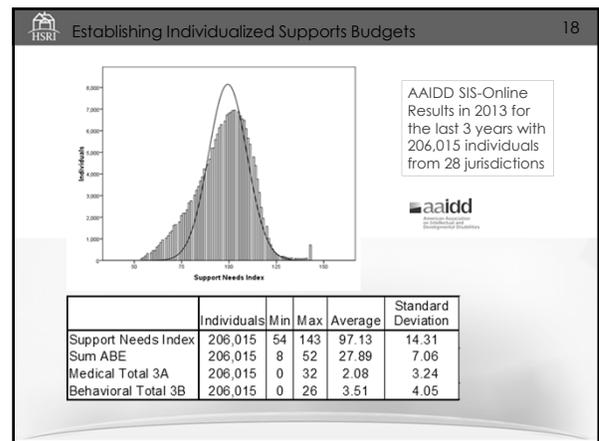
**Establishing a best fit** solution for most but taking care to accommodate individuals with extraordinary needs.



Establishing Individualized Supports Budgets 17

### Supports Intensity Scale

- Administration: Interview the person and others who know the person. Requires solid interviewing skills
- Measures general support needs of an individual producing a number of scores
- Includes basic support need areas like:
  - A. Home Living Activities,
  - B. Community Living Activities,
  - C. Lifelong Learning Activities
  - D. Employment Activities
  - E. Health and Safety Activities
  - F. Social Activities
- SIS ABE – refers to the sum of the scores for these 3 areas that have been found useful in helping resource allocation
- Identifies Medical and Behavior problems which are also significant cost predictors

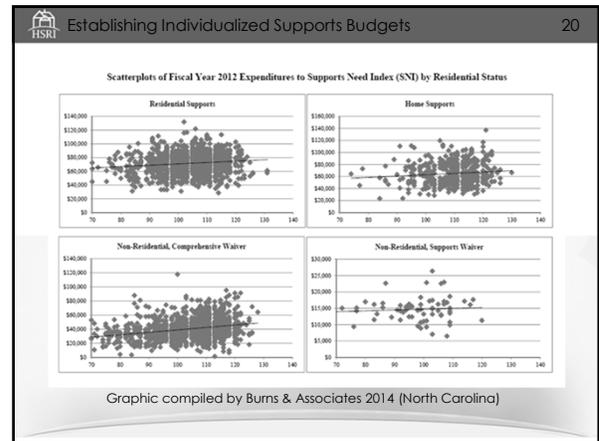


Establishing Individualized Supports Budgets 19

### Comparison Across States

	Number of Individuals	Supports Need Index	Sum of Part A, B, and E	Medical Need Score	Behavioral Need Score
SIS Norm	1,306	100.00	30.00	3.23	4.99
Tennessee *	<b>5,765</b>	<b>102.67</b>	<b>30.36</b>	<b>1.45</b>	<b>2.87</b>
Virginia	1,275	102.82**	30.16**	1.96**	2.64**
Oregon *	5,119	106.33	31.62	1.99	5.06
New Mexico *	3,218	106.31	31.75	3.13	4.82
Utah	4,114	102.15	30.09	2.22	4.09
Rhode Island	3,007	101.75	29.72	2.02	4.19
Kentucky *	3,476	99.76	28.93	1.92	4.28
Georgia	10,574	99.40	28.62	1.39	2.69
Maine *	2,324	98.71	28.35	2.04	4.64
Louisiana *	4,091	98.23	29.95	3.33	3.10
Colorado	6,849	97.49	27.91	2.99	5.55

\* States with partial population for HCBS population \*\*Weighted for entire HCBS population.



Establishing Individualized Supports Budgets 21

### Building a Framework for Service Needs

Policy makers may be introducing new services & rates with different expectations about service use.

Nearly all jurisdictions decide on a level-based framework.

Levels must account for a range of support needs, but also categorical needs.

Very often, a model needs to be "imposed" on a system.

Establishing Individualized Supports Budgets 22

### Developing Levels & Budgets

Sample   Assess & Levels   Residence   Services & Rates   Service Packages   Validate

1. Design a random stratified **sample** for each targeted subpopulation.
2. **Assess** needs using the Supports Intensity Scale (SIS) & assign individuals to **Levels**.
3. Consider **where** people live.
4. Settle on the **service array** & reimbursement **rates**.

Establishing Individualized Supports Budgets 23

### How Levels and Budgets are Developed

4. Build **service packages** by level based on common supports needs and living situation.
  - Base budgets include in home, residential and employment or day services.
  - Some services are managed outside the base, including professional or non-recurring supports.
  - Utilization of services by level is anticipated
  - Service packages are priced by level to establish individualized budgets. Revise as needed.
  - Individuals are not tied to anticipated utilization patterns. Supports budgeting does not limit person-centered choices, but does impose a budgetary cap.
6. Systematically **validate** the service packages and make revisions as needed.

Establishing Individualized Supports Budgets 24

### Looking Things Over

Access	Getting a Budget	Service Planning	Service Delivery	Quality Monitoring
Eligibility	SIS Interview Share SIS Results	The Budget & Service Packages	Arranging for Service Delivery	Voicing Complaints
Understanding the Process	Set Level Assignment Set Supports Budget Inform People of Their Level & Budget	Personal Preferences Exceptions Creating a Service Plan	Service Delivery Paying for Services	Monitoring Making Changes

Supporting Policies, Rules & Regulations and Communication

Establishing Individualized Supports Budgets 25

**Assess & Levels** Focus on Assessment & Levels

Assess needs using the Supports Intensity Scale (SIS) & assign individuals to **Levels**.

1 2 3 4 5 6 7  
Low Support Needs High

"3" – Modest support needs and some behavioral challenges  
"6" – Significant medical support needs  
"7" – Significant behavioral challenges

Establishing Individualized Supports Budgets 26

Seven Level Model

Potential "Add On" Services

Budget Allocation

\$

1 2 3 4 5 6 7  
Low Support Needs High

Base Budgets Per Category

Establishing Individualized Supports Budgets 27

**Services & Rates** Focus on service array & reimbursement rates

Settle on the **service array** & reimbursement **rates**.

<b>Example Base Budget Services</b>	<b>Example Add-On Budget Services</b>
<ul style="list-style-type: none"> <li>▪ Residential services</li> <li>▪ Supported living/ Shared living</li> <li>▪ Day supports</li> <li>▪ Employment services</li> <li>▪ Nursing services</li> <li>▪ Personal assistance</li> <li>▪ In-home (family) services</li> <li>▪ Respite support</li> </ul>	<ul style="list-style-type: none"> <li>▪ Transportation</li> <li>▪ Crisis services</li> <li>▪ Specialized consultation services or therapies</li> <li>▪ Environmental accessibility</li> <li>▪ Assistive technology</li> <li>▪ Nutrition services</li> </ul>

Establishing Individualized Supports Budgets 28

Person centered planning is essential

- **SIS** results may be used to **guide** service planning but not necessarily to drive planning.
- **The** SIS interview may push participants to **discuss** topics they might not ordinarily talk about.
- **Valuable** personal or habilitation goals may lay **outside** the bounds of the SIS interview.
- **Use** conversational & other means to develop **person-centered** plans.

Establishing Individualized Supports Budgets 29

What is needed

- An understanding of future goals for the system.
- Accurate and reliable assessments of the support needs of people served.
- Knowledge of the services individuals can access and the amount of utilization
- Agreement on what the state is willing to pay for services.

Support Needs ↔ Services, Utilization, Rates

Individualized Budgets

With this information, individualized supports budgets can be formed.

Establishing Individualized Supports Budgets 30

**Concluding Remarks & Discussion**

"The final act in performing a creative act is letting go. ... As we create new support practice, the proverbial beast is provoked. We are knocked off our centers as we move into unknown territory without the anchor of our legacy services. This requires... as Rebecca Chan says, [that we] Dance with our Dragons."

Hanns Meissner, *Blue Space*, p. 146

# D6i

## Intensive Individual Wrap Around Services: "One Child at a Time"

Jenny Hoskin-Wyber



**Welcome**

CCS disability action  
Including all people

TE HUNGA HAIA MAURI MO NGA TANGATA KATOA

**Karakia Timatatanga  
A Prayer To Begin With**

*Hutia te rito o te harakeke,  
Kei whea te komako e ko ki mai ki ahau;  
He aha te mea nui o te Ao?  
Ma ku e ko atu, he tangata, he tangata,  
he tangata*

**Overview**

CCS disability action  
Including all people

TE HUNGA HAIA MAURI MO NGA TANGATA KATOA

- Background on a new way of working
- How a rights-based approach can encourage a different way of working.
- The impact of putting the voice of our most marginalised children first.
- How we defined our role in families' lives.
- Q&A

**A Leap of Faith**

CCS disability action  
Including all people

TE HUNGA HAIA MAURI MO NGA TANGATA KATOA

- Ministry of Health (MoH).
- CCS Disability Action.
- More importantly children, young people and their family/whanua.

**Shifting the Focus**

CCS disability action  
Including all people

TE HUNGA HAIA MAURI MO NGA TANGATA KATOA

- Applying the Guiding Principles on the Rights of the Child.
- Recognising that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children.

**Putting Children First:  
Investing Time Early On**

CCS disability action  
Including all people

TE HUNGA HAIA MAURI MO NGA TANGATA KATOA

To support children and young people, first we must hear what they have to say and understand their experience.

OurMuddyBoots.com

**A Partnership Approach**

CCS disability action  
Including all people  
TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

**Let's Talk**

Our role involved:

- Working with families to figure out what support they needed right now and in the future.
- Creating a relationship where it was ok for families to challenge us as providers.
- Create openness and transparency on how we delivered all aspects of the support.

**Assessing the Detail**

CCS disability action  
Including all people  
TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

- Defining the roles of everyone in a child's life to achieve the outcomes the child and their family have identified.
- Where do we fit and how can others support families' goals?



**What We've Learnt**

CCS disability action  
Including all people  
TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

- Time invested is time well spent.
- Children and young people and their families are the real experts in their lives – not us.
- Sometimes it's hard work!



**Why It's Worth It**

CCS disability action  
Including all people  
TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

- Building capacity in families and communities.
- Working together creates innovative solutions to common problems.
- Children and young people are where they belong – in families.



**Thank You**

CCS disability action  
Including all people  
TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

Any Questions?



# D6ii

## We Are Better Together: Celebrating the Creativity, Capacity, and Diversity of Young Adults with Complex Physical DisAbilities!

Brenda MacLauchlan, Rhea Boysen



**ASTONISHED!**  
BETTER TOGETHER

**We Are Better Together**

Celebrating Creativity, Capacity, and  
Diversity of Young Adults with  
Complex Physical DisAbilities

**Astonished!** *a grassroots, user-led, charitable organization*

We work towards inclusive community where young adults with complex physical disAbilities can share their dreams, explore their strengths, and lead others to a more authentically inclusive society.

We focus our efforts to address barriers so young adults with complex physical disAbilities can engage in teaching and learning, experience social/recreational/cultural events, and develop opportunities for accessible employment.

Over 30 adults with complex physical disabilities make up our 'Core Membership' and represent Astonished!

**Presenters:**  
Brenda MacLauchlan, Parent and AI Communication Coordinator  
Rhea Boysen, AI Interim Manager

The Big Sky Centre for Learning and Being Astonished Inc.  
[www.beingastonished.com](http://www.beingastonished.com)

**To inform participants on how we:**

- ❖ developed/maintain our promise to be a user-led organization
- ❖ infuse inclusive community throughout an academic institution
- ❖ situate ourselves as active participants in research
- ❖ use person-centered planning to guide everything we do

**Astonished! currently offers four programs:**

1. The Astonished! Teaching and Learning Centre
2. The Astonished! Social Club
3. Summer Literacy Program
4. Path to Future Endeavors

Video

*How we developed/maintain our promise to be a user-led organization*

- The original idea of Astonished!
- AI Social Club Leadership Team
- AI Program Advisory Committee
- AI Annual General Meeting
- Dignified Space
- Funding Implications

*How we infuse inclusive community throughout an academic institution*

- Leadership that establishes culture
- Memorandum of Understanding
- U of R working group
- Student Researchers
- Mentoring U of R students
- Guest presenters in classes

***How we infuse inclusive community throughout an academic institution*** continued

- Using classrooms throughout the campus
- Practicum Students
- Student Volunteers
- Research Projects
- Inclusive Theatre Class
- Pub and Coffee Shop
- Accessible Campus

***How we situate ourselves as active participants in research***

- PATH (Planning alternative tomorrows with hope)
- Strengths perspective
- Self-directed research
- Research partners
- Research experts

***How we use person-centered planning to guide everything we do***

- Strengths, dreams, and needs process
- PATH (Planning alternative tomorrows with hope)
- Student Researcher Companions
- Individualized Funding
- National Film Board Media Clinic

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**D6iii****Self-determination and Positive Psychology: A Model for Guidance of Practice**

Lisa Woudzia

**Presentation Summary:**

Research in the field of positive psychology tells us that a life of well-being consists of a number of elements which include: positive emotions, engagement, positive relationships, meaning, and achievement. This, I will argue, implies that to live a life of well-being, self-determination is a necessary prerequisite.

None of us is fully autonomous, but the degree to which one has this freedom corresponds with the degree to which one may experience the elements of well-being in their lives. This means that we may not, even if we believe it is in their best interest, impose our values on others, at least when it comes to decisions related to the elements of well-being. I will argue that most planning and support decisions can be related to these elements and that therefore these elements can serve a very useful purpose in terms of guiding general decision making in the pursuit of well-being for ourselves and others. In addition to guiding decision making, adopting the elements as a heuristic also works to ensure that self-determination is respected and guaranteed.

**Learning outcomes for this presentation are for the learner to:**

1. Understand the elements of a life of well being
2. Understand the logic of using the elements of well-being as a heuristic in decision making, including that doing so requires respecting self-determination
3. Understand the process of using the elements of well-being in decision making

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# D8

## Design Principles for a Global Movement

Simon J Duffy

### Design Principles for a Global Movement

Dr Simon J Duffy of The Centre for Welfare Reform



Concurrent Session D8: 90-minute Workshop  
Friday, October 16, 2015, 2:00 pm - 3:30 pm

### Proceed with caution...

What I am going to say may sound critical. But it aims to be both self-critical and constructive. We are probably at a natural stage when we can build on the achievements of the past and go further.



### Proceed with caution...

I'm using "**self-directed support**" as the name for the central innovation that we are interested in. Partly because this is what we agreed to do at a European level. However, this may be the 'wrong' term, especially if we decide to cast the net of our interest more broadly. So, for the purpose of this discussion treat it as a **working variable** - an "**X**" - which we can replace with a better term later on as we clarify our purpose.

1. There has been a powerful international trend towards advancing self-directed support - but it's been **desperately slow**.
2. There is a **confusing array of terms** and lively debates, but a lack of consistent pressure on Governments or mobilisation of popular support.
3. We are often divided by 'a priori' (non empirical) debates about **the perfect model**.
4. We could form an **international group** that helped define terms and good practice - a framework for innovation.

**Part 1** - Design principles for self-directed support

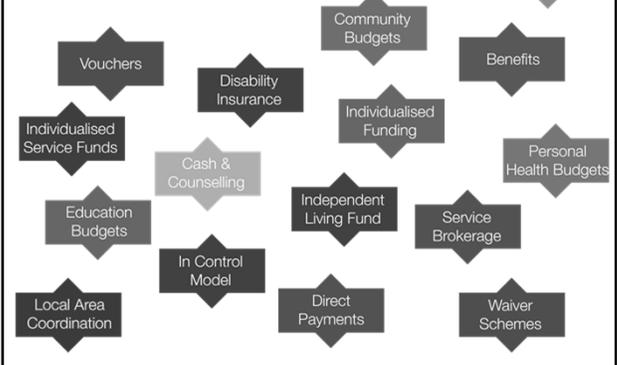
**Part 2** - Building a global movement for change

## 1. Design Principles

Self-directed support has been developing for at least 50 years. However progress has been slow and patchy.

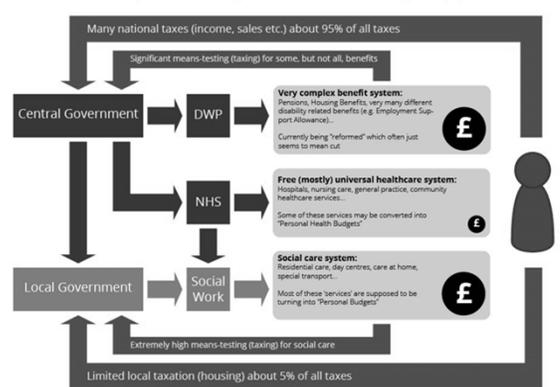


There are many systems of self-directed support...



and the context for such reforms is complex and varies from country to country...

The UK's peculiar system of disability support

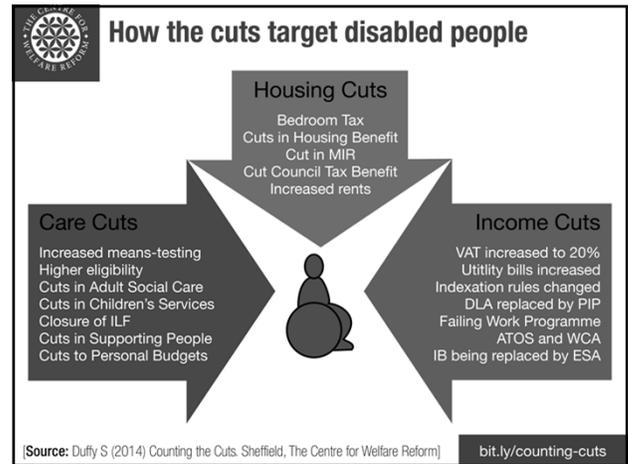
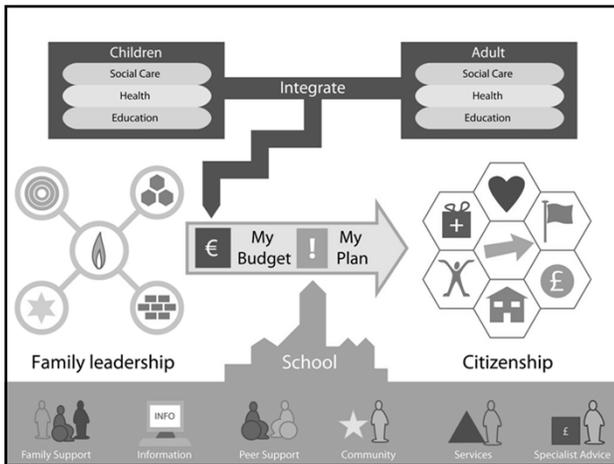


### Self-Directed Support in England

- 1970s **indirect payments** to people
- 1988 - **ILF v1** (high demand)
- 1993 - **ILF v2** (linked to local gov.)
- 1996 - **Direct Payments** (steady growth)
- 2007 - **Personal Budgets** (major policy shift)
- 2009 - **healthcare**
- 2011 - **children with disabilities**
- 2010 - **austerity**

- 1948 - Creation of NHS & National Assistance Act
- 1970s - More than 50 different Disability Benefits (DABs)
- 1980 - Road & Lodging (for residential care) entitlement
- 1988 - NI created (revised 1993 - DWP lead)
- 1992 - Community Care Act shifts responsibility to LA - DfH lead
- 1996 - Disabled Facilities Grant delivered through DfG
- 2003 - Supporting People delivered through DfG
- 2007 - Putting People First: personalisation through local government

today the UK has made progress in some areas, while going backwards in others

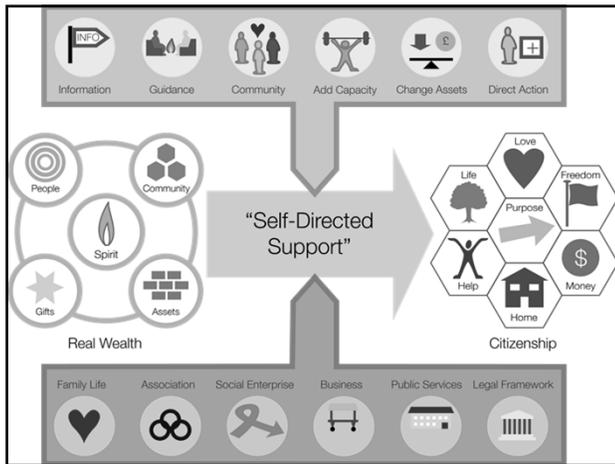


There are many disagreements about how best to organise and implement self-directed support.

1. National system vs. Local systems
2. Funding as entitlements vs. State or professional gift
3. Systems for services vs. Community-focused
4. Safety a critical concern vs. Flexible funding
5. Prevention primary focus vs. Eligibility restricted
6. Brokered system vs. Open system
7. Disability-only vs. Wider scope
8. Free (tax-funded) vs. Means-tested (double taxed)

Let's stand back and not dive into these debates

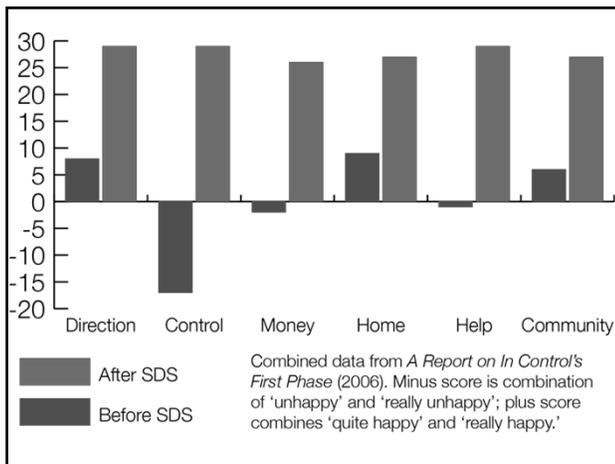
Let's try and specify the system from a distance...



