

Contact Details

**Standards Plus
PO Box 13227
Tauranga 3141
New Zealand**

**Ph: +64 7 579 9688
Fax: +64 7 579 9683**

standardsplus@imaginebetter.co.nz



www.imaginebetter.co.nz



5th International SRV Conference

Canberra ACT, Australia

**“Getting the Good Life:
From Ideas to Actions”**

**Social Role Valorization as a
framework for transforming lives**

Hellenic Club

**Matilda Street
Woden
Canberra
Australia**

21 - 23 September 2011

Hosted by

**IMAGINE
BETTER**



A conference to address the question of what it takes to secure 'The Good Life' for those people who live lives apart from society.

Conference Themes

- Belonging
- Meaningful and Sustainable Relationships
- Contribution

Conference Streams

- Personal stories and experiences, including those from people from marginalised groups
- Research
- Progressive personal and service responses and genuine innovations
- Theoretical perspectives and principles

International Key Note Speakers

Susan Thomas has been an associate of the Training Institute for many years and holds degrees in psychology and special education. She is author of several articles on Normalization and Social Role Valorization and is co-author, with Professor Wolfensberger, of PASSING and other publications. Ms Thomas has also worked for many years in voluntary, informal service to people with disabilities, and poor and homeless people. She has presented workshops with Professor Wolfensberger in many countries. Susan is the Coordinator of Training for the Training Institute.

Ray Lemay holds a M.Sc. in the Education of Emotionally Disturbed Children and is the Executive Director of Integra pour enfants et adultes de Prescott-Russell / Integra Children and Adults of Prescott-Russell in Plantagenet, ON, Canada, a \$36 million multi-service organization with over 450 employees. He has authored articles and books on resilience, normalization and Social Role Valorization (SRV) management.

Notes

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16b

Zana Lutfiyya

Seeing is Believing: How Media Portrayals Affect Belonging in the Community

This presentation will describe how colleagues and I have used SRV to analyze three portrayals of individuals with disabilities. These will include the depiction of intellectual disability in Walt Disney animated films; traumatic brain injury in the movie *Million Dollar Baby* and media reports of a Canadian man's suicide that conflated living with a disability and death.

16c

John Armstrong

The Need for Devaluation; Is Unconsciousness the most Plausible Explanation?

Rather than as a result of repression and unconsciousness, devaluation is a means for living with oneself while also belonging to others (who might also share and reinforce one's perspective), even while performing negative or even reprehensible actions. The need for belonging, in this sense, can be seen as a force creating and enlarging the necessity for devaluation.

16d

Erik Leipoldt

Anchoring Good Life

Supporting good lives for people with disabilities is a difficult task. Not necessarily because of lack of 'resources', complexities, or even a lack of goodwill. It is particularly difficult because increasingly, assigning meaning and purpose to a life, is viewed as a personal task, or choice. That individual task is situated in a values-free consumer culture, where rational decision-making is an important benchmark for human worth.

12.30pm Lunch

1.30pm

Closing Plenary

**Ray Lemay
Meeting the Community
Half Way**

This keynote will explore how SRV can help human services bridge the gap between the parallel universes of valued community and devalued existence.

2.30pm

Closing Ceremony

Janet Klees has been coordinator with the family-governed Deohaeko Support Network for the past 15 years and has been deeply affected by the lives of the people she has come to know. Janet is the author of two books which are directly rooted in the Deohaeko experience, (*We Come Bearing Gifts; Our Presence has Roots*) as well as numerous reports, documents, tools, and writings. Janet works closely with other Scarborough, Ontario families, and several family groups and projects across Durham Region.

Debbie Kilroy OAM, BSocWk, former Prisoner, Psychotherapist, practicing lawyer, Australian Human Rights Medal, and CEO of Sisters Inside, a community organisation that advocates for the human rights of women in the Criminal Justice System. Debbie continues to be a strong activist, locally nationally and internationally, on issues relating to prison abolition. Debbie is the first former prisoner in Australia to be admitted to practice law.

George Durner is an American and a graduate of the University of Loyola in New Orleans. He lives with his wife, Danielle, in a L'Arche community in France and is coordinator of training for the International Federation of L'Arche communities. From 1986 - 1989, George worked for the Georgia Advocacy Office in Atlanta and was responsible for the Citizen Advocacy program offices throughout the state.

Mike Rungie comes with 30 years perspective in the development of SRV. His particular interest has been in the bettering of human services and how to make services more able to support people to be citizens and have good lives. In his CEO role at the ACH Group and more broadly, Mike continually challenges people to be innovative in their thinking around what constitutes the good life especially in regard to vulnerable older people. Mike will bring motivation and enthusiasm to the conference through his presentation that will challenge our thinking.

For full copies of all abstracts please visit
www.imaginebetter.co.nz

Dr Michael Kendrick will provide a summary of the day's proceedings and his own thoughts on these topics. Dr Kendrick is an independent consultant in human services and community work internationally, working in the United States, Canada, Australia, New Zealand and the United Kingdom as well as many other countries. In his work he has occupied a variety of roles including being the Assistant Commissioner for Program Development with the Massachusetts Government, the Director for the Institute for Leadership and Community Development and the Director of the Safeguards Project. He is sought after internationally as a public speaker, trainer, evaluator, consultant and advisor to advocates, governments, agencies and community groups.

Guy Caruso received a B.S. in psychology from Union College and a MS and Ph.D. from Syracuse University, where he studied with Dr Wolf Wolfensberger. He is Western Coordinator for the Institute on Disabilities at Temple University, Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research, and Service.