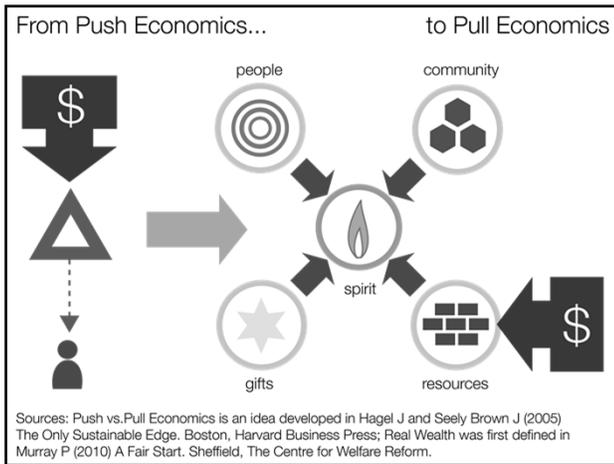
Self-directed support is a system (set of rules) developed by a community to help people to fulfil their citizenship.

What properties would such a system have?

**Primarily** it must be effective - and this would be seen in the quality of the outcomes.

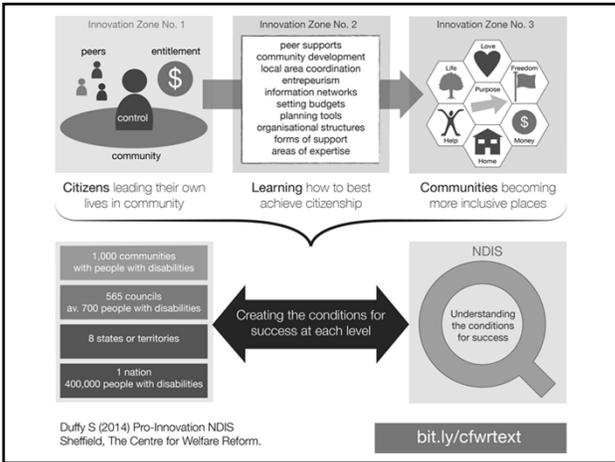


**Secondly** the system is likely to have properties that would be consistent with citizenship.



If something like this is going on at the level of the individual then an effective system might have some of the following properties...

1. **Rights-based** - provides secure foundations
2. **Person-centred** - the right person(s) is in control
3. **Clear** - transparent and easy to understand
4. **Flexible** - high in options
5. **Easy to use** - low in burdens
6. **Community-focused** - encourages connectivity
7. **Sustainable** - supported by the whole community
8. **Innovative** - develops and improves



# Exercise One

Treating this framework as **Version 1.0** (i.e. to be improved) think about the best version of self-directed support in your own community (country or region) and then complete the following card (work in teams if possible).

1. Country or region	
2. Name of system	
3. Who is system for?	
4. Does it provide strong <b>rights</b> ?	
5. Does it put people in <b>control</b> ?	
6. Is it <b>clear</b> and easy to understand?	
7. Does it give people lots of <b>options</b> ?	
8. Is it <b>easy</b> to use and manage?	
9. Does it aid <b>community</b> connections?	
10. Is it backed by <b>public</b> support?	
11. Does it learn, <b>innovate</b> and improve?	
12. Overall are people achieving <b>citizenship</b> ?	

## Exercise Two

**In groups discuss:**

- How can you improve on version 1 of the principles?
- Which terms do you prefer for self-directed support or its element?

**Provide feedback...**

## 2. A Global Movement

On our journey we have faced many challenges

- **Vested-interests** are often capable of adapting to new ideas without making meaningful change.
- It is all too easy for good ideas to be turned into **panaceas**.
- Public sector implementation is often insensitive to the need for on-going organic innovation and **simplification**.
- Academic debate is very often too **abstract** (good vs. bad) and ignores 'the devil in the detail'.
- Our goal, **citizenship**, is poorly understood and often replaced with less meaningful goals.
- We are prone to forget that systems are merely **frameworks for citizen action** - there best impacts are merely facilitative.
- Natural allies are often **divided** in the battle for state support.

Here is one way of  
envisioning the challenge  
before us...

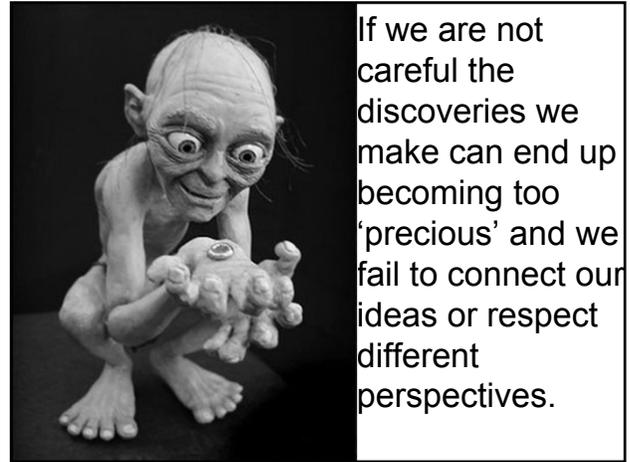
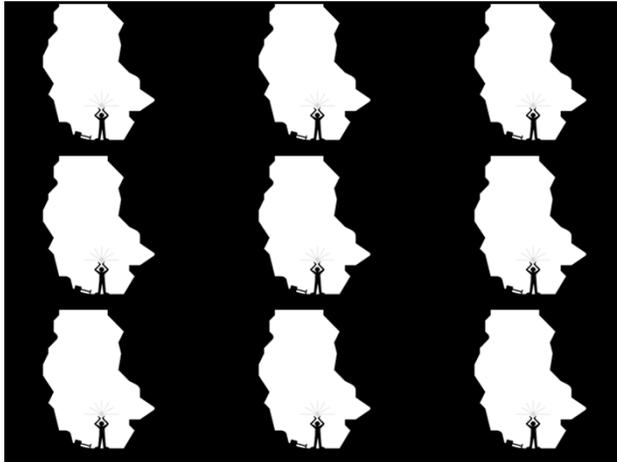
The discovery of self-directed support emerged out of the battle to end institutionalisation. This means our starting point was far from ideal and our perspective on good practice is necessarily limited. We are like people who have only just stopped digging a great big hole for ourselves.



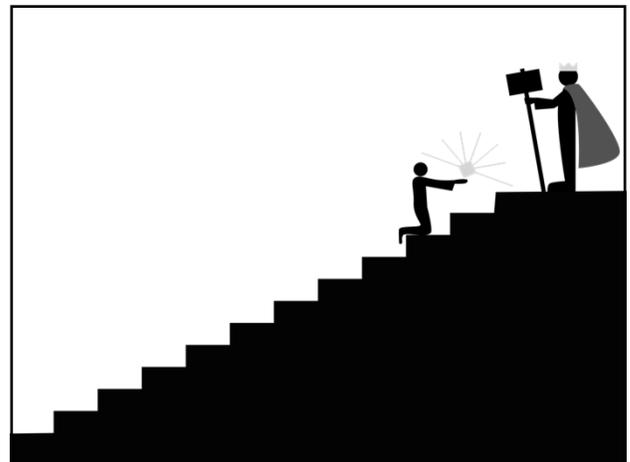
However in this hole we have often discovered insights or created innovations which can help us advance citizenship.



But we are each separated by our own organisation, community, region or country and by natural differences in perspective that flow from our thinking and experience.

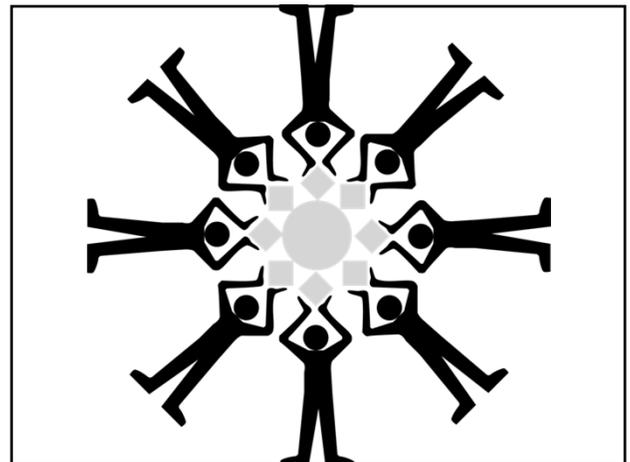


We can also find ourselves having to offer our innovations to the 'powerful' despite knowing that this will often lead to distortions and poor implementation.



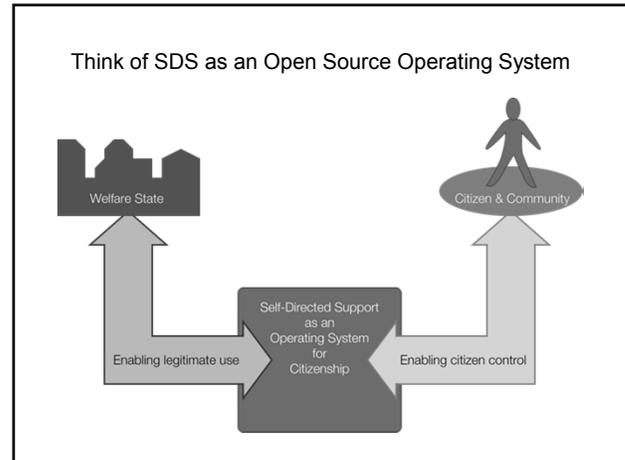
**Could we act differently?**

Could we organise our collective intelligence and our communities into a **global movement** for citizenship and justice?



**Could we act differently?**

Could we better respect the diverse efforts to find the best solution in the context of local constraints.



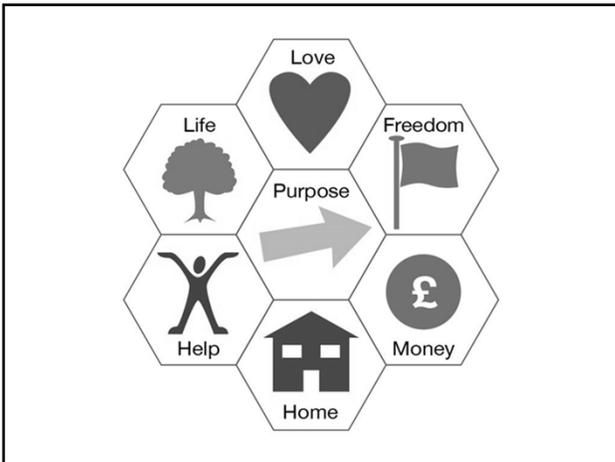
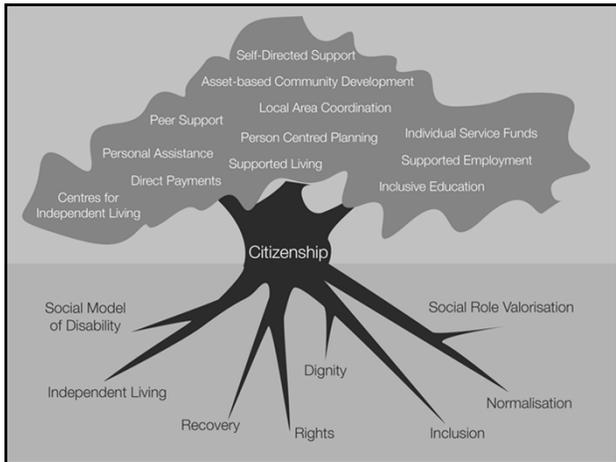
Things to think about

1. The design must be measured by the **goal**. Do we need to define **citizenship**?
2. Innovation is **dynamic** and context dependent. How can we best respect difference?
3. Not everything can be figured out in advance. How can we better respect the **evidence**?
4. Citizenship cannot be gifted. How can we work with **communities** to build the case for change?
5. How we achieve our ends should be consistent with our ends. How can we **behave like citizens**?

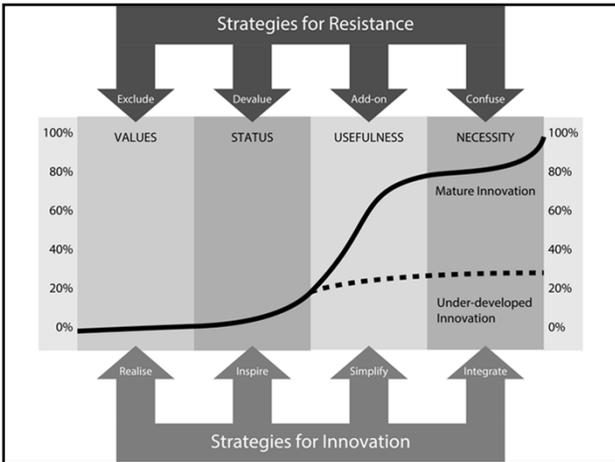
1. Designing with purpose

“**Design** is a funny word. Some people think design means how it looks. But of course, if you dig deeper, it's really how it works. The design of the Mac wasn't what it looked like, although that was part of it. Primarily, it was how it worked. To design something really well, you have to get it. You have to really get what it's all about. It takes a passionate commitment to really **thoroughly understand something**, chew it up, not just quickly swallow it. Most people don't take the time to do that.”

Steve Jobs



## 2. Respecting the innovation process



“That’s been one of my mantras — focus and simplicity. Simple can be harder than complex: **You have to work hard to get your thinking clean to make it simple.** But it’s worth it in the end because once you get there, you can move mountains.”

Steve Jobs

## 3. Learning from the evidence

“For every complicated problem, there is a solution that is simple, direct, understandable and **wrong.**”

H L Mencken

## 4. Building alliances

“We are obliged to surrender to **the will of the strong.** Big companies, cities and municipalities decide what is best for us. This is about power. Why do I feel a **lack of power** in my own life?”



Sami Helle at European Parliament, November 2013

## 5. Working together

Do without doing.  
Act without action.  
Savour the flavourless.  
Treat the small as large,  
the few as many.

Meet injury  
with the power of goodness.

Study the hard while it's easy.  
Do big things while they're small.  
The hardest jobs in the world start out easy,  
the great affairs of the world start small.

Lao Tzu - Tao Te Ching

So the wise soul,  
by never dealing with great things,  
gets great things done.

Now since taking things too lightly makes them worthless,  
and taking things too easy makes them hard,  
the wise soul,  
by treating the easy as hard,  
doesn't find anything hard.

## Exercise Three

## For discussion in groups

- Anybody here up for being part of this?
- Which organisations might be good allies?
- Are there current initiatives we could build on?
- What would be some good practical first steps?

## Feedback

## For more information:

- [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)
- @simonjduffy and @CforWR
- [simon@centreforwelfarereform.org](mailto:simon@centreforwelfarereform.org)
- [www.facebook.com/centreforwelfarereform](http://www.facebook.com/centreforwelfarereform)



## Learning objectives

- Be more aware of the range of possible design principles for self-directed support
- Be able to define some of the competing goals of self-directed support
- Agree on the best language or clarified language options for system design
- Agree or clarify some of the competing design principles for a good system
- Be more aware of the role of innovation principles in the design process

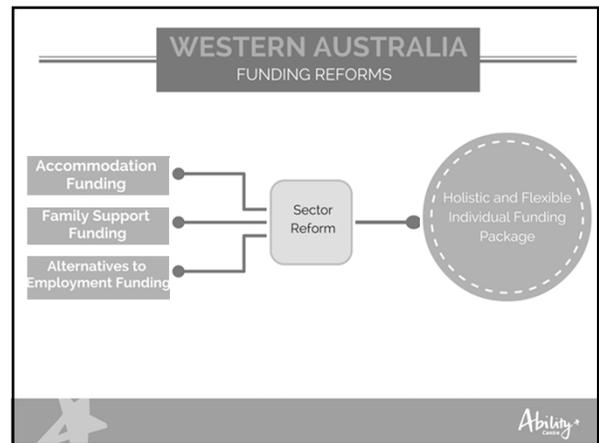
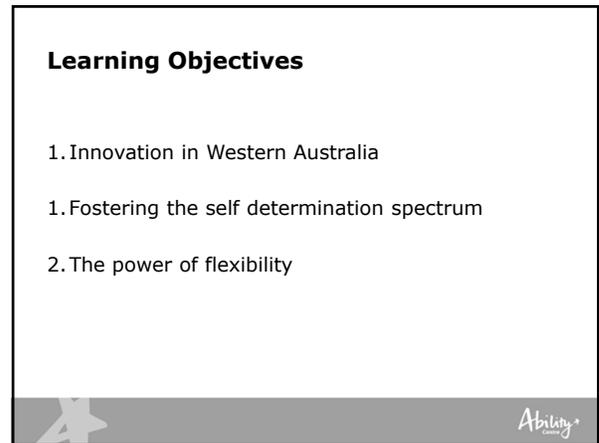
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# D9i

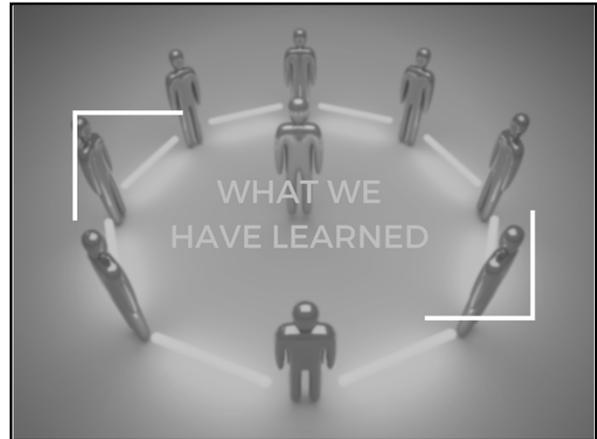
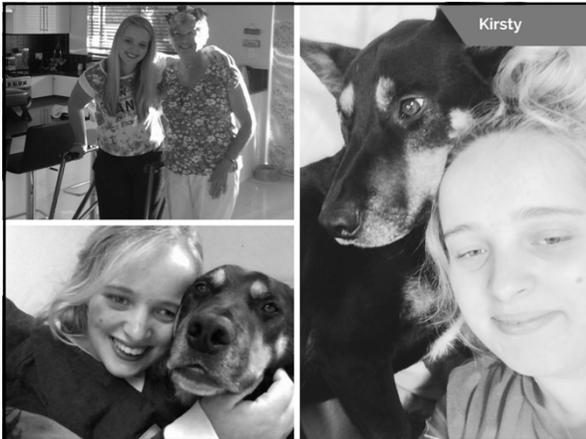
## The Power of Flexible Supports and the Self-Determination Spectrum

Renay Eade



SELF DIRECTION SPECTRUM			
All options can work effectively irrespective of support needs	Individuals with complex needs may require more advocacy & assistance	Relationship & empowerment based	All supports are designed and planned by the individual
Supports are flexible and can include pre-approved purchases			
Choice and Control	Partnership Model		Self Managed Model
Individual	Staffing -When I want my support -Who I want to support me -What I want support with	Finances -How I spend my funding -Review my budget	Staffing & Finances -All employment and financial responsibilities excluding those below
Optional	-Recruitment -Training -Leave coverage	-Purchases	
Organisation	-HR/IR matters	-Budget prep -Reporting & acquittals	-Budget prep -Reporting & acquittals





## D9ii

## Building an Interactive Coaching Tool to Facilitate the Transition to Individualized Funding

Annick Janson

This presentation will outline how collecting, analyzing and disseminating stories from Individualized Funding (IF) users can support transitioning to self-direction.

### Learning Objectives

1. Address the challenge of informing families
2. Illustrate the impact that Individualised funding has on people's lives
3. Develop Collaborative Learning Models between caregivers
4. Increase the effectiveness of professionals working with families

### Collecting stories:

All 45 participants in a Consumer Leadership Development programme reflected on the novel ideas they explored whilst transitioning to IF and the difference IF has had on their lives. The researcher adopted a narrative interviewing methodology (Béres, 2014, White and Epston, 1990) specifically designed and tested to capture participants' tacit knowledge (Janson and Davies, 2014). IF users described their first challenge: to understand their agency in shaping their 'good life' and grasp the range of the new options open to them.

### Analysing stories:

This novel procedure involves processing video interview data through thematic analysis and subsequently post-producing it to best serve knowledge-building. Participants tell their stories in their own voice as opposed to through text summaries and have commented that they feel well represented. The knowledge that is important for people to share about Individualized Funding spans across four key areas: Building natural supports/networks, Mobility and technology, A place to call home and Being productive.

Video narratives were embedded in an attractive flexible tool to be introduced in conversation and thereafter emailed to users learning from peer stories.

These stories also function to illustrate the transformational impact that using Individualised Funding has on people's lives.

### Story-sharing:

Sharing knowledge through stories is perceived as critical to build capacity in the disability sector, but there are significant limitations to this sharing happening face to face. Accessing peer stories electronically overcomes some of these limitations and enables people to be inspired into action. Our audience has commented on the fact that they engage with these video clips as the combination of sound and body language of people sharing what new opportunities opened up to them in the transition to self-direction has many advantages over text-based stories. Participants stress that this dissemination mode makes unique contributions over receiving information from professionals – peer stories contain 'tacit knowledge' viz. knowledge that is tried and tested' (Nonaka and Teece, 2001).

A large body of evidence is emerging describing the Social Impact that this transition has created – through families reporting multiple ways of leading social change and making a difference in their communities whilst living a meaningful life. People sharing their stories often inspires others to act, and illustrates the transformation possible with individualised funding.

Data collected and analysed via Google analytics help develop our understanding about how participants reach the video clips, the learning paths they follow after viewing them and how they gradually build their knowledge by following associated hyperlinks. The project infographics (attached) illustrates radically different learning paths for large subgroups in our audience. For instance, whilst 26% of our audience were emailed the story links, another 19% went on to listen to other stories from the referral end screen that YouTube offers when a story is finished, whilst a further 12% actively searched for such materials on YouTube. The latter two figures reveal that YouTube is a powerful engagement conduit for family story-sharing for almost a third of our audience.

This indicates how social media can contribute to our aims of distributing these stories - independently of any active dissemination effort on our part. Another point of interest is the rise of listeners' numbers who access the YouTube stories via









# E1ii

## Relational Citizenship and Residents of Long-Term Dementia Care: A New Ethic of Practice

Pia C Kontos

### Learning Objectives:

By the end of this session audience members will understand the following:

1. What is relational citizenship?
2. How the novel practices of elder-clowning can support the relational citizenship of individuals with dementia?
3. How elder-clowning can help us to think about how family care partners and staff of long-term care settings can support the relational citizenship entitlements of individuals with more advanced dementia.

### Summary:

A citizenship perspective redresses some of the gaps inherent in personhood- and relationship-centred approaches to dementia care in that it contextualizes individuals in terms of relationships individuals have with the state and its institutions. It has additionally repositioned individuals in the early stages of dementia as citizen-workers, yielding social and psychological benefits associated with activism, self-advocacy, and the companionship of others with similar impairment. Yet this classic model of citizenship, and its emphasis on self-cognizance rests on the ideal type of the cognitively fit and healthy and thereby deepens the social devaluation of those with significant cognitive impairment living in long-term care. Further, it has yet to be influenced by the emerging theoretical subfield of embodiment, which has placed the body and embodied practices at the centre of dementia representations and of care. In consequence, it has overlooked the importance of the body for self- and relational-expression, and in-the-moment experiences of directing and receiving humane care. What is needed is the fashioning of a relationship-based citizenship model – premised on the understanding that capacities, senses, and experiences of bodies are central to the exercise of human agency and interconnectedness, and the reciprocal nature of engagement – that must be fully supported at the micro level of direct care. Drawing on findings from an evaluation study of elder-clowning in long-term care, we argue that this novel arts-based practice, which involves affective, non-verbal, and imaginative engagement, supports the relational citizenship of individuals with dementia.

### References:

4. Miller, K.L., Kontos, P. (Accepted). The use of elder-clowning to foster relational citizenship in dementia care. In T. Alm Andreassen, J.F. Gubrium and P.K. Solvang (Eds.), *Reimagining the Human Service Relationship*. Columbia University Press: New York.
5. Kontos, P., Miller, K.L., Mitchell, G., Stirling-Twist, J. (2015). Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia. *Dementia: The International Journal of Social Research and Practice*. DOI: 10.1177/1471301215580895
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## E1iii

## Relationship Based Approach to Support: Another Way of Doing Business

Leanne Peipman, Margaret Vermeij-Irvin

Session Learning Objectives:

1. Provide an understanding of a relationship based approach
2. Discuss the importance of language and communication in implementing a relationship based approach
3. Learn about outcomes for people receiving support from a relationship based approach

Relationships in the delivery of support and assistance to people with a disability are generally viewed as a consequence. Traditionally the focus of service delivery is on the person, the plan, the tasks to be performed and the outcomes to be achieved.

The relationship based approach identifies relationships as the focus and the means by which the person can achieve their plan, have tasks attended to and achieve their desired outcomes.

The following are more common approaches and principles to providing assistance and support:

- Inherent Dignity of the Individual
- Principles of Social Justice - rights, equity, participation and access
- Social Role Valorisation
- Least Restrictive Alternative
- Dignity of Risk
- Duty of Care
- Holistic Approach
- Person Centered Approach
- Strengths Based Approach

(Please note the principles and approaches listed above are not an exhaustive list.)

The Relationship Based Approach (RBA) provides the means by which all other approaches and principles can be integrated and actioned and focuses on the relationships of all participants in the provision of support and assistance.

In the Health Sector there has been a movement in the development and research of Relationship Centered Care (RCC). The Pew Fetzner Taskforce on Advancing Psychosocial Health Education in 1992 was engaged to analyse the health care system. The Report released by the task force identified Relationship Centered Care as an important framework and approach whereby all participants appreciate and respect their relationships. Acknowledging the relationship between patient and health professional is important to the wellness of the patient. This was a progression on patient centered care which remains in the current healthcare system today.

RCC is based on four primary principles:

1. The personhood of the participants
2. Affect and emotion are important
3. Healthcare relationships occur in the context of reciprocal influence
4. The moral value of genuine relationships In the relationship centered care approach

RBA in principle is reflective of the RCC.

RBA acknowledges relationships:

- Between all participants are of the highest priority
- Are not a consequence of support but are a fundamental foundation of support
- Create pathways to empowerment and citizenship
- Provide modelling for the development of unpaid relationships
- Are organic (birth, life and death)
- 

Traditional service approach to support primarily focusses on the systems and outputs or outcomes including some of the following:

- Personal Care assistance
- Domestic Support
- Medication Assistance
- Community Access
- Respite

A Traditional service approach may be more inclined to use the following strategies to address relationships:

Prevention Strategy: ensure a regular turnover of personnel providing support to ensure relationships do not develop

Organisational Professional Boundaries: policies, practices and training

Intervention Strategy: attempt to resolve relationship conflicts or issues as they arise

The Relationship Based Approach uses the following with regards to relationships:

Development Strategy: Ensure the people supporting and assisting are matched with the person, the person accessing support has the final decision on their team members, provide focus and information on relationship development in this context to both parties

Monitoring Strategy: regularly have contact with all participants to monitor the relationship, identify changes, milestones and hurdles in the relationship, understanding and learning to implement relationship boundaries

Termination Strategy: determine future direction of the relationship through participants, acknowledge the stage of the relationship and where applicable develop a terminations strategy, celebrate the relationship and address potential loss  
People who require support and assistance to live good lives have indicated that trust, reliability, humour and responsiveness are among the four highest requirements of their team members.

Matching people is significant in the processes of the RBA and people have the final decision on the people in their team. People provide the direction to their team members and have the final say when a team member is no longer required. Rather than be passive recipients of rostered staff over whom they have no influence the RBA approach means the person accessing support and assistance makes the choices required to make the arrangement work for them, is in control of their team and experiences the consequences of their choices and control.

### Communication

Communication is the life force of relationships and if there is no communication there is no relationship. There is only two people operating in complete isolation. It is the most important skill in the relationship based approach. Communication occurs in many ways and is individually unique. It is an extremely important part of training and development for each participant. Training can occur in many ways and can take place individually in an informal way to meet each individual's needs or more formally.

One of the tools used in communication is language. As we know language is very powerful and is extremely important in the relationship based approach.

### Language

Language as tool for communication was used in the process of changing the culture of the organisation to facilitate the relationship based approach. We started with people not "doing" people. The common language of the people working in the organisation when supporting people was to say, "I am going to doing Joe....". Apart from being illegal in some places this language objectifies a person and makes them a task. The development of appropriate language used in the organisation has been critical to the relationship based approach to support.

The following is a sample of the language used in the organisation to support a relationship based approach:

#### Traditional Words and Phrases

- Shift
- Rosters
- Workers
- Disabled people
- "Doing" a person
- Letting or permitting a person to do something
- Carers, family, friends

#### Homelife Words and Phrases

- Support times
- Support schedules
- Team members
- People with a disability
- Supporting a person
- Supporting a persons' choice
- Significant others

Two case studies will be shown in the form of 2 minute video clips showing the outcomes for people receiving support from a relationship based approach.

### References:

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## E2i

### The Importance of a Resource Centre

Paul Gauthier, Chris Hofley, Joanne Taylor

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1. Offering training and education around becoming a successful CSIL (Choice in Supports for Independent Living) Employer
  - CSIL manual and videos, webinars and workshops
  - Applying for Individualized Funding, Supported Lifestyle Plans, Preparation for Meeting your Case Manager, and Transitioning from Institution to Independent Living
  - Preparing for Staffing, Creating a Budget, Job descriptions, Back-Up Plan
  - Being a Lawful Employer, WorkSafeBC, Source Deductions, Employee Standards
2. Offering a staffing database of Caregivers for our clients
  - Hosting Application Sessions to recruit qualified Caregivers
  - Hosting Group Interviews with clients and potential Caregivers
  - Initially set up our clients with Schedule of Caregivers and manage ongoing replacement as needed
  - Providing Emergency Back Up Staffing as needed
3. Participating within the larger community
  - Working with other non-profit organizations to bring about unity and support for our diverse communities
  - Attending Information Forums and Fairs to promote our resource centre
  - Involvement with Association of CSIL Employers (A.C.E.) to promote increases in CSIL Employee Wages

## E2ii

## Implementing the Right to Legal Capacity, Challenges from a European Perspective

Camille Latimier

### Learning Objectives:

1. Propose a comparative analysis of the situation of legal capacity in Europe
2. Critically analyse the implementation of Article 12 in different jurisdictions
3. Share experiences in implementing the UN Convention on the Rights of Persons with Disabilities and interesting practices
4. Exchange about advocacy work
5. Share a regional policy approach

### Summary of the presentation:

The presentation will start with a brief description of the situation with regards to legal capacity in Europe. The different countries could so far be grouped in these three categories:

1. Old fashioned models – countries where laws from the 1960s are still in place with a complete deprivation of rights - or “legal death”
2. Modernized guardianship laws – example from France (reform of 2007) and Italy (support manager)
3. Models based on self-determination –examples from Germany (1992) and Sweden (god man)

The presentation will then look at the way forward. With the ratification of the UN CRDP, there is a general trend of reforms. Legal capacity is one of the areas with the largest number of reforms at the national level linked to CRPD ratification. Most countries are reviewing their laws on legal capacity– reforms have taken place in Belgium, Croatia, Czech Republic Hungary, Malta, Latvia, Slovenia. While legal reforms include some aspects of supported decision-making, in several cases the law continues to permit some restrictions on legal capacity. Reforms tend rather to implement „modern guardianship“ laws in an attempt to comply with Article 12. Significant further steps are required to fully implement article 12 UNCRPD. Another wave of promising reforms in Bulgaria, Finland and especially Ireland are under preparation.

The example of the reform in the Czech Republic will be looked at in detail. The new Civil Code (entered into force in January 2014) includes a range of measures: support in decision-making, representation by a family member, appointment of a guardian without restriction of legal capacity (legal representation) and partial guardianship, including the possibility to create a guardianship board.

We will explain the limits of the new provisions and the problems linked to the practice since January 2014. Some key decisions have helped the implementation of the new Civil Code in positive ways and show that new models can be successfully used to keep full legal capacity. However, the set-up of the new models limits their practical implementation, because there is lack of sufficient safeguards for the people who use them. Two case studies from a pilot project in the Czech Republic will be presented.

The presentation will conclude with some positive results and outcomes of pilot projects happening in the region.

### References:

- Blankman, Kees, 'Guardianship Models in the Netherlands and Western Europe', *International Journal of Law and Psychiatry*, 1997, 20(1), 47-57
- Council of Europe, Commissioner for Human Rights, WHO GETS TO DECIDE?, Right to legal capacity for persons with intellectual and psychosocial disabilities, CommDH/IssuePaper(2012)2
- European Union Agency for Fundamental Rights, The right to political participation of persons with mental health problems and persons with intellectual disabilities, November 2010, available at: [http://fra.europa.eu/sites/default/files/fra-2010-report-vote-disability\\_en.pdf](http://fra.europa.eu/sites/default/files/fra-2010-report-vote-disability_en.pdf)
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- European Union Agency for Fundamental Rights, Laws about being able to make important decisions for yourself, easy read publication, September 2013, available at: [http://fra.europa.eu/sites/default/files/fra-2013-easy-read-laws-for-decision-making\\_en\\_0.pdf](http://fra.europa.eu/sites/default/files/fra-2013-easy-read-laws-for-decision-making_en_0.pdf)
- Flynn, Eilionoir; Arstein-Kerslake, Anna, "Legislating personhood: realising the right to support in exercising legal capacity",







## E3ii

## Self-Determination: Adults with Intellectual Disability and the Support of Family

Bernadette Curryer

### Session Description:

This presentation will describe an Australian study into the lived experiences of adults with intellectual disability as they undertake aspects of self-determination, such as goal-setting, choice and decision-making, with a focus on the support given by family.

### Learning Objectives:

Participants in this session will gain

1. An overview of the literature including the main barriers to self-determination from the perspective of adults with intellectual disability, and their family members.
2. A greater awareness of the lived experience of adults with intellectual disability as they undertake aspects of self-determination and be able to identify emerging themes relating to this experience.

### Summary of Presentation

"I don't know, I will have to ask Mum."

The inspiration for this study came from the inability of a young man, with a moderate level of intellectual disability, to indicate whether he was interested in a proposed social activity. His repeated response, "I don't know, I will have to ask Mum", raised questions in my mind. Was this an indication of family control? Did he doubt his right to choose? Or was he not able to make up his mind without assistance? These questions are particularly relevant in the current changing environment in Australia, where there is a general movement towards increased choice and control for people with disability (Curryer, Stancliffe, & Dew, 2015). The changing environment is evidenced by Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) which supports the rights and freedom of people with disability, promoting individual autonomy, independence, choice- and decision-making. The newly commenced National Disability Insurance Scheme (NDIS) marks a major change to the way services will be provided to people with disabilities in Australia. It will provide individualised funding for eligible people with disability based on need and person-centred planning. It recognises that individuals with a disability have a right to "exercise choice and control, [and] be equal partners in decisions that affect their lives" (DisabilityCare Australia, 2013, p. 16). The recently revised Australian National Standards for Disability Services specifically recognise the rights of an individual with a disability "to make decisions about and exercise control over their own lives" (Australian Government Department of Social Services, 2013, p. 11).

### Definition of Self-Determination

Self-determination is a concept that can guide the implementation of increased choice and control. One definition of self-determination is "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 2003, p. 177). While another definition refers to "individuals exercising the degree of control they desire over those areas of life they consider important" (Abery & Stancliffe, 2003, p. 44).

### Literature Review

There has been limited research into self-determination from the perspective of adults with intellectual disability or their family, however, what has been done clearly identifies barriers to self-determination. Adults with intellectual disability reported that the barriers to control and choice in their lives included:

- Over-protective parents (Haigh et al., 2013; Jahoda & Markova, 2004; Shogren & Broussard, 2011)
- The need to constantly prove one's ability (Jahoda & Markova, 2004)
- Support that is not responsive to actual needs (Shogren & Broussard, 2011).

In contrast, the barriers identified by families involved:

- Concerns about the person's vulnerability and limited decision-making capacity, skill level and awareness of consequences (Mitchell, 2012; Murphy, Clegg, & Almack, 2011; Power, 2008; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012; van Hooren, Widdershoven, van der Bruggen, van den Borne, & Curfs, 2005)
- The complexity and risk involved in choice making (Mitchell, 2012)
- The belief that the family is responsible for the protection of, and know what is best for, the individual (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009; Dyke, Bourke, Llewellyn, & Leonard, 2013; Foley, 2013; Knox & Bigby, 2007; Mitchell,

2012; Saaltink et al., 2012)

- The need for decisions to be in line with family values and norms (Saaltink et al., 2012).

As a result of such concerns, adults with intellectual disability may have little involvement in decision-making (Dyke et al., 2013; Knox & Bigby, 2007) or be actively persuaded to make decisions based on family values rather than their own personal preferences (Saaltink et al., 2012). Parents may take on the role of unauthorised decision-makers (Foley, 2013), even overruling the choices of their adult children (Pilnick, Clegg, Murphy, & Almack, 2011).

#### Research Question

These different perspectives led to the research question: What are the support experiences of adults with an intellectual disability as they undertake aspects of self-determination? This question will be examined with a focus on the support received from the family.

#### Methodology

Interpretative Phenomenological Analysis (IPA) is being used as it aims to capture the experience and perception of the research participants in relation to a specific event. Through interpretative analysis, the researcher is able to “think about ‘what it means’ for the participants to have made these claims, and to have expressed these feelings and concerns in this particular situation” (Larkin, Watts, & Clifton, 2006, p. 104).

#### Data Collection

Eight people with a mild to moderate intellectual disability participated in semi-structured, in-depth, one on one interviews. An initial and follow-up interview was conducted with each participant. Participants’ ages ranged from 21 – 48 years, both males (4) and females (4) were interviewed, some still lived with family (4) while others lived independently from the family either in subsidized government housing(3) or disability service supported accommodation (1). Participants’ employment status included open employment (1), supported employment (4) and unemployment (3).

#### Preliminary Emerging Themes

The preliminary analysis of the data has identified five emerging themes.

##### 1. Strong connection to family

All participants recognise the importance of their family. Family provides them with a sense of belonging. They appreciate being treated like everyone else, just ‘one of the kids’. However, this relationship is not seen as one-sided, rather as a reciprocal relationship, particularly as parents age.

##### 2. Family as a source of support

The family provides a range of support, both practical and emotional. Opinions and options are offered as part of the decision-making process.

##### 3. Developing self-determination – learning for myself

Most participants had a clear belief in their ability to set goals, make choices and decisions, solve problems and speak up for themselves. They felt it was important that they be given a chance to learn, and this is best done by doing things for themselves. However they also acknowledge that decision making can be stressful and at times they look to the family for help.

##### 4. I am in control of my life, however sometimes my family has the final say

Despite all participants reporting that they felt a positive sense of control of their own life, there were times when approval from the family for certain decisions was needed. Such limitations to the level of individual control, together with an awareness of the need to compromise, were generally accepted without questioning.

##### 5. Challenges in family relationships

Although the family was clearly valued, this did not mean that challenges within families were not present. Participants had to cope with the loss of family members due to a variety of reasons including death, parental marriage breakdown and family arguments. Some limited their contact with family members who were not a positive source of support. Some felt pressure to ‘get along nicely’ with certain family members, or to choose sides. For others, family encouragement to become more independent was perceived as being pushed away, not being loved.

#### What’s next?

This current research is part of a larger, three phase study. These results will inform the next phase of focus groups of key family members. This will be followed by dyadic interviews of individuals with a key family member, allowing comparison of responses.

## Contact Details

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## E3iii

## Are We There Yet?

Ann M Greer

## Learning Objectives:

1. To demonstrate that services, individuals and families can work together to create the best life possible
2. Demonstrate the part that community plays in the lives of people with disabilities and their families
3. Maximise the message that a good life is possible for everyone - regardless of the level of disability or the behavioural challenge.

O'Brien and Lyle's "five valued experiences" (Framework for Accomplishment, 1989) has been the foundation of the service and a means to focus in developing a more desirable future for the people served:

Community presence: How can we increase the presence of a person in local community life? How can we help people have more control and choice in life?

Community participation: How can we expand and deepen people's friendships?

Promoting choice: How can we help people have more control and choice in life?

Supporting contribution: How can we assist people to develop more competencies and contribute their unique gifts?

Valued roles: How can we enhance the reputation people have and increase the number of valued ways people can contribute?

Social Role Valorization is the theory underpinning support based on three areas – Valued Roles, Positive Image and enhanced growth and development.

Values and beliefs that underpin Community Connection.

1. That individuals with a disability have a right to live and participate in their communities.
2. That individuals with a disability and their families have a right to a good life in the ordinary sense that we all understand.
3. That community life and relationships cannot be artificially duplicated or approximated by placing individuals with a disability in group or institutional settings.
4. That people deserve a life they don't need a break from – not a break from a life characterized by intolerable pressure.
5. That individuals with a disability deserve the support they need to maintain good standing within their relationships and to not be seen as a burden.
6. That the families of individuals with a disability deserve the support they need to maintain their health and wellbeing.
7. That parents and families are the right and proper advocates for their sons and daughters who are not able to speak for themselves
8. That we listen to individuals with a disability through all communication means to maximize their own personal choice and control.
9. That we advocate all responsible bodies, so that they are aware of the extent and nature of these needs.
10. That support is always one-to-one, with a matched person selected by the individual with a disability and their families.

# E4i

## Beyond Public Sector Funding: Accessing the Community to Support Individuals with IDD

John Agosta, Faythe Aiken



**Human Services Research Institute**

**Beyond Public Sector Funding: Accessing the Community to Support Individuals with Intellectual and Developmental Disabilities**

Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding  
2015 International Conference

October 15 - Saturday, October 17, 2015

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Beyond Public Sector Funding 2

### Today's Agenda

- What We Believe & the Challenges Ahead
- Listening first to people with I/DD
- A need for mutual support beyond public funding
  - Community assets
  - Peer support
  - Exchange networks
  - Cooperatives
- Questions & Discussion




Beyond Public Sector Funding 3

### We Believe...

*...that people with intellectual and developmental disabilities have the right to live, love, work, play, and pursue their life aspirations just as others do in their community with the support they need.*



[www.theriotrocks.org](http://www.theriotrocks.org)



Beyond Public Sector Funding 4

### State of the Field

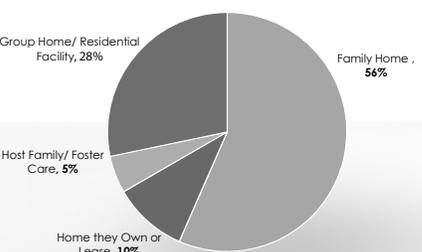
- Enduring demands for community integration & self direction.
- Fiscal pressures
- Increasing demand for services
- Workforce factors
- The way things are

→ **Policy Decisions**



Beyond Public Sector Funding 5

**More people with I/DD are choosing to stay in their family homes (Type of residence for people with I/DD: 2012)**



Residence Type	Percentage
Family Home	56%
Group Home/ Residential Facility	28%
Home they Own or Lease	10%
Host Family/ Foster Care	5%



Beyond Public Sector Funding 12

"Thank you for everything that you've done... for all the services that there are... But what you built, we don't want!"



Rebecca Cokley  
Executive Director  
US National Council on Disability

HSRI

The System Stinks!

You can trust us. We're professionals!

What a relief!

HSRI Beyond Public Sector Funding 8

### An Overall View...

Lives of people with IDD & their families

People with IDD & their support needs

Community assets & individual efforts

Possibly shrinking available public services... in face of growing demand.

Harkins, Green, Jacobson & Agosta 2011

HSRI Beyond Public Sector Funding 13

### Listening First to Self-Advocates

**Self-Advocates Say that ... Self-Determination means that:**

- I am a person like all people.
- I make my own choices.
- I am the boss of my own life.
- I make my decisions in my own life.
- I do for myself... and don't depend on others so much.

Meeting of Self-Advocates from six states

9

HSRI Beyond Public Sector Funding 14

### Hot Topics of Conversation

- Living on one's own
- Getting a job... The job I want.
- Dating... Sexuality...
- House rules
- To be the boss of my own life

Put your hand on a hot stove for a minute, and it seems like an hour. Sit with a pretty girl for an hour, and it seems like a minute. THAT'S relativity. Albert Einstein

10

HSRI Beyond Public Sector Funding 11

People with disabilities still live in institutions?

What the...? It's 2010 People!

The Shelteredworkasaurus

STOP FEEDING THE DINOSAUR

We want real jobs!

www.theriotrocks.org

HSRI Beyond Public Sector Funding 12

Trying to kiss while on a date (with staff...)

Staff

Staff should get their own dates!

HEY!!! No eating in the TV Room!

Are you kidding me?

HSRI Beyond Public Sector Funding 13

## Here's a Thought

In life, there are four essential needs...

- To have something to do
- To have someone to love
- To have something to believe in
- To have something to hope for



Lou Holtz addressing the Notre Dame football team, 2005

HSRI Beyond Public Sector Funding 14

## Let's do a quick Gap Analysis in our heads...

A Gap Analysis is an assessment that compares the actual to potential or desired performance.

Compare the expectations of self-advocates with:

- The expectations embedded in the system.
- The service array in the field.
- The outcomes achieved.



HSRI Beyond Public Sector Funding 15

## Mutual Support Beyond Public Funding

- One of the strongest assets any community has is its people.
- Beyond individual efforts, any community also has an array of community-serving entities, such as churches, schools, and clubs.
- Future systems must seek to forge alliances between individuals with disabilities and their family members, and the array of community assets available to find additional means of support.



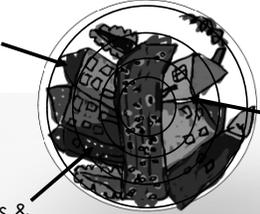
HSRI Beyond Public Sector Funding 16

## How We Think Of Some Communities



HSRI Beyond Public Sector Funding 17

## Another Way To Think.... Community Assets



HSRI Beyond Public Sector Funding 18

## The Way Things Are...

Services are provided to people living in isolated households.



Dependency on services

Isolation

Fail to build culture & capacity to increase opportunity for mutual support & use community resources

19 Beyond Public Sector Funding

### The Way Forward... Public services work together to use community assets with mutual support.

20 Beyond Public Sector Funding

### Mutual Support through Exchange Networks, Peer Support and Cooperatives

Existing public services should be complemented by establishing networks of mutual support so that individuals with I/DD and their families may:

- Make efficient use of public services (Medicaid).
- Work cooperatively to achieve common goals.
- Utilize supports available from local businesses.
- Provide supports to one another (exchange network) and socialize.
- Contribute in meaningful ways to the community.

A 'service life' is not the outcome that all families want for their children. They want their children to have a natural life in the community.

Beth Kessler  
Oregon DD Council

21 Beyond Public Sector Funding

### Exchange Networks

Directory of Time Banks  
Search the World!  
<http://community.timebanks.org/>

22 Beyond Public Sector Funding

23 Beyond Public Sector Funding

### Peer Support

Peer Support Networks are not meant to take the place of public services. They are intended to generate complementary supports within communities. Participants unite voluntarily to support one another. A coordinator is needed to advise and organize the Network, though it is shaped by needs and preferences of its members. Participants help one another by offering mutual support and sharing resources.

24 Beyond Public Sector Funding

#### Dreams N' Goals Jabbers

A game for self-advocates!

#### Gifts N' Giving Jabbers

A game for self-advocates!

Beyond Public Sector Funding 25

## Human Service Cooperatives

In a cooperative participants unite to address common or individual needs through mutual support and/or joint action.



Beyond Public Sector Funding 26

### Human Service Cooperatives

Co-ops can offer informal social supports or formal agency support, such as:

- Mentoring
- Tutoring
- Job support
- Social organization
- Social support
- Home-based service planning
- Employment support and job development

Co-ops may ask that members contribute by:

- Paying a membership fee
- Offering their time to organized events

Co-op members have access to:

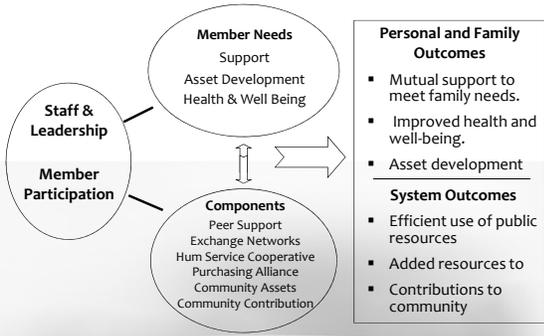
- All co-op events
- Co-op clubs
- The co-op directory of all members

*Families are not just service recipients, they also have the opportunity to give back.*

*Jennifer Knapp, Community Choices Illinois*

Beyond Public Sector Funding 27

### The General Approach...



**Staff & Leadership**

**Member Participation**

**Member Needs**  
Support  
Asset Development  
Health & Well Being

**Components**  
Peer Support  
Exchange Networks  
Hum Service Cooperative  
Purchasing Alliance  
Community Assets  
Community Contribution

**Personal and Family Outcomes**

- Mutual support to meet family needs.
- Improved health and well-being.
- Asset development

**System Outcomes**

- Efficient use of public resources
- Added resources to
- Contributions to community

Beyond Public Sector Funding 28

### So Let's Get Started!!

Talk... Discuss...  
Deliberate.... Change!

- Change imposes choice.
- Choice imposes ambiguity.
- Ambiguity promotes discussion.
- Discussion promotes deliberation.
- Deliberation forms opinion.
- Opinion leads to action.



Beyond Public Sector Funding 29

### Need and Opportunity

A service system for [people with disabilities] & others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."



Alfred Dam (undated)  
Denmark

# E4ii

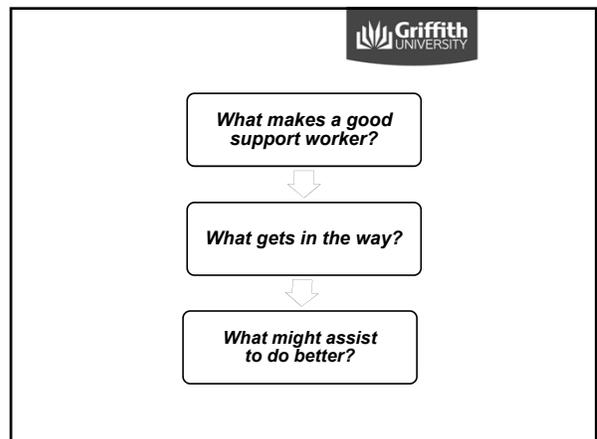
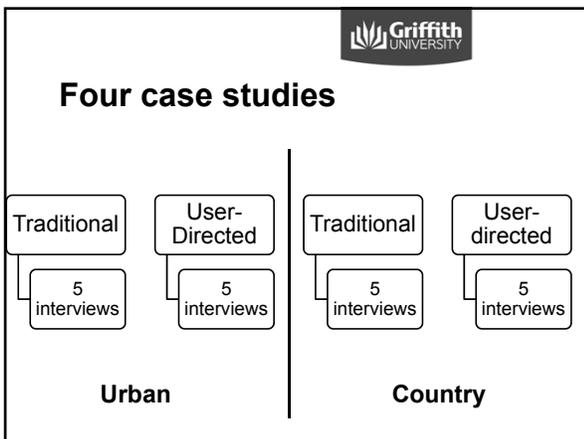
## A Seven-Step Process for Self-Direction of Service

Margaret L Ward



### Seven steps for user-direction

Margaret Ward





### What makes a good support worker?

- A natural aptitude for the work
- A good match with the service-user
- Capacity to manage relationships



### What gets in the way?

- Reliance on broad-based training
- Arbitrary limits on the relationships
- Lack of clear purpose for the support
- Fear of taking risks
- Inconsistent staffing arrangements.

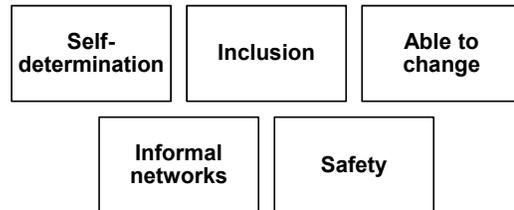


### What might assist to do better?

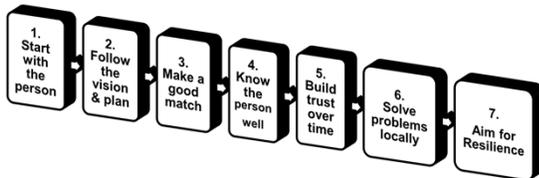
- Clearly defined vision and plan
- Relationships built on trust over time
- An individually-crafted support team
- Problem-solving close to the service-user



### What does “good support” mean?



### What does good support look like?



### Seven steps to user-direction



### Barriers for traditional services

- Congregate care
- Reliance on pre-service training
- Management of risk through rules
- Arbitrary limits on relationships



### Challenges for user-directed services

- Empowered service-users are favoured
- Potential conflicts of interest
- Personal cost of time and energy



End

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# E4iii

## Building Alignment around a Vision: End To End, Top To Bottom and Back To the Top

Terry Kilmister, Marsha Marshall

INDIVIDUALISED FUNDING AGENCY



**"Building alignment around a vision:  
end to end, top to bottom and back  
to the top"**

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INDIVIDUALISED FUNDING .... putting YOU IN CHARGE

**Manawanui in Charge Ltd**

- Limited Liability company
- 4 shareholders
- One wholly owned subsidiary company
- In excess of 2000 clients, NZ-wide
- \$6M company
- Administers \$50M of client funds
- Operates NZ-wide
- Board of 7 directors – 2 independent
- 44 full time staff



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INDIVIDUALISED FUNDING .... putting YOU IN CHARGE

**Model and philosophy**

- IF users employ their own staff to service their needs – run their own business
- We set out to assist IF users to live a life that is as 'ordinary' as possible
- We are not the employer of support staff
- The only direct service we offer is consulting and coaching to help IF users make good choices
- IF users pay a percentage of their grant as a fee for service
- We stay out of their lives to the greatest extent possible
- Once established IF users choose whether or not to use our additional support and education services



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INDIVIDUALISED FUNDING .... putting YOU IN CHARGE

**The right focus for planning and reporting**

- Board-level planning that addresses outcomes or **Ends**
- Operational level planning that addresses activities/actions or **Means**
- Management reporting that addresses governance concerns, i.e. Focuses on the achievement of outcomes, not operational activity



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INDIVIDUALISED FUNDING .... putting YOU IN CHARGE

**CEO Job Description**

Deliver the outcomes as stated in the Statement of Strategic Direction and in doing so remain within the scope of delegated authority granted by the board.



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INDIVIDUALISED FUNDING .... putting YOU IN CHARGE

**Building blocks and glue**

- Mutual trust between board and CEO
- Evidence based reporting and direction setting
- Commitment to innovation and risk taking
- Financial strength
- Careful selection of directors and staff
- Investment in research and evaluation
- Continuous performance assessment at all levels
- Strong, positive organisational culture
- Leadership at every level of the organisation
- A flexible and rewarding workplace
- Absolute commitment to our philosophy



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**INDIVIDUALISED FUNDING .... putting YOU IN CHARGE**

**Tying it all together**

- Critical attention to roles
- The right people in the right jobs at all levels
- Deep commitment to our philosophy and to standards of service and business
- Planning and monitoring that is interlinked from the top to the bottom and back up again
- A strong connection to the people we serve
- A philosophy and practice of continuous improvement

  
INDIVIDUALISED FUNDING SUPPORT

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## Claiming Full Citizenship

“Building alignment around a vision: end to end, top to bottom and back to the top”

### Role clarity at both governance and management levels

For a board to be fully effective it is essential that it is comprised of people who understand their governing role and have the required skills to execute this. A board must add value and justify its costs. It is not uncommon to find boards that become a top tier of management, who are seen by management to be in this role and that consequentially fail to bring the wisdom, oversight, advice, connections, experience and leadership required of a board.

A board exists to serve the interests of an organisation’s ‘legal’ owners, be these shareholders, members, or any other category of owner who has the authority to endorse or alter the organisation’s constitution. Those people for whom the organisation exists but who cannot exercise legal rights over the board and the organisation might also be thought of as owners, ‘moral owners’. Such moral owners rarely have legal or constitutional authority. Regardless, the board stands in for this group too, ensuring that the organisation operates on their behalf.

Management serves the board. As simple and obvious as this sounds it is not infrequently misunderstood and often deliberately ignored. Several factors contribute to such a misunderstanding. It is not uncommon for CEOs to outlive the majority of their board members. Such a CEO sees board members coming and going resulting in boardroom continuity being rooted in the CEO rather than in the board. Both CEOs and board members fall into a ‘role misplacement’ hole in which neither can derive a solid footing.

It is not uncommon for board members to rely on the CEO for information and advice in order to carry out their job. Many, if not most, CEOs could run the organisation to good effect without a board but few boards could function without a CEO. When a board is not composed of people with the right understandings and skills, over-reliance on the CEO is often seen as the only way the board can maintain momentum. Role confusion that results can lead to a form of damaging role reversal.

A well functioning board, understanding its accountability to the organisation’s owners, delegates aspects of this accountability to management (usually via a CEO) on the basis of a set of delegated authorities. Ideally these are underpinned by an explicit understanding of what cannot, or should not, be delegated to management. On the one hand a board ought not delegate those matters that are paramount to its duty of care under the law. On the other hand it ought to delegate those matters that require management expertise and time to enact. Defining these is critical to role clarity and accountability.

### Getting the right people on board

The not-for-profit sector in New Zealand is increasingly embracing the benefits to be obtained by appointing independent, experienced people to their boards, people who, prior to appointment, might have little or no experience of the organisation. Such appointments are commonly made by the board without direct reference to organisation members, the criteria for such appointments stated in the organisation's constitution. Board appointed independent directors are usually appointed for their governance and strategic skills or for their community or business connections that align with the organisation's strategic intent.

New Zealand community sector boards frequently use Board Appointment Panels to manage the election and appointment processes. Such panels commonly include key board members and a membership representative and are led by an external, disinterested third party with expertise in the board appointment and governance space.

New Zealand not-for-profit boards are typically quite small, often with no more than seven directors. It is not uncommon for there to be up to three independent, appointed directors.

### The right board members with the right skills design the organisation's future

The board's primary role is to serve the owners' interests by ensuring that the organisation delivers the 'right outcomes' to the 'right people' in the 'right way'. The starting point for this is in the design of a statement of strategic direction, perhaps called a Strategic Plan or a Statement of Strategic Intent. Ideally this statement/plan addresses and states the results to be delivered. While this principle is readily and widely acknowledged by board members in all jurisdictions, the reality is that it is rarely practiced. The vast majority of strategic plans written in both the not-for-profit and corporate sectors are written (often by management) as a series of activities to be undertaken. Such plans fail to state what must be achieved, instead, stating what must be done. The consequence of this is that management reporting against such strategic documents almost without exception addresses the 'doing', not what the doing delivers or is designed to deliver. The result is that the board focused on actions rather than outcomes.

Few boards are capable of designing a sound strategic plan without the assistance and expertise of senior management. While the design process might be carried out as a partnership between board and management, the outcome of such a partnership is owned by the board. Only the board can change this governance level plan.

The Statement of Strategic Direction/Strategic Plan typically makes clear the organisation's Purpose, its aspirations or Vision for the desired future (often an expansion of the Purpose Statement), not uncommonly a set of Values or Statement of Philosophical Underpinning, and a set of Key Result Areas KRAs and Key Performance Indicators or KPIs. The KPIs often form the basis for the CEO's performance accountability.

A well structured strategic plan is an expression of a deep-level understanding of the market/sector, key market players and the organisation's capability to deliver the right outcomes. It does not confuse outcomes with actions, governance with management or the short-term with the long-term. It will stand the test of time, perhaps requiring small refinements and reprioritising, but the outcomes, the vision and the philosophical underpinnings should not require significant change.

Management is best placed to design how the outcomes are best achieved and to drive the Purpose and Vision into the bowels of the organisation

The CEO and all other staff employed by an organisation must be carefully selected for their capability and skills required to deliver the right results, be these as the financial manager delivering up-to-date and accurate financial data and information or programme staff operating the organisation's programmes and services to the required standards. It behoves a board, therefore, to both charge and support management to make best use of staff expertise by designing operational plans that will deliver the outcomes required by the board. The Purpose and Vision should be reflected in the operational planning down to the lowest level, thus promulgated throughout the organisation. Every staff member then knows why the organisation exists, what it does and what their part is in delivering the outcomes to the people the organisation exists to serve. Knowledge of and loyalty to a common purpose is critical to the organisation's success. Ensuring this is a key component of the CEO's role.

The board might ask the CEO to walk it through the operational plans so that board members can achieve a level of comfort with the depth of thinking and alignment with the upper-level plan. But the operational plans should remain owned by the CEO, not the board. A board ought not sign off or approve the operational plans. Such action takes ownership away from the CEO who typically needs to know that he or she can make changes to their operational plans whenever required without having to seek board permission.

### Strategic plans are living documents

A strategic plan is an attempt to predict the future and to provide a framework that controls the delivery of desired outcomes. Despite the best plans, the external world is rarely fully aligned with an organisation's intentions. While the big picture or the highest level outcomes might remain stable, the next level strategies and, further down the tactics, might need to change in order to meet external influences or as the result of innovation or new thinking.

Every board meeting should have a component that is, in effect, a mini strategic retreat in response to CEO reporting, to board member initiated dialogue or some other reporting or influencing factor. The veracity of the desired outcomes, the high-level strategies to achieve the outcomes, the successes and failures along the way and the challenges facing the organisation are then constantly under examination by the board. Board members' wisdom and experience is available to the CEO and the organisation to think through challenges at the highest level. This said, care should be taken to ensure that boards do not fall into the trap of advising managers about how to do their job. Board advice is, rather, conceptual, reflective, and exploratory from which management draws the wisdom and guidance on which to base their decision-making, the results of which they are held to account for.

### A well structured and clearly defined statement of delegation to the CEO is an essential board tool

It is critical that both the board and the CEO have a clear and unequivocal understanding of what is delegated to the CEO and what remains within the board's decision-making authority. There are several commonly applied ways to document such delegation.

1. Many not-for-profit organisations use a prescriptive approach by stating what the CEO must or should do. This approach fails most tests because what must be done is so expansive and ever changing that it is impossible to create an effective and current list of requirements.
2. Many organisations in both the not-for-profit and the commercial sectors restrict their statement of delegation to financial matters. This also fails as the CEO's delegated authorities extend well beyond financial matters.
3. Many community sector organisations use a proscriptive approach by stating what the CEO cannot or must not do thereby defining the boundary between the board's and the CEO's authorities and accountabilities. The board preserves its duty of care by making clear what decisions or actions the CEO cannot make or take, these being available to the board alone. Some boards using this model struggle with the negative language and become conceptually confused, believing that the model assigns too much authority to the CEO when in fact it only assigns as much as is agreed by the board.
4. It is commonplace in the corporate sector for boards to adopt a Powers Reserved to the Board approach in which the board assigned to itself a range of powers or authorities that are not available to the CEO. All powers or actions not reserved to the board are, by definition, available to the CEO. This approach can fail when a CEO elects to drive the proverbial truck through the gaps in the list of powers and take actions that no reasonable board would expect to be required to state as being reserved to itself, or that should not be exercised at all.

### Risk management is both a board and management responsibility

It might be said that the board is the organisation's highest level risk management forum. These days most board members appreciate that it is they who could stand in court and whose reputations are on the line when major organisational risks are not well managed and the law is broken, or there is wide-scale organisational failure. While certain risks must be managed at the board level, for the most part the day-to-day management of organisational risk is delegated to management.

There are three commonly applied key risk management documents:

1. The strategic plan is an attempt to manage the external risks surrounding the organisation's future direction and achievements.
2. Board and operational policies are the way both the board and the CEO manage internal risks that could harm the organisation or undermine its internal effectiveness and efficiency.
3. There might be a risk register in which major risks, internal and external, are documented and monitored.

Board accountability is to the organisation's owners. CEO accountability is to the board

Boards commonly express their accountability to their owners via their Annual Report and statements made at the AGM. Shareholders and members have their say in response by electing directors to, or removing directors from, the board.

The CEO is accountable to the board. The CEO's Job Description requires just two components that can be wrapped into a simple, short sentence:

"Deliver the outcomes stated in the Statement of Strategic Direction and in doing so remain within the scope of delegated authority granted by the board."

Underpinning this short Job Description is, of course, a well defined set of outcomes to be delivered and a statement of delegated authorities.

CEO accountability should be continuous, structured and robust. The reality of CEO life is that his or her performance is assessed by board members at every board meeting. Every time a CEO speaks or presents a paper to the board, judgement is exercised, mostly silently and privately, but judgement is made just the same. Ideally board members express their pleasure or displeasure at the time, rather than leaving it until a later time. When there is open and honest feedback between a CEO and his or her board there is no consequential need for the typically applied annual performance appraisal. This is not to say that there ought not be an annual event when the board (or board committee) and the CEO sit down to reflect on the year, to wrap-up the results of the continuous feedback and dialogue and examine the working partnership. However, there should be no surprises at such a meeting.

It is commonplace these days for boards to undergo some form of regular performance review. The processes most commonly used are based on self-assessment with individual board members offering their personal thoughts about aspects of the board's performance and, increasingly, about their peers' and their own performance. While it might be argued that this process has many flaws, nonetheless it offers the opportunity for, what is otherwise, a busy and preoccupied board to pause and reflect on its governance processes and systems.

### Connecting with the clients

The vast majority of not-for-profit or community sector organisations are established to serve the needs of a sector of the population with particular needs that are, or could otherwise be, left unserved. Yet unlike shareholders of a publically listed company who are in effect the legal owners of the company, not-for-profit sector clients, for the most part, do not have the authority to either sit at the board table or exercise ownership rights at an AGM. They are not owners in the same sense that the organisation's members are. Given that its clients are the reason for the not-for-profit organisation's existence and appreciating that they cannot formally influence the organisation, it is imperative that the organisation establishes a variety of means to ensure client input into the operational processes. Starting in the boardroom board members must expand their fiduciary or stewardship role beyond the legal duties to incorporate the interests of the clients who have no 'legal ownership' authority. Acting as a 'surrogate owner', the board fills this gap. It thus becomes imperative that the board understands the needs of the organisation's clients, is familiar with their issues and challenges and has an appreciation of the environment they must traverse in order to live their lives to the full.

In the social services sector it is not uncommon to find board members with 'lived experience' of the organisation's focus. Similarly people with 'lived experience' often find work in the operational organisation. Such connections are not, however, sufficient. The organisation must find ways to regularly connect directly with its clients, hear their feedback, understand their issues, needs and requirements and be confident that the services offered are designed to serve the client's best interests, not the organisation's. Client satisfaction surveys, advisory groups, focus groups, inclusion in planning systems, engagement in on-line forums and various other means of connecting the client to the organisation are essential components in well functioning, client-centred organisation.

### The building blocks and glue that hold the board CEO interrelationship in place

While the partnership between the board and its CEO is not a partnership of equals - it is rather an employer-employee relationship - the notion of a partnership is one way of considering how each assists the other to carry out their role and responsibilities. Given that board members are, in effect, part-time participants in an organisation's life, it behoves management to make every reasonable effort to assist the board members to meet their duties and to add value to the organisation. Reporting should be linked to governance interests and criteria, not merely a description of management actions. Papers should be as short as is required to make clear what needs to be taken into account in board-decision-making. Board members should be presented with information, not just data. Data, when presented, should be analysed with the implications made clear so that board members can consider and determine what the response should be.

The board, in turn, must make clear to the CEO what it is that he or she is required to deliver. The board needs to understand the capacity (e.g. financial resources) and capability (e.g. the competence of key staff) of the organisation so that unreasonable and unachievable expectations are not placed on the CEO. The CEO needs to know that the wisdom, experience and expertise of board members is available as a sounding board for management initiatives and actions.

Most importantly there must be trust between the two parties. The board must be sure that the CEO provides honest, accurate and timely information, seeks help as required and is unafraid to present both bad news and good news. The CEO, in turn, must be confident that the presentation of bad news is not used as an opportunity by the board or board members to address issues that should have been addressed in a more timely manner; in other words that it's safe to declare failure.

Although it is the CEO who is held to account for all operational matters, nonetheless the board needs to be confident that the CEO has the support of a strong and capable management team and that they, in turn, are supported by competent staff members.

Two-way openness, honesty and trust are essential components for effective intra-organisation communication and relationship building. This applies to the relationship between board members and the board as a whole and its CEO.

The CEO needs to know that all board members are committed to the organisation's philosophy and plans, that he or she will not be sabotaged by an individual board member or group of board members who declare their disagreement with board decisions by attacking the CEO as a way of addressing their dissatisfactions. In other words, the CEO needs confidence that the board 'speaks with one voice' when addressing him or her, and that intra-board differences are not played out through the CEO. Effective and safe communication gives the CEO confidence that organisational progress and challenges can be fully discussed and that innovation, even when this entails risk, will be constructively discussed, examined and, as appropriate, supported.

### Creating an organisation that functions as a whole

Although an organisation is made up of a number of individual functional parts serviced by individual workers, in order to deliver its intended results the organisation must function as a unified whole, each part and every individual contributing to the effort and outcome. Few not-for-profit organisations are so large that individual workers know only their small part in the overall set of organisational functions. It thus becomes easier to achieve commitment to a bigger picture than it is in, say, a large manufacturing enterprise. Further, many people choosing to work in a not-for-profit enterprise do so because they believe in the work done by the organisation. Building alignment around a vision from top to bottom, side to side in such an organisation is much easier to achieve than in the large commercial company.

When the organisation's Purpose and Vision cascade throughout its planning processes headlining every level of planning, staff at every level are reminded of the bigger picture of why the organisation exists and what their role and contribution is in contributing to the achievement of the desired outcomes.

### Statement of Strategic Intent

#### Purpose

Manawanui exists so that people using IF will lead their lives with the widest choice, control and flexibility for optimal independence.

#### Philosophical Underpinning

Individualised Funding embodies a fundamental human rights issue – that all people have the right to make decisions about their life choices and to direct their personal support services in a manner that best meets their desires and needs.

IF is based on a philosophy of person-centred control in which everyone has the right to a life that is as 'ordinary' as possible and to have a maximum feasible amount of control and choice over that life, i.e. it is a catalyst for enabling self-determination.

#### Values

- Being authentic
- Being thought leaders
- Going beyond excellence
- Being courageous
- Rangatiratanga (self determination)

#### Key Result Areas

##### Client focused KRAs

##### KRA 1 Client outcomes

oIF clients have maximum possible choice, influence and control over the decisions affecting their lives.

## KRA 2 Support systems and processes

- oClient independence is maximised.
- oThe impact of potentially harmful choices is minimised, i.e. choices that sit outside of legal, contractual, moral, and safety parameters.
- oIF clients' outcomes are achieved within individual funding parameters.
- oIF clients achieve their desired outcomes with minimum intrusion/visibility by MiC personnel and systems.

## Organisation focused KRAs

## KRA 3 Business systems

- oEfficient, robust and effective business systems support all aspects of MiC operations.

## KRA 4 Organisation development and growth

- oCompany growth is consistent with our ability to ensure sustainability and relevance.
- oWe retain a dominant market share in IF.

## KRA 5 Industry reputation

- oWe maintain our position as the dominant thought leader in the field of IF.
- oOur reputation and success enhances community and government trust in IF.

## KRA 6 Good Governance

- oThe board's policy framework is the basis for high quality governance, vision and organisational leadership.
- oThe governance process adds value to MiC and to management's thinking and decision-making.

## Sustainability and Growth

## Underpinning strategies:

- We will use our institutional knowledge and intellectual property to continually improve what we do so that we are the Individualised Funding agency of choice in New Zealand.
- Through networking and collaboration opportunities, nationally, regionally and internationally, we will deliver world-renown services.
- We will remain the market leader as the result of the depth and strength of our thinking and actions. Such market leadership will not necessarily reflect size, i.e. biggest does not equal best.
- We will ensure that organisational sustainability underpins growth.
- We will seek revenue diversification and margins to invest in empirically sound strategies, both organic and opportunistic.
- We will prioritise our contribution to NZ and international thinking on IF.
- We will foster a climate in which 'wild ideas' are regarded as the 'germs of possibility' to be investigated and, as agreed, tried.
- We will expand the product range (different models of IF, enhancements and technology) and the range of people who can benefit from IF (EIF, DHBs, MSD, ACC).
- We will make every reasonable effort to diversify the funding base. We will analyse risk, ROI and opportunity to ensure sustainable growth.
- We will pursue the thought leadership space with enthusiasm and vigour both in New Zealand and internationally.
- We will develop international credibility and capability.
- We will identify, analyse and pursue strategic partnerships necessary to enable us to realise our strategies and vision.

## Manawanui in Charge Ltd

- A limited liability charitable company incorporated under the Companies Act 1993
- Four not-for-profit disability sector organisation shareholders
- Founded in 2004 as a pilot for Individualised Funding
- Currently assists in excess of 2000 people to manage their government funded supports using Individualised Funding
- Is a \$6M company that administers in excess of \$50M of client funds
- Funding sources include Government Ministries and District Health Boards. Strategies to further diversify are aimed at assisting more people to individualise any supports they receive or employ
- Employs 26 administration/management staff
- Employs 18 Coaches who work directly with IF users
- Operates throughout New Zealand

- Has a board of 7 remunerated directors selected for corporate governance expertise, business skills and experience, commitment to MiC's philosophy and the capacity to assist MiC achieve its vision.
  - 5 shareholder nominated directors
  - 2 independent directors
  - All directors go through a selection process managed by a Board Appointment Panel chaired by an independent governance specialist.

Model and Philosophy

- IF users employ their own staff to assist them to manage their needs. They determine who delivers their supports, how and when.
- MiC provides consulting and coaching designed to assist IF users to establish and manage their funding and all accompanying administrative and legislative requirements.
- MiC offers additional services linked to IF management that IF users choose to use.
- IF users pay a percentage of their funding to MiC for services provided.
- MiC is committed to assisting IF users to live a life that is as ordinary and independent as possible.
- We stay out of the lives of IF uses to the greatest extent possible but are always available to provide support and guidance.

Board of Directors

Name	Special contribution	Background skills and experience
<b>Karen Beard-Greer</b>	Board Chair Deep-level disability sector knowledge Currently CEO of shareholder organisation	Commercial and not for profit management and governance experience
<b>Terry Kilmister (Independent Director)</b>	Corporate governance expertise Disability sector management background	Corporate governance consultant with national and international commercial and NFP organisations
<b>Alastair McLay</b>	Accountant Lived experience as a disabled person	Commercial and NFP management and governance background
<b>Gary Williams</b>	Maori. Ngāti Porou. Disability sector consultant Lived experience as a disabled person Strong national profile as an advocate and influencer Connections in Government Ministries and Maori organisational life	NFP management and governance experience
<b>Diana Puketapu (Independent Director)</b>	Maori. Ngāti Porou Accountant Connections in Maori organisational life Corporate governance expertise	Commercial and NFP background in senior financial roles. High-level corporate governance profile in NZ sporting and commercial life
<b>Raewyn Kirkman</b>	Maori. Ngāti Kahungunu HR specialist Connections in Maori organisational life	Management background in commercial and NFP organisational life. Broad corporate governance experience
<b>Geneva Harrison</b>	Maori. Ngāti Te Aupouri, Ngāti Kahu and Te Rarawa Lawyer Connections in Government Ministries and Maori organisational life	Health service Chief Executive and Governance experience

Management

CEO	Marsha Marshall. Ex Ministry of Health Manager with special responsibilities for establishing IF in NZ
GM	Louise Dickenson. Lawyer. Ex Ministry of Health
Leadership team	HR, Communication and Marketing, Projects, and Quality Advisors
Financial	CFO and 7 financial specialists/accountants
Business Analysis	Three business analysts supporting business development
Coaches	18 Coaches supporting IF uses
Learning and Development	Four planners and educators
General Admin	Two office administrators



# E5ii

## Measuring, Insuring, and Supporting True Community Inclusion: Provider Practices and Research Perspectives

Caitlin Bailey, Julie Bershinsky, Marian Saulino, Kristen Loomis

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**Abstract :**

True community participation and social inclusion for people with IDD remains a priority. However, the operationalization of community participation and social inclusion has so far focused on the degree of physical presence in the community (Amado et al., 2013). Merely physical presence in community settings does not guarantee community membership. There are a vast range of services and supports that call their practices community-based and inclusive; but likely, few of them truly are.

This study will review current legislation, research and measurement on community participation and include a summary of NCI measures. We will address disparities between how we measure inclusion, what we call inclusive, and what we do to ensure meaningful community membership. We'll present a study of approximately 50 provider organizations describing their policies, practices and outcomes related to community and social inclusion. Finally, we'll highlight the outcomes and service models of two leading organizations that provide quality services in people's chosen communities that ensure social participation and integration.

This project bridges gaps between providers and researchers to explore similarities and differences between operations and outcomes of successful models of community and social inclusion and national developments. This collaboration can be a model for other providers, researchers and stakeholders in the disabilities field to increase sharing of information and to inform the measurement of community and social inclusion for researchers.

Participants will learn how community inclusion is commonly operationalized, the resulting limitations, how leading organizations approach community inclusion, and how their outcomes compare to national data and research.

**Learning Objectives:**

1. Learn how community inclusion is commonly operationalized, the resulting limitations, how leading organizations approach community inclusion, and how their outcomes compare to national data and research

**Synopsis:**

This collaboration between two organizations providing entirely person-directed services and researchers from National Leadership Consortium and Human Services Research Institute explores the meaning of true community participation, the best practices of ensuring true community inclusion, and frames it in a national context.

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# E5iii

## The System of the Future: The Origin and Creation of Self-Determination in the United States Including Its History, Setbacks and Victories

Tom Nerney, Patricia Carver, James W Conroy

### Self-Determination: Evidence & Outcomes in the U.S.

Presentation Prepared for:  
*Claiming Full Citizenship: Self Determination,  
Personalization and Individualized Funding  
2015 International Conference*

Full Written Report is at: [www.outcome.org](http://www.outcome.org) under the heading **The Evidence for Self-determination and Personal Budgeting**

James W. Conroy, Ph.D.  
Center for Outcome Analysis

### The Original Concept

- **Self Determination:**
- If people gain control (\$),
- Their lives will improve,
- And costs will decrease
  - (or not increase)

### Money and Quality

- **From a financial analyst Dad in NY:**
  - **My son was in a 6 bed ICF.**
  - **It cost \$100,000 a year.**
- **I pulled him out**
- **because my son didn't have**
  - **a \$100,000 life.**

### Why should others believe that self-determination works?

- Stories
- Scientific research
- Always need both --- depends on audience
- How does policy really work?
  - Reforms As Experiments; Political system sells certainty, solutions, sure things

### Where's the Proof!!!!???

- Robert Wood Johnson Foundation
- We did our first outcome study in NH
- Funded a national impact assessment
- (Outcomes)
- 1998-2002
- Excellent "Before and After" data from seven states
- We also did studies in three non-RWJF states (CA, NJ, NC)
- We have solid data now from TEN states

### A Brief History

- 1993 Original Proposal to RWJF
- 1995 Statewide in New Hampshire
- 1996 RWJF Decision to go National
- 1997 Grants to 19 States
- 1998 10 More Planning Grants
- 1998 National Evaluation Begins
- 1998 10 More States Join With State Funds
- 1999 Michigan shows positive results
- 2000 Michigan, Ohio, Wisconsin, Hawaii

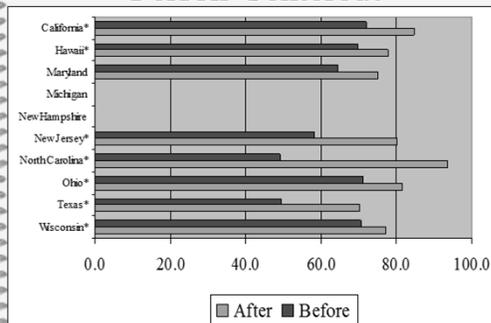
### Numbers: National Evaluation

- CA 120
- HI 74
- MD 15
- MI 135
- NH 42
- NJ 200
- NC 40
- OH 62
- TX 50
- WI 89
- Total 827

### Power and Control

- In order for people to gain power and control over their lives,
- First the individual planning process has to become highly **person-centered**,
- Respecting the wishes and hopes of the person and the person’s freely chosen allies first and foremost.
- Next – Individual Budgets – the tool of control

### Did Planning Become More Person-Centered?

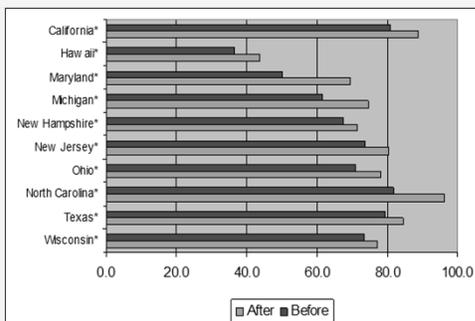


### OK, PCP Increased – But Did Power Shift Toward the People?

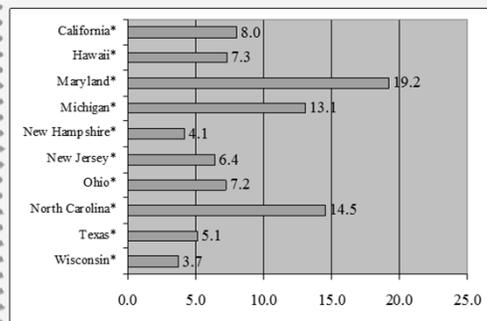
- It’s important to know
- Because PCP is only a **process**
- A genuine shift in power would be an **outcome** –
- A **change** that a lot of people would really like!



### Did Power Really Shift?



### How Much Power Shift?



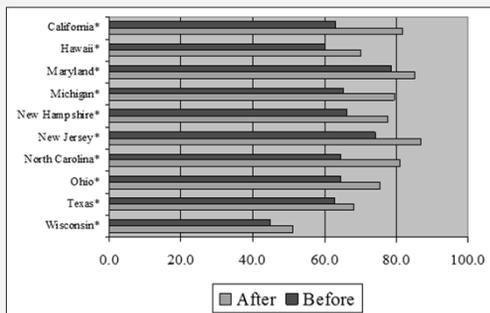
### Power Over Resources?

- Yes, that definitely shifted
- Choice of home
- Choice of how personal funds are spent
- Choice of how residential public funds are spent
- Choice of provider
- Choice of support coordinator

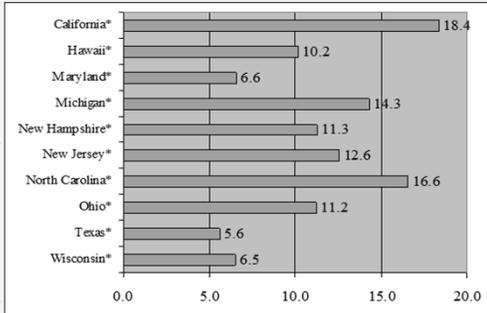
### OK, Power Shifted Toward the People – But Did The Qualities of Their Lives Improve?

- The Quality of Life Changes Scale
- Asked people to rate the qualities of their lives
- In 14 areas
- When they were just beginning self-determination
- And at about 3 years into the process
- Data from 9 states:

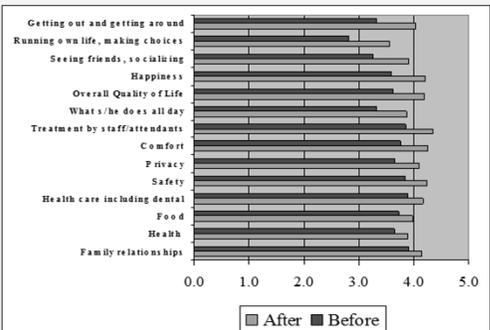
### Improvement in Perceived Quality of Life in 14 Out of 14 Areas – in Every State!



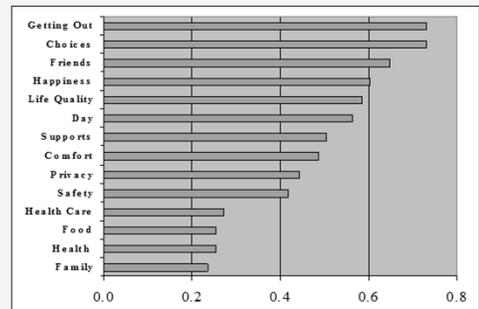
### How Large Were These Perceived Improvements in Quality?

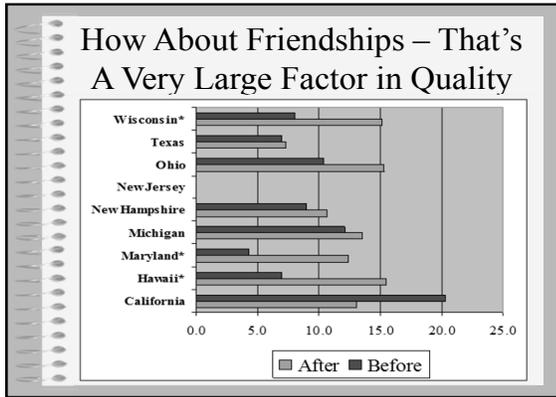


### Those Reports Were From the People, and From Paid Folks – What Did the Families Perceive?

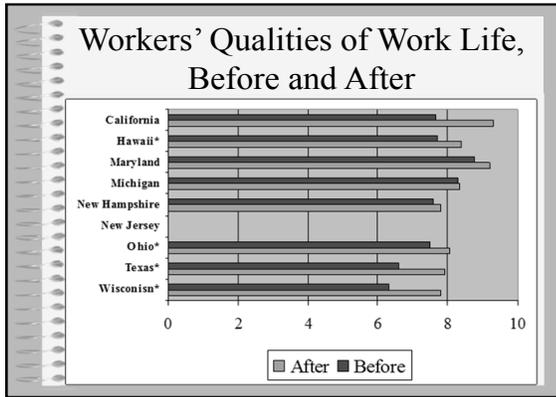


### What Were the Largest Benefits the Families Saw?





- ### What About the Workers?
- The workforce is a critical issue, right?
  - Workers are really the determinant of quality when all is said and done
  - Doesn't self-determination just make their jobs even harder?
  - Isn't there resentment about giving up power and control?
  - Won't they like their jobs less?



- ### Money
- The third part of the theory was that costs would stay the same
  - Or go down
  - When people and their allies got control of resources
  - Did that happen?
- 

- ### Five Solid Cost Studies
- NH: Down 12% to 15%, depending on estimates
  - MI: Down 6% to 9%, depending on estimates
  - NJ: The same as Waiver traditional models (much less than ICFs/MR or Special Needs Group Home)
  - CA: All the participants' costs went up over 3 years, but a lot less than comparable non-participants
    - Now we have a 10 year follow-up too
  - Also: Caldwell J, Heller T. Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellect Dev Disabil.* 2007 Jun;43(5):161-73.

### Cost Increases in CA, 2000-2002

	Start	End	Percent Change
<b>Participants</b>	<b>\$976</b>	<b>\$1,581</b>	<b>62%</b>
<b>Comparison</b>	<b>\$632</b>	<b>\$1,378</b>	<b>118%</b>

- ### The Strength of the Evidence
- Hard data from samples of participants
  - In 10 states
  - Over 800 people tracked for up to 3 years
  - Remarkably consistent in positive direction
  - Variable in size of the effects
  - Partly because of recruitment of different kinds of people

## LOST LIVES

## THE PAUCITY OF QUALITY IN HUMAN SERVICES

An international call for norming quality on universal human aspirations

Tom Nerney

To date most disability quality assurance systems have ignored almost every critical component of quality that all individuals would choose as necessary for a minimally adequate quality life. In addition the unspoken "bargain" made with many individuals who need support is to require all or most of their everyday freedoms to be surrendered in return for support. This raises a core public policy question: can we ever have quality in a system that does not support freedom?

How we define and measure what we mean by quality in the arena of disability creates the foundation for how long term services and supports are organized and reimbursed. Most importantly, how we answer this question has profound implications for individuals with disabilities and for the costs associated with our definition of quality.

Our aging population in need of support too often end up in nursing homes the least desirable alternative according to every American poll of older Americans. Those with intellectual and other developmental disabilities participate in programs that more often than not confer a badge of inferiority. Many are in work activity programs earning less than minimum wage—often much less. They are on a par with convicted felons in our prisons. Others wander or are driven aimlessly throughout our communities like tourists with no money. This is a form of publicly funded loitering. There are exceptions of course but states and countries sorely need to elevate the status of all individuals with disabilities to one of full citizenship. Medicaid, e.g. in the US needs to stop funding segregation and create fiscal incentives to do the right thing including the production of private income. All countries need to reevaluate what constitutes quality. Until all of us posit quality standards based on universal human aspirations, there will be no real freedom and hence only second class citizenship. Self-Determination will simply become another rhetorical device.

What has developed very naturally based on diffuse and no-definition "person centered planning" type of quality norming is the construction and sale of a product or commodity called a human service program. Key to this approach is the adoption of qualitative standards featured by most corporations and industries--primarily consumer satisfaction. This has even resulted in calling those served "consumers" and some of these individuals inadvertently adopting the language of consumerism to define themselves. What are they consumers of? Public funding? The standard remains the same - the J. D. Power commercial and industry norm for quality. The concentration on documenting services rather than outcomes and life quality has been carried to an absurd length.

## Background

The entire Medicaid program in the US spends in excess of 340 billion dollars annually. Approximately one third of that is spent on institutional and community services for individuals of all ages who have a disability. These dollars represent a critical component of each state budget and have been identified by organizations such as the National Governor's Association as the single greatest fiscal threat facing state budgets. In some states the Medicaid line item represents the single greatest state expenditure. Medicaid currently serves almost 50 million Americans or approximately 20% of the entire population of the United States. Long term support services consume just fewer than 40% of total Medicaid expenditures for 14 million of the entire number served under Medicaid.

The Medicaid system is essentially a state program with federal oversight and matching dollars that is indexed to the relative poverty of the state. That said, each state makes its own commitment to serving individuals. State commitments vary widely from a per person low of \$2,722 in New Mexico to highs of over \$7,000 in states like New York, Connecticut, Maine and Rhode Island. The national average expenditure per person is \$4,202. It is a regulation driven program of incredible complexity and detailed organization characterized by a sense of liability and fear of transgressing one or more of countless regulations.

The Medicaid program is in serious fiscal trouble. States are routinely denying eligibility or limiting it severely. The cost of current services is becoming prohibitive. Hundreds of thousands are on waiting lists - some for many years. More will become eligible under the health reform bill recently signed by the President. Nursing homes and public institutions capture the lion's share of Medicaid long term care expenditures. Per capita expenditures in these types of institutions frequently are two to three times more costly than community supports.

The current Medicaid program is on a collision course with demographics. As America ages, the sheer number of those needing support will overwhelm the current system. Within the developmental disability population more individuals live at home with an aging caregiver than are currently served. For historical and other reasons the mental health population has never achieved anything resembling equity in the way Medicaid dollars are allocated. Before our eyes, the current

system is already collapsing.

An example illustrates the very best that this current system can provide. A young adult needs assistance in many activities of daily living. Eligible for Medicaid funding, this person soon finds out that the contracted homecare agency often provides different people to help, are often late and sometimes don't show up at all. However, a new program has just been adopted by the state and this individual is allowed to hire whomever he wishes including friends and relatives. He successfully hires a former schoolmate who provides these services in a timely fashion. This new program is called (among other things) self-direction or participant driven services.

This new and progressive approach is then evaluated. There is no question that the "program" is successful. When interviewed by independent evaluators the person served expresses satisfaction with the services he has planned and receives. The present human service system, even under its most progressive interpretation, has chosen services as the norm for what constitutes quality. And so the ultimate qualitative goal is an expression of satisfaction with the services delivered, as it is in virtually all quality assurance systems. In this example there is a service outcome that makes getting up in the morning and carrying out basic activities of daily living possible. This is the very best that can be accomplished under the present system. Why is it inadequate?

What has developed very naturally based on this type of quality norming is the construction and sale of a product or commodity called a human service program. Key to this approach is the adoption of qualitative standards featured by most corporations and industries--primarily consumer satisfaction. This has even resulted in calling those served "consumers" and some of these individuals inadvertently adopting the language of consumerism to define themselves. The standard remains the same - the J. D. Power commercial and industry norm for quality. The concentration on documenting services rather than outcomes has been carried to an absurd length.

### Self-Determination

By norming quality on the person's ability to use both public and private funds to craft a meaningful life in the community, we would take a far different path with our Medicaid dollars and other countries funding streams, our service definitions and the type of planning done by individuals

Attention to the desires and aspirations of those served are close to afterthoughts in a complex system that is so vast and so regulated that it is beyond the understanding of any one person.

There are no consequences if personal goals are not reached. In fact, in most states the unspoken purpose of a quality assurance system is reduced to health and safety concerns—a worthwhile goal but one that goes to the beating heart of where this complex system focuses on liability at the expense of real life goals. For liability issues there are consequences. For real quality of life issues there are no consequences if they are not met.

Central to the pretense of real quality and personal control, and central to the need to stay within program and service boundaries, is the embracing of what is called "person centered planning", a phrase that supposedly places the person with a disability at the center of the planning process for the provision of services. This is the major way that the human service industry pretends at real quality. A "person centered plan" is vital to what is currently deemed quality for the person because it can now be "demonstrated" that the individual plan is now "owned and endorsed" by the person to be served within a system that features low or no expectations.

There is no universally acceptable definition for what "person centered" means. Each state gets to define its meaning and it may even differ from place to place within the same jurisdiction. This renders the very notion of person centered planning essentially meaningless. In fact, it constitutes a form of paternalism and is frequently rife with conflict of interest. Whatever authority is ceded to the individual with a disability during this planning process can be withdrawn or overridden at any time by managers of the current system. The "authority" of the person served then is neither authentic nor binding. Worse still is the typical composition of the planning team often mandated by state regulation, professional traditions or provider rules: staff of the service provider, the case manager and often other professionals. This can be done with the person present or not and with family/allies present or not. In other words, conflict of interest is built into the very system. Those who are required, or typically assist in planning, frequently have a financial stake in ongoing and future support and service elements selected in the plan. The Centers for Medicare and Medicaid Services (CMS) only recently recognized this conflict of interest and it is not recognized as a problem at the state level. It also constitutes one of the strongest predictors of increases in cost. There is never an incentive to get better value for the dollars when the planning group's self-interest depends on how the budget is apportioned.

The present system of services then is founded on quality concerns devoted more to system operations, service programs and their operation than to the quality of life of the person to be served. Much more time and effort in many systems are devoted to billing, billing codes, service definitions and reimbursement issues than to quality.

By norming quality on the person's ability to use both public and private funds to craft a meaningful life in the community, we would take a far different path with our Medicaid Waiver dollars, our service definitions and the type of planning done by individuals.

We can see this by returning to the example of the young man cited at the beginning of this paper who eventually gets to hire his friend to provide services. What is wrong with this is not the authority to hire a friend and thereby improve his services. What is wrong is what is left out and ignored.

In all probability we would find out with a clearer analysis that this man is probably personally impoverished, may have no control over transportation, and has no close friends or even the support to make close friends by being an integral part of his community. The best of the old system ignores or only partially addresses what gives every other person quality in their lives: a place to call home with control over the front door; community membership; long term relationships; and, at least a plan to address poverty. The best of the current system gives an individual the services to get up in the morning. Conversely, by norming quality on key universal human aspirations, this individual would now have a reason to get up in the morning. This is one essential difference between self-direction and self-determination.

### The System of the Future

Across this country and hopefully others, individuals with and without disabilities universally include the following indices of what constitutes quality or would constitute quality in their lives:

- A safe place to call home with authority over anyone who enters and especially anyone who needs to touch his/her body
- Real membership in, and contribution to, the community with control over the means of transportation
- The support needed to continue relationships and forge new ones, including intimate ones
- Support to end near total impoverishment virtually required at the intersection of Medicaid and Social Security
- More healthy lives based on more meaningful lives with relationships key to promoting health

Norming human service on the lives and the aspirations of individuals with and without disabilities is central to individuals leading self-determined lives. What has evolved in the Medicaid funded human service programs is a set of standards that focus on service delivery and largely ignore standards universally understood to be central to our very humanity. If our public policy supports equal citizenship for individuals with disabilities then it needs to offer the potential for achieving equal quality for these same individuals--equal to what every citizen takes for granted. This means that an elderly person with a disability will not only be supported to live in his own home but (as a result of person controlled planning) to name just one example, keep his family and social relations intact. A person in recovery will be able to freely choose those supports which meet clinical needs and also have a holistic plan for living a full life where any clinical goals are in support of a full and meaningful life. An individual with a developmental disability will be able to take monies available and leave non outcome-based day programs. Instead, this individual can pursue a meaningful job or begin self-employment. From wandering in small groups around the community, each individual will be able to construct and carry out activities that truly connect with the community or result in real work. From earning below minimum wage, (which gives the lie to "medical necessity") the individual plan can now include tools to reach each of the goals articulated in these examples. In these, and in all other examples of personal planning, human services are provided in support of a full life. They become tools in pursuit of a life rather than ends in themselves. The present system has it exactly backwards. What would have to be in place to make self-determination a reality?

First, a conflict of interest-free plan and budget, driven by the person to be served, would be developed with freely chosen assistance as desired. The plan would include how the person is going to address crafting a meaningful life in the community using the universal human aspirations listed above as bedrock for the plan: a place to call home, real membership in the community with control over the means of transportation, continued or newly developed long term relationships and friendships, a plan to utilize some new resources (brokers/peer supports are two examples) to help with this plan and its implementation, strategies to address forced impoverishment and improved health. Depending on age, a plan to get a job or start a microenterprise will be routine, a plan to achieve passive as well as active income will become a natural part of the human support system. In other words, the introduction of private resources to the publicly funded system will become commonplace because it is essential.





E7i

**Spectrum Society’s Journey of Agency Transformation In Support of Personalized Options**

Ernie Baatz, Susan Stanfield



**Spectrum Society**  
FOR COMMUNITY LIVING

“Claiming Full Citizenship” Conference Presentation  
October 15-17, 2015  
Vancouver, B.C.

[www.spectrumsociety.org](http://www.spectrumsociety.org)

**Spectrum Society’s Journey of Agency Transformation in Support of Personalized Options**

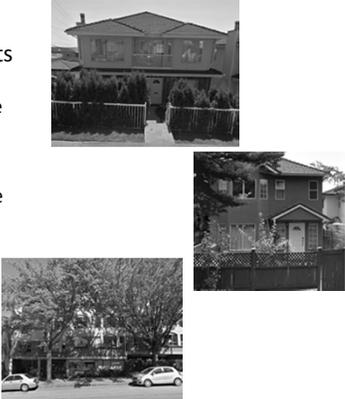
Learning objectives:

- Hear the story of one agency’s journey from traditional to personalized services
- Hear examples of partnership agreements defined between the service provider, individuals and their networks

**Spectrum Society for Community Living**

- Started in 1987
- 130 people served
  - From institutions
  - From other services / agencies
  - Youth in transition to adult services

- Woodlands downsizing projects 1988-1993
  - Assisted 23 people to move into homes in Vancouver
  - One or two people per home
  - Community based day support (no centre)



- Limitations of agency-operated homes
  - Funding tied to the resource, not the person
  - Difficult to unbundle the funding if one person wants to move
  - Pressure to fill “vacancies”
  - Dual role of the agency as landlord and service provider can lead to conflicts
  - Competing demands from multiple external agents (licensing, funders, BC Housing)
  - Responsibility for property maintenance and upkeep



*Linda’s home*

- No day program centre
  - Community-based
  - Discovery
    - Exploration, trial & error
    - Identify personal interests, strengths, gifts
    - “life tasting”
  - Generic rather than specialized options
    - Recreation, employment, activities of daily living
    - “abundant community”
  - Local presence
    - Neighbourhoods
    - Walking, public transit
    - “same place, same time”



- One person at a time
  - Individualized budgets
    - IF / host agency agreements
    - Unbundling group contracts
  - Right relationship
    - Partnership with the person / family
    - Recruitment of staff and caregivers
  - Natural authority
    - Supported decision making
    - Representation agreements

- Agency Transformation
  - Strategic Planning
    - 2010-2013: “Commitment to Partnership”
    - 2014-2017: “Commitment to Relational Leadership”
  - Small Projects
    - Personal Support Networks Demonstration Project (2006)
    - Better Networks Project (2010)
  - Service design
    - Leadership development
    - Supports Facilitators, Kaleidoscope

- ### Service Plans
- Agreement between Spectrum and Individual and their Network
  - Describes how responsibilities for supports are shared
  - Developed before services start
  - Reviewed Annually

- ### Service Plans – What’s Included
- Who controls and maintains housing
  - How are staff selected, trained, evaluated
  - Who assists with personal funds
  - Who assists with medical professionals and appointments
  - Who is involved in managing the budget





## E7iii

## Together is Better: Collective Family-Governed Use of IF in Policy and Practice

Catrina Johnson, Arlene Zuckernick, Tamara Kulusic

### Learning Objectives:

#### Audience members will:

1. Become knowledgeable about models of collective family governance
2. Consider policy approaches to collective family governance
3. Examine the practices of family-governed groups using the example of InclusionWorks!
4. Evaluate the potential of family-governed models to address the challenges of Individualized Funding

### Presentation Summary

In British Columbia and other jurisdictions, Collective Family Governance is emerging as an alternative to traditional IF/participant-directed models of support. Expressed in different organizational forms – from incorporated non-profits and co-operatives to agency hosted, unincorporated collectives (Kendrick, 2011), Collective Family Governance is a model that not only pools funds, but combines the knowledge, experience, networks, and ideas of a small group while offering peer and family support. Leveraging resources within the group and the community, Collective Family Governance is not only cost-effective, the model is values-based and has the potential to build community capacity and act as a catalyst for change to traditional disability services (i.e. day programs). This presentation considers the model in practice, through the example of InclusionWorks! a collective family-governed model encompassing several groups in BC and explores the possibilities and challenges in creating policy on Collective Family Governance.

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## Together is Better: Collective Family-Governed Use of Individualized Funding in Policy and Practice

**Presenters:**

**Catriona Johnson, Parent Lead, InclusionWorks! Saanich**  
**Tamara Kulusic, Manager of Policy and Program Development, CLBC**  
**Arlene Zuckernick, Parent Lead, InclusionWorks! Victoria**

## What do we know about Individualized Funding/Self-Direction?

- Enables greater independence and community inclusion, provides greater flexibility and reliability of services, generates higher satisfaction, and improves quality of life, physical health and emotional well-being.
- Increases the capacity of individuals, families and communities, promotes integration of individuals in community, and allows for creative programmatic solutions, in some cases at a cost less than traditional services.

(Laragy & Ottman, 2011; Halliwell & Glendinning, 1998; Stainton & Boyce, 2002; Simon-Rusinowitz, et al., 2005; Witcher, et al., 2000; Glendinning, 2008; Carlson, et al., 2007; Blackman, 2007; Lord & Hutchison, 2003; Stainton et al., 2009).

## However, take up has been slow....

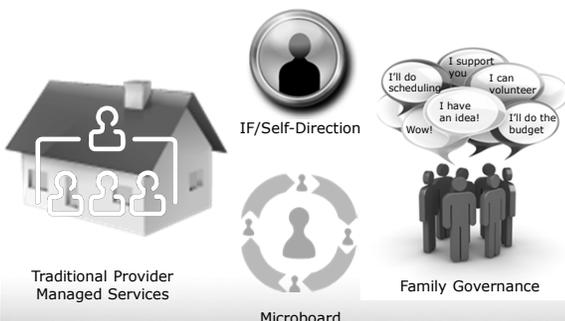
- Criticisms relate to the safety of individuals, the difficulties in managing budgets and services, and the risks of inequality, dependency, increased isolation and lack of peer support.
- Concerns over the strength and stability of support systems, accountability over public funds, its disproportionate use by middle class individuals/families, and its role in a larger movement towards the privatization and individualization of welfare, the erosion of public responsibility, and the weakening of public services and, further, the collective voice in support of a strong, public system of supports.

(Glendinning et al., 2008; Riddell et al., 2005; Blackman, 2007; Leece & Leece, 2006; Barnett & Barnett, 2006; Lawson, 2007; Gleeson & Kearns, 2001; O'Brien, 2001).

## What is Collective Family Governance?

- A way for "families to work together to identify and meet their needs."
- 3 collective models:
  - Unincorporated/unaffiliated, collectively governed mini-projects to create individualized and other service arrangements
  - Collectively member governed organizations to create individualized and other service arrangements [e.g. incorporated cooperatives and mini-agencies]
  - Agency hosted, unincorporated, collectively member governed organizations to create individualized and other service arrangements
    - (CLBC, 2009, p. 2; see also Kendrick, M., 2011).

## Families consider Possible Models of Support



## Examples of Collective Family Governance

- The Benambra Intentional Community Co-operative (Canberra, Australia)
- Homes West Association (Brisbane, Australia)
- Lifestyle Options Incorporated (Stones Corner, Australia)
- Deohaeko Support Network (Pickering, ON)
- GIFTS: Gulf Islands Families Together Society (Saltspring Island, BC)
- Coco Café: Cedar Opportunities Co-operative (Cedar, BC)
- Comox Valley Youth Project (Courtney, BC)



### History of InclusionWorks! Victoria

- o Started in 2010: Little or no government funding for adults with disabilities.
- o Two Single Moms hatched a plan, and included other families – some with and some without funding.
- o IW! Victoria started with 7 families (now has 8).
- o Given 38 CLBC hrs/wk initially (now 120).
- o Staff – started with 2 contract support workers (now has 4).



### Following InclusionWorks! Victoria...

#### **InclusionWorks! Saanich**

- o 2012
- o Started with 6 families.
- o Initially provided with 56.5 CLBC hrs/wk (now has 99.5).
- o Started with 2 contract support workers (now has 3.5).

#### **InclusionWorks! South Island**

- o 2014
- o Started with 11 families.
- o Initially provided 88 hrs/wk.
- o Started with 3.5 contract support workers.
- o Started this last September.

**InclusionWorks! North Shore starting up on Mainland and InclusionWorks! 2015 forming in Victoria.**

### Philosophy and Values

- o We believe that:
  - Self-advocates and families are best positioned to make choices regarding their future and with the appropriate opportunities, training, and support, can make a meaningful contribution;
  - Canadian society is enriched by inclusion;
  - The presumption of legal capacity should be upheld through supported decision-making;
  - Everyone is entitled to have friends; and
  - We adhere to the principle of the "dignity of risk."



### Family Governance means

- Self-advocates and family members form the decision-making team for all matters
- Self-advocates and family members select the support workers, who are hired or contracted through a Host Agency
- Self-advocates and family members decide how to use resources
- Self-advocates and family members determine programming
- Self-advocates and family members form partnerships.



### Why InclusionWorks!

Right to continue as part of community



Limited funds available for Community Inclusion



Differing needs from previous generations

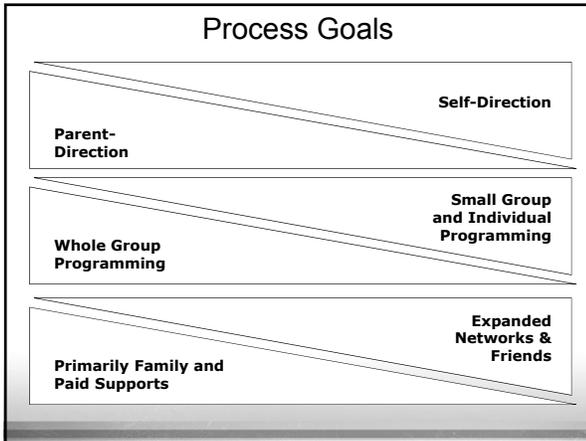


Families wish to take more responsibility

### InclusionWorks! is...

- o A model of family governance in which transitioning youth and their families collaborate during a five year transition period.
- o Individualized, age appropriate, challenging programming for each participant.
- o Activities up to 7 hours daily, 5 days a week with focus on employment, life skills, friendships, and inclusion in community.
- o Uses community spaces and programs as much as possible.





- ### InclusionWorks! Community Partners
- o **Community Living BC**
  - o **Community Living Victoria (Host Agency)**
  - o **South Island Distance Education School (SIDES)**
  - o **University of Victoria Faculty of Education (Centre for Outreach Education - CORE)**
  - o **GT Hiring Solutions (WorkBC)**
  - o Flow Communications
  - o Camosun College Community and Education Assistant Program/Family and Child Studies Program
  - o Lifetime Networks
  - o EntreActive
  - o The Vital Program
  - o University of Victoria Child and Youth Care Program/Physical Education Program/Applied Theatre Program/CanAssist
  - o Gordon Head, Cedar Hill, West Shore, Pearkes and Commonwealth Recreation Centers
  - o Vic West Community Centre
  - o Woivod Dance
  - o Pacific Institute for Sports Excellence
  - o Finding the Balance Yoga
  - o Power to Be Society
  - o Conservatory of Music
  - o Local Businesses
  - o Independent Consultants

### Financial Structure

- All government (IF) and other funding/resources received by the participants is pooled.
- Families pay a small monthly amount.

### Why Family Governance...

“An issue for this generation is that many services provision models provided for adults with disabilities in Canada today, such as day programs, group homes, vocational services, and post-secondary options remain largely unchanged over the last 20 years and have not evolved to meet the assumed unique needs of this (current) transitioning group of young adults with disabilities.”

o From: Leif Rasmussen, Kathleen Haggith and Jillian Roberts  
Transition to Adulthood, Moving Needs Into Practice: A Canadian Community Partnership Response to New Adult Service Needs for Individuals with Disabilities, Relational Child & Youth Care Practice, Volume 25, No 3 2011

Concern About IF/Self-Direction	How Family Governance Addresses
Ability to manage supports and budgets	Diverse skills; Stronger likelihood of organizational and budget skills in group
Too bureaucratic	Combination host agency/FG lessens bureaucracy
Cost effectiveness	Leveraging of resources increased
Safety of individual	Small village; More eyes on person
Risk of Fraud in \$/Services	Host Agency; More eyes on \$ and services
Isolation of individual	Peer group; Community Inclusion
Lack of Family Support	Built-in Support Network
Privatization	Community development model
Reduced collective advocacy	Small collective; principles of social justice; linked groups; person and family driven
Risk-Averse	Support for risk-taking; risk-takers bring group along; flexibility
Individualistic	Interdependent; Programming without walls
Quality	More ideas; healthy tension of individual vs group; dependent on each other to make it work

- ### History: The Think Tank on Family Governance and Beyond
- o Grass roots project
  - o Benefits of Collective Family Governance
  - o Pilot projects
  - o Characteristics of sustainable groups
  - o Board Coffee and Conversation
  - o Dovetailing with the IF agenda

### Policy on Family Governance

- Legitimizes model
- Directs staff
- Links to mission, IF policies, strategies, systems
- Clarifies roles and responsibilities
- Provides operational framework for families and self-advocates, and funder
- Offers protections to families and self-advocates
- Risks being prescriptive and/or rigid
- Risks stifling innovation
- Potential drift from intent
- Risks becoming top-down instead of grassroots

### Development of Policy

- Enabling approach
- In partnership with self-advocates and families
- In consultation with Host Agencies
- Building on IF policy
- Guidance
- Innovation

### Family-governed groups

- Health and safety needs
- Collective vision
- Programming priorities
- Allocation of resources
- Process to address conflicts
- When someone wants to leave
- Disbanding of group
- Other

### Questions?



[www.inclusionworks.ca](http://www.inclusionworks.ca)  
[arlenezuck@gmail.com](mailto:arlenezuck@gmail.com)  
[catriona123@gmail.com](mailto:catriona123@gmail.com)



[www.communitylivingbc.ca](http://www.communitylivingbc.ca)  
[Tamara.Kulusic@gov.bc.ca](mailto:Tamara.Kulusic@gov.bc.ca)

## E8i

# Individualized Funding in Canada: a Pan-Canadian Review of Emerging Policy and Program Implementation

Gordon Kyle, Patti Chiappetta, Judy Hannah

## INDIVIDUALIZED FUNDING IN CANADA

Presented October 17, 2015  
 Claiming Full Citizenship 2015  
 International Conference

Presented by:  
 Member of the National  
 Individualized Funding Discussion  
 Group

## Canadian Provinces and Territories



## Individualized funding Advocacy

- ▣ IF began as result of pressure brought by advocates, for example:
  - British Columbia: 1970's - families of residents of Woodlands Institution advocate for IF as model for funding closure
  - Alberta: 1980's - families of individuals with significant challenges who could not obtain support through service providers
  - Ontario: June 1980 - Judith Snow secures order in council for first individualized funding arrangement

## Policy and Legislative Reform

- ▣ Comprehensive policy frameworks in some jurisdictions (Alberta)
- ▣ Funding mechanisms and evolving policy in other jurisdictions (Saskatchewan, Manitoba, Ontario, New Brunswick, Prince Edward Island)
- ▣ Slow implementation in others (Newfoundland, Nova Scotia, BC\*)

## A Little More Detail

- ▣ Ontario
- ▣ Manitoba
- ▣ Saskatchewan
- ▣ Alberta

## Ontario

- ▣ First IF program 1982 for respite services
- ▣ First IF legislation introduced in 2008
- ▣ At present IF represents about 8% of funding for supports and services to people who have an intellectual disability
- ▣ Capped at \$35,000 (25 plus 10)
- ▣ Difficult to access full range of support for creating a home in community
- ▣ Policy framework still under development
- ▣ Growing recognition of the value of independent facilitation

### Manitoba

- ❑ In the Company of Friends (ICOF) launched as a pilot project in 1993
- ❑ ICOF – individualized, one-source funding
- ❑ ICOF embraces Support Networks
- ❑ Manitoba Vulnerable Person’s Act 1996
- ❑ Innovative LIFE Options Inc. (LIFE) created in 2000 provides resources, guidance and support

### Saskatchewan

- ❑ Joint community – government policy development since 2012
- ❑ Demonstration project June 2014 - December 2015
- ❑ Final decision hoped for in spring 2016
- ❑ Want IF to be option on menu of services
- ❑ Funding will be based on individual plan and needs within standard funding guidelines

### Alberta

- ❑ IF for families of children (under 18 yrs of age) in place for 40+ years; over 90% access supports through IF
- ❑ IF for adults in place for 30+ years; 15 % access IF (down from 30% in early years); growing annually
- ❑ Inclusion Alberta established province’s first and only resource centre to assist adults and their families in all aspects of IF
- ❑ All IF flows to individuals/families directly
- ❑ No upper limits to funding

### National Individualized Funding Discussion Group

- ❑ Formed to promote national dialogue and to coordinate advocacy action on IF
- ❑ 9 of 10 provinces represented on discussion group
- ❑ Range of perspectives included (family members, researchers, academics, service providers, policy experts, etc.)

### Individualized Funding – A Framework for Effective Implementation

- ❑ Recognizes IF as significant tool for advancing goals of UN Convention
- ❑ Developed as resource for government, families and service providers
- ❑ Aimed at working towards a consistent understanding of what IF is, the role it plays in providing supports and strategies for advancing implementation

### Four Key Principles

- ❑ Self determination
- ❑ Individual control of needed supports and services
- ❑ Supports that are person-directed, comprehensive, flexible, responsive and reflective of what the person envisions for their life
- ❑ Role of family and friends recognized and given legitimate status

### Six Essential Elements

- ❑ Eligibility
- ❑ Funding
- ❑ Planning
- ❑ Supports for Implementation
- ❑ Quality Evaluation
- ❑ Accountability

### Eligibility

- ❑ Criteria is fair and transparent and is based on disability related support needs
- ❑ Universally available to all eligible individuals
- ❑ Not based on perception of persons ability to administer the funds

### Funding

- ❑ Based on person directed plan developed by the individual
- ❑ Involved direct payment to the individual (or designated supporter)
- ❑ Is subject to transparent ceilings and guidelines

### Planning

- ❑ Is directed by the individual
- ❑ Planning functions are separate from eligibility, service deliver and funding functions
- ❑ Be available as needed over time

### Supports for Implementation

- ❑ A support structure is necessary
- ❑ In may be informal (Support Circle, family/friends) or formal (Microboard, resource centre)
- ❑ Supports are distinct from funding, eligibility and assessment process
- ❑ Provision of legal framework for supported decision making

### Quality and Evaluation

- ❑ Success is self measured
- ❑ Ongoing evaluation
- ❑ Clear quality standards of services are in place
- ❑ Safeguards to protect rights
- ❑ Appeal mechanisms exist
- ❑ Issues that arise (policy and/or service delivery) are monitored and attended to





# Is a Diagnosis of Mild Cognitive Impairment a Blessing or a Curse?

Arlene J Astell, Amy Hwang



**Is a Diagnosis of Mild Cognitive Impairment a Blessing or a Curse?**

**Arlene J. Astell**  
Centre for Assistive Technology and Connected Healthcare, University of Sheffield, UK &  
Ontario Shores Centre for Mental Health Sciences, Canada



<ul style="list-style-type: none"> <li>• University of Toronto</li> <li>• Alex Mihailidis</li> <li>• Rajjeet Phull</li> <li>• Amy Hwang</li> </ul>	<ul style="list-style-type: none"> <li>University of Sheffield</li> <li>Arlene Astell</li> <li>Tim Gomersal</li> </ul>
<ul style="list-style-type: none"> <li>• Simon Fraser University</li> <li>• Andrew Sixsmith</li> <li>• Piper Jackson</li> </ul>	<ul style="list-style-type: none"> <li>Karolinska Institutet</li> <li>Louise Nygård</li> <li>Eva Lindqvist</li> <li>Annika Vasiliou</li> </ul>

**Background: What is MCI?**

- First appearances in the clinical literature in 1990s
- “[A] boundary or transitional state between normal aging and dementia” (Petersen et al. 1999, p. 303)
- But - not all develop dementia
- Does not affect daily functioning – though more complex activities may be affected

**Controversies**

- Several diagnostic criteria have been proposed, with different levels of subtyping.
- Prevalence rates between 3 and 42% (Ward et al. 2012) – one consequence of divergent criteria / operationalisation?
- What exactly is ‘normal aging’ anyway?



**Research aims: part 1**

- To synthesise the existing qualitative literature on people’s experiences of being diagnosed, and living with, a MCI diagnosis
  - How do people make sense of the label?
  - What are the psychosocial implications of being diagnosed?
- Metasynthesis: A qualitative approach to putting studies together

**Findings**

- Two overarching, conceptual themes developed:
  1. ‘MCI and myself in time’
    - Past
    - Present
    - Future
  2. ‘Living with ambiguity’
    - ‘normal’, ‘non-normal’, or ‘pathological’?
    - Uncertainty in diagnosis and information

### Theme 2(i): Uncertainty of diagnosis / info

- People were told about MCI in lots of different ways throughout the literature.
- “My feeling is there is a lot of guesswork involved and that people don’t really know. Do you have early-stage Alzheimer’s? Do you have MCI? Is there a difference? [...] It’s like trying to make sense of nonsense” (Beard & Neary, 2013, p. 138).

### Theme 2(ii): ‘normal’, ‘non-normal’, or ‘pathological’?

- People questioned whether MCI was a ‘real’ problem, or ‘just part of aging’.
- “Well... I think I was relieved [...] I was concerned probably like everyone else would [be], that I had Alzheimer’s, and then he said, ‘you don’t have Alzheimer’s,’ and you know that’s like taking a cloud off your shoulder [...] so giving it a title, you can call it anything you want, but it’s not Alzheimer’s, so I can live with it” (Lingler et al. 2006, p. 795-796)

### Research aims: Part 2

- Collaborate with people who receive an MCI diagnosis to understand the impact on them and their families over time.
- Identify areas where they would like more information/support/assistance
- Examine role for technology in enabling people to live as well as possible

### Conclusions

- MCI diagnosis as ‘double-edged sword’:
  - Benefits: Earlier intervention, support, self-management, legitimacy of medical label
  - Drawbacks: Ambiguity of label; stigmatising of older age?
- Important to understand clinical communication around MCI
- People want to understand what to expect, how to access advice and support, how to make plans for the future

# E9i

## Together, One Dream

Nancy Wallace-Gero, Marilyn Godard, Raymond Renaud



**Together, One Dream**  
 Claiming Full Citizenship: Self Determination,  
 Personalization and Individualized Funding: 2015  
 International Conference  
 Saturday, October 17, 2015, 9:30 a.m.  
 Vancouver, BC

### Presenters

**Raymond Renaud**  
 Self Advocate, New Day, Leaders of Today

**Marilyn Godard**  
 Co-founder and Member of Ensemble Advisory Council

**Nancy Wallace-Gero**  
 Executive Director, Community Living Essex County

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### Together One Dream Model

- ‘Together, One Dream’ is a supportive, collaborative approach, where the health and wellbeing of people of all ages with an intellectual disability and their families is valued and improved.
- This model is key to keeping the agency on course for families and people supported, and helps guide the ongoing transformation of services and supports in Essex County.

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### Why Are We Here?

- To share the benefits of the successful and sustainable ‘Together, One Dream’ model
- To highlight how shared values enhances supports and services that are responsive to each person and their family
- To provide tools to assist you to develop a similar model

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### Together , One Dream Model

- Innovative partnership between Community Living Essex County, Ensemble (families), New Day, Leaders of Today (self advocates)
- The model ensures people receiving supports and families have a strong voice at all tables
- Open communication promotes increased dialogue and improves understanding - resulting in better service and support responses

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### About the Model (continued)

- Merging each partner’s resources and expertise can lead to greater options in approaches to strengthen and build new supports
- The agency provides financial support to each independent partner to ensure sustainability

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**New Day's Mission:**

*"Committed to informing and teaching others about rights, duties and how to advocate for oneself. By sharing our abilities we can inspire people to believe in themselves and open minds to new possibilities."*

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**History of New Day**

- New Day, Leaders of Today was created in 2004 by people with disabilities, in order to:
  - Discuss what is important to them
  - Learn how to get their messages across
  - Improve self-advocacy leadership within the agency
  - Initiate direct involvement in changing community attitudes (closure of institutions), influence needed societal changes and affect positive change at the agency

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**What We Do at New Day**

- All members are equal, therefore, there are no titles within the group
- General membership meets once per month,
- Small working group meets twice per month
- Develop an annual theme – "How to Build Independence" (2015)

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**What We Do (continued)**

- Provide training to employees and external groups (KARE training, Speaker's Bureau to schools, clubs, etc.)
- Membership on a variety of agency committees to provide input on many topics
- Assist the agency in writing policies and documents in plain language
- Advocate with elected officials at all levels of government

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**Agency Support to New Day**

- Provides trained support staff ("helpers") to assist advocates to accomplish New Day's plans
- Assist with financial management of New Day budget
- Provides office space, equipment, administrative support, transportation and anything else needed

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**Ensemble's Vision:**

*"All people with disabilities will be respected, supported, and embraced as valuable contributors to their community."*

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### History of Ensemble

- Started by 2 moms whose lives had been affected by their children’s diagnosis of a disability
- They felt the need to connect with others, create a unified voice to engage with professionals and affect change
- They approached Community Living Essex County to gain support for the formation of a family leadership group

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### What We Do at Ensemble

- Ensure an independent voice for families that influences the creative development of responsive support models
- Family’s needs are promoted and impact strategic planning throughout our community
- Parents become the teachers and the professionals become the students.

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### What We Do (continued)

- Provide timely and current information in an understandable and respectful manner; resulting in the removal of **isolation** and the promotion of **empowerment**
- Provide a family leadership perspective – within the agency, throughout the community and with all levels of government

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### Agency Support to Ensemble

- Financial support – budget of approximately \$40, 000 per year
- Provides office space, equipment and administrative support
- Family consultants have open access to dedicated professionals
- Undertaking joint ventures with the agency and people receiving services
- The agency assists with and applies for grants and issues donation receipts on Ensemble’s behalf

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COMMUNITY LIVING  
Essex County  
*Inspiring Possibilities*

Community Living Essex County’s Vision:

*“A community that celebrates inclusion and inspires possibilities.”*

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### History of Community Living Essex County

- The organization was started 55 years ago by parents who insisted that their children have the opportunity to learn and grow in their home community
- Our history is founded on families making decisions and the organization responding
- As the agency grew, it became less family driven and more of a range of options provided by the agency – driven by government policies and funding agreements. The agency became very structured and somewhat less responsive to individual family requests.

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**History (continued)**

- The earliest services included a pre-school day nursery program, a day school program for school-aged children and school transportation
- The agency continued in a journey to listen to families and people receiving services – it was a foundational value
- Categories of services are no longer relevant – what families and people receiving services want is what matters!

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**Together, One Dream  
Working Together**

- In 2014 the organization was accredited by Focus Accreditation with the highest level of accreditation - Ensemble and New Day were a very important part of the accreditation process
- Ensemble and New Day work with the organization to train all employees, to give employees an understanding of the lived experiences of people receiving services and their families

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**Together, One Dream  
Working Together (continued)**

- Participate together in seminars, workshops and presentations to provide information and resources from all perspectives
- New Day, Ensemble and the agency will work together when there is an issue that needs to be solved and advocate together for all people, including those we do not support directly

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**Together, One Dream  
Video**

7 minutes 4 seconds

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**Benefits of the Partnership**

- Enhances positive, person-directed outcomes
- Allows proactive, efficient and meaningful delivery of agency supports and services
- Provides a voice from those with the lived experience
- Creates a shared understanding – eliminating assumptions
  - Partners understand each other's roles
  - Able to identify shared values/visions





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**Benefits of the Partnership (continued)**

- Promotes information sharing and good communication
- Facilitates an understanding of how supports, services and funding works – reduces confusion
- Informs families in a timely way about Ministry changes – especially in a time of Transformation in the DS Sector
- Provides a supportive connection between direct support professionals, families and people receiving services





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### Essential Elements – New Day

- Self-advocate volunteers, with a desire to stand up for what they believe in
- Agency and all direct support professionals make a commitment to be involved in supporting the goals of New Day
- New Day decides what is important to them and identifies the resources they need to move forward
- Separate email address, business cards and phone extension to receive and provide information
- Have confidence to request funding and assistance for New Day as they determine the need.

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### Essential Elements - Ensemble

- Volunteer family members willing to sit on the Advisory Council, attend regular meetings and guide family leadership consultants
- Agency must provide support and make an ongoing commitment
- Separate email address, business cards, phone extension and website
- Contracts with self employed family leadership consultants, providing structure, accountability, and sustainability
- Consultants commit to office hours, prompt responses to phone calls/emails and ongoing community networking
- Work from a workplan approved by the Advisory Council

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### Essential Elements - Agency

- Agency Board of Directors must be invested and willing to take on the commitment of the partnerships
  - Operating in a true partnership and really listening to and valuing the partner groups
  - The entire agency staff must be oriented to and open to working together with the partner groups
  - Family leadership expertise will challenge the agency to think and behave differently
- Board of Directors must be willing to make a financial commitment to ensure the sustainability of the partners, based on presentation of clear objectives and a workplan of activities.

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### New Day

#### Challenges:

- Never enough money
- Broadening membership
- Active and involved membership
- Communication in ways that reach everyone
- Breaking down barriers to inclusion
- Finding the right support

#### Solutions:

- Fundraising; Grants; Open communication with agency for financial assistance
- Community outreach; increased awareness throughout agency
- Engage the members of the group in choosing topics of greatest interest
- New Day is accessible though telephone, email, meetings and through presentations
- Promoting ability and involvement
- Careful selection to ensure a good match in skills and understanding of role as a support to New Day

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### Ensemble

#### Challenges:

- Raising community profile and understanding of the role
- Engaging more families and community members
- Remain focused on issues that are important to families
- Limited resources

#### Solutions:

- Online presence; committee involvement; community presentations
- Assertive marketing and public awareness campaign utilizing partners, website and social media
- Advisory Council meets regularly and is made up of family members – working from an Annual Work Plan
- Additional resources are secured through grants; utilizing students, interns and volunteers

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### Community Living Essex County

#### Challenges:

- Additional costs and strain on limited resources
- Ongoing Board of Directors' commitment
- Partner workplans must support the agency's vision
- Decisions take time

#### Solutions:

- Willing to commit human and financial resources to the partnerships – a real priority!
- Accomplishments and benefits outweigh the cost
- Open and ongoing communication with partners – involvement in all major strategic decisions
- Listen to the voice of each partner – and understanding the varied perspectives – results in better decisions

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### In Summary...

- ‘Together, One Dream’ partnership works well because each partner believes in **inclusion, advocacy, working together, community involvement – and realizes decisions are better together!**
- Each partner is interdependent on each other in a healthy relationship – that also promotes and values differing perspectives
- We are proud of the work we have done together – and equally very proud of the individual accomplishments of New Day, Ensemble and Community Living Essex County

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### Questions?

SPECIAL THANK YOU TO



FOR MAKING THIS PRESENTATION POSSIBLE!

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### Contact Information

- **New Day, Leaders of Today**  
[newday@communitylivingessex.org](mailto:newday@communitylivingessex.org)
- **Ensemble**  
[ensemble@communitylivingessex.org](mailto:ensemble@communitylivingessex.org)
- **Community Living Essex County**  
[nancywallacegero@communitylivingessex.org](mailto:nancywallacegero@communitylivingessex.org)

Connect with us online!



## E9ii

## Much More to Life than Services: Strengths-Based Practice Unpacked

Bob Rhodes

An introductory discussion about how the nature of institutions compromises their stated intentions  
And how a Framework for Strengths-Based Practice both:

- Supports citizens to assume greater control and pursue their 'Good Life'
- And challenges institutions to redesign systems and alter mindsets that obstruct the realisation of their fundamental purposes

As I've only 20 minutes to present, I'll refer you to my book, *Much More to Life than Services* and our website, [www.livesthroughfriends.org](http://www.livesthroughfriends.org) if you want to know more about LivesthroughFriends history and practice.

The key messages in my presentation will be:

- Design against demand not against expertise – lessons from Vanguard Thinking Method cases/ Seddon et al
- Develop expertise in the light of demand – be what's required and not limited by what we do/professional straight-jacket
- Apply lessons from Asset or Strengths-based Thinking and Practice – (refer to Hammer and Saw, Mike Green) – especially in respect of understanding the natures of Institutions as against Citizens' Associations.
- Consider changing the 'Question' from Needs and Services to Assets and Aspirations to what really matters? – learned most from Vicki Cammack and Al Etmanski (PLAN) here in Vancouver

What happens when we make time to listen? I'll explore this very quickly through the medium of 3 stories: Joe Powell, Ray Cox, Kieran

So it's about what happens, what we do, having listened...

An example: Tony Phillips (speaking after 30 tumultuous and successful years, and more than 25 sustained initiatives, responding to what people are saying) – "I trained to be a Social Worker and had to leave the system in order to practice." "To do that I needed to be a businessman, a community builder, a developer, a house builder, a counsellor and mentor, a trainer..."; the list goes on.

And for us at, as it is now, LivesthroughFriends - as we reflected on what we practice, teach and consult around – we identified what we call the 'Framework' within which we approach our work.

- Support and challenge people to get clear about what really matters to them and how they want their lives to develop – a clear direction of travel
- Help people strengthen and/or build a network of reciprocal relationships and secure social capital
- Develop ourselves and others as effective and creative thinkers, possibilities makers, and problem solvers – able to respond to what we hear
- Support people to grow as contributing citizens – engaged with others in their communities
- Understanding all the assets – never starting with the 'money' – and valuing those things that cannot be bought
- Committing to the journey for as long as we are called upon – life is not comprised of disjointed episodes

And, to conclude, I'll quickly recount a current story – Matthew (pseudonym).

Recommended Reading and Books Referenced

The Abundant Community John McKnight and Peter Block Berrett-Koehler ISBN: 978-1-60509-564-4

Go MAD – The Art of Making a Difference Andy Gilbert Go Mad Books Tel: 01509 891313 Amazon have it!

ABCD in Action – When People Care Enough to Act Green, Moore, O'Brien & McKnight Inclusion Press ISBN – 10: 1-895418-74-7

Much More to Life than Services Bob Rhodes FastPrint/Big Lottery ISBN: 978184426808-5

Delivering Public Services that Work Vol 1 John Seddon & Peter Middleton Triarchy Press ISBN: 978 - 0956263162

Delivering Public Services that Work Vol 2 Charlotte Pell and John Seddon Triarchy Press ISBN - 1908009685

The Whitehall Effect John Seddon Triarchy Press ISBN: 978-1-909470-45-3

# E9iii

## Empowering Self Advocates to Take Action: A BC Cooperative

James White, Michael McLellan, Ryan Groth, Barb Goode



### ESATTA

#### Empowering Self Advocates To Take Action Cooperative

*"We support Self Advocates to find their voices through workshops and training"*

#### What is a Cooperative?

A cooperative is a group of people helping each other out to achieve a common goal



#### Why We Developed ESATTA Workers Cooperative

- Always wanted to be our own Boss
- Have more control over what I do for a job
- Feel like I am needed
- Can use my skills FOR A GOOD PURPOSE
- Use our life experiences to develop useful workshops
- Leadership to create new ideas



#### ESATTA's Purpose

Help people find their way in life through training sessions, education and sharing experiences.



#### Direction we are taking with the Coop

We teach People Planning Together have developed workshops on Self esteem , Breaking Down Barriers, Grief ,lead World Cafes, have developed customized workshops for clients & guide people on how to develop a cooperative



## LIGHT YOUR PATH WHILE LIVING LIFE IN THE FAST LANE

Presented by : Empowering Self Advocates to take Action Cooperative members



- This training is designed to give you some tools and techniques to help you recognize the direction you want to take with issues you may have around Self Esteem and confidence.



## People Planning Together

Updated June 2009 with input from:

Gladys Duran - Semihamoo House Society  
 Jennifer Dibello and Dayna Davis - Oregon  
 James White - Community Living British Columbia  
 Bob Sattler - The Planning Place  
 Ed Little - Mentor Oregon Brokerage Services  
 P. Sue Kullen - Planning Innovations  
 Julie Palette & Judy Duffy - HSA Canada



The Learning Community

Original authors : P. Sue Kullen with support from The Learning Community for Person Centered Practices with Crawford County Human Services and LEAP - April 2004

### Why develop a plan on yourself?

People develop plans for a lot of different reasons. What you put into the plan depends on how you want to use it and what you want to do with it. You may want to use it for any one (or more) of the following reasons -



- To learn more about yourself
- To help other people understand how to support you
- To give to your case manager/support coordinator to use in developing your plan together
- To write your own person centered plan for your support agency to use.

How you want to use it effects what you need to put into it. If you are just using it for yourself then you put in (or leave out) whatever you want.



If you want it to be your "official" plan then it may need to have all of the information required by your support agency.



- The program is designed to help people:
  - Plan a good life in the community for themselves or with their family
  - member;
  - Understand a range of options for support in their community;
  - Design personalized support options using new skills and knowledge;
  - Navigate systems and negotiate for themselves or their family
  - member; and
  - Develop advocacy and leadership skills.

## Why do we need CILLI?

- Community Consultations Showed a Need for:
  - Help with learning systems of services and supports
  - Space to imagine a life beyond systems
  - Understanding our own place in planning and decision making

Plan → Goal

**Planning Tool**

What is important to me and for me about taking the CILLI course

Examples: I want to take the CILLI course so I can have more control over how I live my life. I chose who my friends are. I watch what I want on TV. I eat the foods I want to have. I work at a job that I love. I go out to events when I want. I buy the things I want. I go on trips to places I want to go to.

Examples: I want to learn how to make wise decisions around my health. How to chose a safe place to live. The best way to meet people that are real friends. How to eat the right things and keep healthy. When I am having fun how to do it in a safe healthy way. like where I go for fun , who I hang with and what I share with people and what is personal.

**Goals:** Pg2  
 These are the things I want to accomplish to be more involved in my community:

1: 

2:

3:

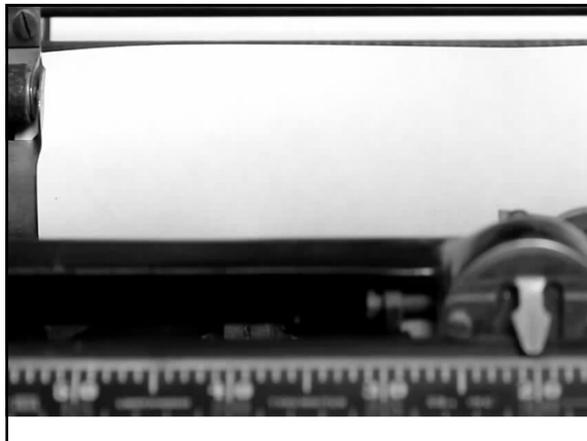
**Examples:** I will go to church once a week and talk to a new person every time. I will go to the singles dance and introduce myself to two people. I will volunteer at the SPCA. I will learn how to dance so I can ask a girl to dance. I will join a book club to meet new people.

**Supports** I need and want when taking the CILLI course:



**Examples:** I need support to read the material in the CILLI course. I need someone to help me with my assignments. I need someone to explain some of the words used in the course material. I need support to use the computer. I need reminders when the expert sessions are being held. I need support writing out my information when completing the modules. I need support getting to the retreat. I need support with my confidences speaking in public.

Pg1



**BREAKING DOWN BARRIERS**  
 Presented By **ESATTA COOP**



**GRIEF**

How to cope when you lose someone special in your life

**James One Page Profile**



*To help me get through the loss of my love, Jan*

**What people need to know about me...**

- I need to be busy to help me do the daily chores we all do, and not think about upsetting stuff
- I'm okay, don't worry just give me some of your time to have fun, or just talk
- I am strong and don't show a lot of emotion but it is there brewing, so I may shed a tear now and then, don't be alarmed it helps me deal with my loss
- I love to be around positive people
- I was with Jan for 32 years. I talk about her a lot it helps me think of the good times. I need this to come to terms with my loss. I am okay if you are uncomfortable talking about this. Just let me know in a kind way and I will change the subject.
- I am not fragile I can have fun with the best of them please treat me like I always have.

**What I don't need...**

- Please don't tell me how I will get over the loss
- I don't need people telling me what to do. I can make my own decisions
- Questions about how she died
- I can't work right now I get stressed in high pressure situations. My work is intense. Just need a bit of time to get it together
- People feeling sorry for me. Just tell me how sorry you are for my loss. I find it hard to respond to this sometimes so I just thank people for their kind words.

**What helps me feel better...**

- Going for long walks
- Getting hugs from my friends
- Phone calls to talk sometimes about Jan or just about life
- Spending time with friends
- Enjoying a good bottle of wine
- Being around my grandkids and with family
- Being invited out for meals, or going to music events
- Being out in the wilderness around trees and hiking
- Going out kayaking
- Going to plays or live music
- Exercise at the gym
- Camping or road trips

**Other things...**

- My wife had a long battle with cancer or heart disease she lost her battle with the illness
- It was 32 years I was with Jan, I may be indecisive around things she did for me, bear with me. I don't mind your input just don't tell me what or how to do it unless I ask.
- I just want to go to music events and any fun community functions. Don't forget about me let me know what's happening out there so I can enjoy my community.

### Panel Discussion on Loss

- What are some of the things you have done to help you get through your journey grieving the person you have lost?
- Who are the people you go to for the support you need?
- What takes you to a place that helps you feel happy?
- If you had one thing you could share with people on how to cope with loss what would it look like?

### The Future

- Good paying jobs
- Making a difference
- Helping people change their lives
- Contributing to society
- Feeling good about ourselves
- Dream large live large!



### ESATTA MEMBERS

- Gladys Duran           Surrey
- Barb Goode            Burnaby
- Ryan Groth            Vancouver
- James White           Vancouver
- Michael Mclellan      Courtenay
- Tanya Norman         Powell River
- Sheenagh Morrison    Victoria

### Time for Questions

- Please feel free to ask any questions you have. We are also available a [esatta.coop@gmail.com](mailto:esatta.coop@gmail.com) if you want to chat more with us more about what we are doing. Thank you for your time, our work is something we are very passionate about and love it when we have the opportunity to share it with people that are interested.





P1

## Sexual Rights and the Sexual Citizenship of People with Disabilities

Elene Lam

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People with disabilities should enjoy the same human rights as other members of society. However, the sexual rights of people with disabilities are always being neglected. Sexual citizenship includes control over, and access to, the body, feelings and relationships, as well as the gender identity and experiences of these persons. Their sexual citizenship is being limited, not only because they are inaccessible for physical or mental reasons, but also because of how people without such limitations perceive the sexuality of people with disabilities.

Sexual citizenship regulates who should be involved in sexual activities and relationships and what type of sexual activities are acceptable. The ideology of society governs our assumptions about sexual behaviour and expression. Traditionally, sexual behaviour has to be justified and it should be related to marriage, a loving relationship or reproduction.

People with disabilities are often assumed, and are perceived to be, a group of people who could not have sexual lives; this especially is believed to be the case for those who do not have a partner. They are not encouraged to discuss their sexual needs, intimacy and desires, very few social services organizations are working on their sexual rights or are providing support to enable them to develop sexual relationships and experiences.

The presentation will explore the ideology which regulate our understanding of the sexual rights of people with disabilities and will describe a program which provided support for people with disabilities to gain access to their sexual rights by working with the people with disabilities, sex therapists and sex workers. The presentation also will create space for developing innovative programs to support the members of the community who need assistance in reclaiming their sexual citizenship.

### Learning Objectives

1. Understand how the sexual citizenship of people with disability is being limited
2. Realize how to recognize it and help them to reclaim the citizenship

### Synopsis

The presentation also will create space for developing innovative programs to support the members of the community who need assistance in reclaiming their sexual citizenship.

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## P2

**The Theory and Practices of Mediated Learning Experience**

Shankar Prasad Gautam, Ram Bahadur Thapa Magar, Buddhi Bahadur Thapa,  
Mohan Kumar Thapa

**Author #1**

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**Author #4**

Mohan Kumar Thapa  
General Secretary  
Nepal Disabled And Helpless Empowerment Center (NDHEC)

**1. Background/Rational/Research Topics and aims:**

Mediated Learning Experience is a central organizing concept while dealing with modifiable of children in general and in the development of children with special needs in particular. All three terms-mediation, learning and experience, are important to the concept. Learning with the MLE indicates that mediation by an intentional adult is not just a process of transmission but refers to an area of activity that becomes the content of the interaction. Experience in MLE is the reciprocal, emotional, affective and motivational aspect of the interaction that melds the activity into a meaningful and structural whole. Leading to self- awareness, structural change and cognitive development, as such mediated learning experience is an extremely powerful tool in sharing a child existence. Our goal as parents, educators and caregivers, is to help the child to learn and develop his learning potential, thereby facilitating his integration into his family and society and his functioning in the best possible way.

**2. Theoretical framework:**

Nepal is one of the poorest countries with regard to education, health, transportation sector. Nepal is the country where there are 12% disabled people. Among them around 5% of people are developmental delays. The trend of children with developmental delay is increasing day by day due to the lack of education and health facilities to the children as well as the conceived mother. So the developmental delay, mental retarded, CP of children has been one of the challenges for Nepal.

**3. Methods/Methodology of Research design:**

The research related on Mediated Learning Experience is done through different training, seminars, field visits to the people working in these sectors. Also different organizations helped a lot by conducting training and programme in different levels of the work.

**4. Results/(Expected) findings/conclusions:**

Our team has found out the improvement of Disabled children and people in the world. There are identified aspects of mediated learning experience:

- Mediation of the Feeling of belonging
- Mediation for Intentional and Reciprocity
- Mediation for Transcendence
- Mediation of Meaning
- Mediation of Feeling of Competence
- Mediation of Regulation and Control of Behavior
- Mediation of Sharing Behavior
- Mediation of Individuation and Psychological Differentiation
- Mediation of Goal Seeking, Goal Setting and Goal Achieving Behavior
- Mediation of Challenge: The Search of Novelty and Complexity
- Mediation of an Awareness of the Human Being as a Changing Entity
- Mediation of the Search for an Optimistic Alternative

**Conclusions:** Our research and special education methodology seems to be so much useful in claiming Full Citizenship: Self Determination, Personalization and Individualized Funding 2015 International Conference in Canada and most of the European countries, USA etc.. Those children and people who are CP, Mental retarded, Developmental Delay, and other dis-











**P7**

**A Path towards the Future... My Future.**

Susan Beayni

Rebecca Beayni is a young woman, who, by her life example and persistent effort, advocates for social change for the undervalued and marginalized. Rebecca is an active citizen in her community with a full and engaging life. Through this dynamic life Rebecca challenges us to move towards positive social change.

Rebecca lives with a physical and developmental disability that requires complete dependency for her care on family and supporters. She has complex communication needs.

While recognizing her vulnerability, Rebecca inspires those around her to think beyond their preconceived notions of who are the valuable people in our society.

The purpose of this session is to outline Rebecca’s journey with family, friends, and community in planning and finding opportunities for her to discover interests and passions at every stage of her development. This journey will inspire others to think about citizenship and relationship possibilities for people with disabilities. The second purpose is to highlight the building blocks that are necessary for Rebecca and others to live meaningful lives in their communities. Some of these building blocks are: Individualized Funding, Independent Facilitation, Person Directed Planning, Supported Decision Making and a Personal Support Network (Circle) which Rebecca has had for 23 years. This presentation will illustrate how these building blocks work together in a seamless way when families and their allies work from the same set of values and processes.

This poster presentation provided by Rebecca’s mother will include from the movies “Dance in the Shadow. The Story of Rebecca” and “Revel in the Light”. Information about Partners for Planning Online Resource Network will be provided. Rebecca’s two films can be seen in the Doc zone of this site: [hub.partnersforplanning.ca](http://hub.partnersforplanning.ca). Copies of the films will be available for purchase.

**Learning Objectives**

Individuals, families and those who support them, will have a better understanding of and ability to work with the building blocks that, along with individualized funding enable people to live full, meaningful lives contributing to their communities as full citizens.

Participants will become inspired, better informed, and more confident in planning a better life for themselves and others.

**Synopsis**

This session will outline how Rebecca, a woman with complex needs, has journeyed with family, friends, and community in creating a meaningful life. This inspiring life is based on building blocks that work together in a seamless way and illustrate how powerful it is when families and their allies work from the same set of values and processes. [www.rebeccabeayni.com](http://www.rebeccabeayni.com)









# P13

## How can Technology & Startup Principles Enable Individualized Funding?

Derik Ng

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In this session I demonstrate the ways that technology, cloud computing, lean management principles, and other concepts can be borrowed from startup/entrepreneurial culture into Individualized Funding. The tone of the session is playful and fun, packed with clever insights and ideas that can change the way we operate.

Microboards and tech startups are essentially both micro-enterprises and share some common challenges. Individuals and their supporters who are setting up IF models need new tools and systems that will allow them work smarter. Like tech startups, they want to attract good people they trust, foster culture & values, grow together, stay connected to one another - all with a lean, user friendly, low maintenance method. Specifically, we'll look at how founders operate personally and professionally and how they stay inspired and excited about their initiative.

I'll provide the audience with some fun learning tools including a IF Canvas (based on the startup business model canvas), the IF/Startup Mashup Dictionary, and a deck of Startup Principles Cards we'll use to reflect on their personal IF situation. These tools will help participants start to play around with the idea of borrowing concepts from Silicon Valley. With the cards, participants will brainstorm and share their own ideas for improving their systems and models for managing Individualized Funding. As a group we'll generate an idea wall as a report back exercise.

### Learning Objectives

1. A creative & fun session - the interactive session will encourage wild idea generation, leaving participants feeling excited and empowered & full of ideas they are ready to try
2. Work smarter, not harder - participants will partake in a solutions focused conversation where they gain new insights that can help improve their processes
3. Feedback loops - participants will understand how they might try something, built it, measure or understand if it's working or not, and reflect and learn... then repeat. session activities will introduce the idea that IF solutions are flexible, personal and should be constantly shift/improving as the person it's built around changes

### Synopsis

Let's explore how technology, cloud computing, lean management principles, and other ideas from startup culture can help individuals take control of their services and enable them to manage their own funding. This interactive session uses learning tools like the startup principles deck to invite participants to generate their own solutions.

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# P15

## Using a Social Audit Methodology to Assist Transition to Personalised Supports

Robbi Williams

This presentation describes how a Social Audit methodology was applied in a disability service agency to assist their reflective practice towards personalised supports. The agency requested this work as a means to assist their transition to personalised supports in an environment of Individualised Funding.

Using the Citizenship Support Model to generate a 20- question methodology about agency practice, a social audit was undertaken at the agency, enquiring into the agency's beliefs and practices in relation to the life chances of the people the agency serves.

An internal audit, undertaken by agency staff, was followed by an external audit conducted by a team comprising a person living with disability, a family member, and two persons from other community agencies.

The results illustrate the difference between internal and external perspectives on the agency's work, and the agency's struggle to identify authentic evidence of improved life chances. Results also suggested agency culture changes as a result of the process of the social audit itself.

Conclusions are drawn on the role of a life-chances social audit methodology in assisting assist service agencies build a truer picture of the orientation and impact of their services, and how the use of this methodology can contribute to agency culture change towards the goal of personalised supports. In particular, this includes how an agency can reframe and understand its work, not as a service response to disability but as a framework of support to advance a person's life chances.

### Learning Objectives

1. Learn about how a social audit methodology can be used to assist an agency reflect on its practice and the extent of its current helpfulness;
2. Learn about a specific social audit methodology based on an enquiry into life chances, using the Four Capitals approach
3. Learn about how the process of social audit itself can contribute to authentic culture change at the agency

### Synopsis

This presentation examines the use of a life-chances social audit methodology as a way to assist a service agency reflect on the extent of its true helpfulness.

Using an external audit team comprising persons with a lived experience of disability, the audit revealed the differences in perceptions of helpfulness, the absence of outcomes measurement, and how the audit itself can become a tool for nurturing an agency culture change towards more personalised supports in support of life chances.

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# P17

## The Paradox of Choice and Why Small Budgets Require Braver Ideas

Charlie Barker-Gavigan, Colin Gavigan, Terry Daly

We assume that more choice means better options and greater satisfaction. Within the changing world of Self-directed care and personalisation we hear lots about a changing 'care marketplace' and hope and believe that there will be an abundance of choice in health/care services/supports that will address imbalances of power and give us a responsive culture of what we want and need to transform the lives of those requiring additional support.

Social Care Ideas Factory (SCIF) brings vast experience and practice related to the implementation of Scotland's pioneering Social Care (Self-directed support) (Scotland) Act 2013.

SCIF will use group participative facilitation and practical individual/small group exercises to demonstrate how SCIF co-produces with people to discover, hear and amplify their voices, increase their trust in themselves and action more imaginative peer support ideas together.

Delegates will experience firsthand three brave, distinct people led ideas that support a changing 'care marketplace', promote people led commissioning and leadership from the community up to inform choice and have more confident say in shaping daily lives.

1. Trendspotters: disabled people movement to support independence in everyday life, spot trends, provide consumer feedback and inspire care beyond a commodity to buy
2. Wee Enterprisers: kitchen table micro business with disabled entrepreneurs
3. Sherpa Union: person centered, international leadership movement from the community up

Delegates will gain insight, practice skills into how individuals & partners differing outcomes can be met, how to grow ideas with people to maximize choice, control, perceptions & expectations.

### Learning Objectives

1. Participants will be able to list and appraise their own individual and group collective knowledge /skills to grow and develop more authentic people led ideas
2. Participants will be able to identify the linkage between care market development and commissioning for outcomes by applying people led ideas to deliver greater influence and translation.
3. Participants will be able to utilize people led feedback to develop supports that reflect peoples' lives
4. Participants will test decision making and co-production models
5. Participants will generate ideas that reduce bureaucracy, increase asset sharing and demonstrate lean budgeting

### Synopsis

We assume that more choice means better options, more control and greater satisfaction.

Within the changing world of Self-directed care and Personalization we hear lots about a changing care market. How can we ensure care is more than another commodity?

Co-producing people led ideas ensure reclamation at home and in the community. Social Care Ideas Factory bring their Scottish perspective and lived experience.

# Claiming Full Citizenship

Self Determination • Personalization • Individualized Funding

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