Joe Osburn has worked with families and children since 1964. His work has focused primarily on the use and dissemination of Social Role Valorization Theory as a major safeguard in the lives of handicapped, poor, elderly, and other socially vulnerable people. He maintains informal personal contact with socially vulnerable people and their family members. He has a long-standing affiliation with Wolf Wolfensberger, and is a member of the North American SRV Council, and an editor of, and contributor to, the SRV Journal.

14c **Marg Rodgers**
Leading Others: From Ideas to Action

This paper will explore the long term investment made by the Community Resource Unit over more than 20 years to the teaching of Social Role Valorisation and the community to then assisting people to put this theory into practice to improve the lives of people with disabilities.

15a **Father Noel O'Neil**
Applying SRV in South Korea

This presentation will be an introduction to the history and social roles of persons with disabilities within the rapidly changing culture of South Korea since the Korean War.

15b **Jan Dooddy**
Providing Shared Living Services in Massachusetts: Real World Considerations

This presentation will examine our achievements as well as the struggles we face while striving to provide Shared Living services that are of high quality and respond to people's desires and needs.

15c **Elizabeth Nueville**
Ideas that Work across Time and Place: Teaching and Using SRV in Moldova

A look at the challenges and benefits we have encountered in introducing SRV into a society with few SRV principles embedded into its existing services, the struggles to avoid re-creating western service models, and the dilemmas over making promises to people that must be kept.

15d **David Heckendorf**
Getting the Good Life. Does the Law need SRV?

The politic system and organisational structures of caring agents have evolved over centuries to simultaneously exclude us (i.e. people with profound disabilities) from the processes of decision-making and law-making.

16a **Ray Lemay**
Excellence is Rare

Research shows that in the public not for profit or private not for profit sectors, excellence tends to be very rare indeed: most studies show that organizations are mostly mediocre or worse. This workshop will review the characteristics of excellent organizations: how they are organized, how they are led, and what they do.

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Programme

10.30am WORKSHOP STREAMS (Please choose two workshop groupings)

13a **Jo Massarelli, Joe Osburn & Beth French** **Safeguarding SRV: The Need, the Challenge, the Means**

Maintaining high levels of integrity and validity in SRV dissemination necessarily depends upon SRV trainers and training. However, this raises some very basic questions: what kind/s of SRV training are important? Is there an "orthodox" or paradigmatic version of SRV, and if so, can and should it be maintained? Will SRV teachers participate in a credentialing process? What would motivate them to do so?

13b **Marc Tumeinski** **Valued Social Roles and the Good Things in life: The Missing Link**

SRV in its 10 theme form clearly lays out the goal of helping societally devalued people to have greater access to the good things of life via valued social roles. Within the SRV training culture and within agencies, how can we help make that connection more legitimized, recognized and actualized?

13c **Judith Sandys, Jane Barken & Beth French** **The Appearance of APPEAR**

In 2009 Wolfensberger published a monograph entitled: Observing, Recording And Addressing Personal Physical Appearance By Means Of The APPEAR Tool. Nevertheless, despite the strength of much of the narrative, there are a number of weaknesses to APPEAR. This presentation will focus on several of these.

14a **Jack Yates** **SRV and Person Centred Planning**

Jack will share his experience and reflections on using person-centered planning with over five hundred persons and families, especially certain questions and topics which seem not to be asked by other practitioners.

14b **Sandi Seymour** **Parent Perspectives on the SRV Path and the Holes in the Road**

This presentation will consider how SRV principles inform advocacy in getting a good life for someone you love who is defined by their ability difference.

Wednesday 21st September 2011

8.00am Registrations open

9.00am Welcome to Country
Opening Address
Welcome by the Australasian SRV Group

9.30am **Opening Plenary**
Guy Caruso & Joe Osburn
'Best Practice' may Jeopardise Getting the Good Life if not Understood from an SRV Perspective

This presentation will illustrate these connections with examples of "best practices" in the areas of individualization, autonomy and rights, and relationships. It will also illustrate how pursuing these practices in isolation from SRV is less fruitful and sometimes confusing.

10.15am **Celebration of the Work of Wolf Wolfensberger**

Wolfensberger first published an article about SRV as an alternative framework to Normalisation in 1983 and since then has continued to evolve the theory. His personal and academic contributions have been much wider than this, and it is with great pleasure that we take this opportunity to celebrate the work of Wolf Wolfensberger.

11.00am **Morning Tea**

11.30am **Plenary Session** **Mike Rungie** **The Good Life**

This presentation will challenge people to be innovative in their thinking around what constitutes a good life, especially in regard to older people.

Storyteller
Christopher & Guy Lewis
My Own Good Life

12.30pm **Lunch**

1.30pm **Plenary Session**
Debbie Kilroy
The Injustice of Incarceration: Seeking Belonging Post-Prison

This paper explores the devaluation and wounding of, and alternative possibilities for, people who enter and leave prison. These people frequently have learning disabilities, mental health issues, drug habits, are poor and disadvantaged, and/or Aboriginal and Torres Strait Islander people. They enter a harsh and punishing system with the stigmata of difference. This paper looks at further wounding that occurs and explore what typically happens upon leaving prison. Factors which assist people to find roles in community that allow them to contribute and to belong will be identified.

Storyteller
Megan Sweeney
Home is Where the Heart Is

2.30pm WORKSHOP STREAMS

Please choose two workshop groupings (e.g. 1a, 1b, 1c & 4a, 4b, 4c) for 1st and 2nd preferences. Participants are requested to remain in their workshop grouping for the full session.

1a Lisa Bridle
Choosing who Belongs

This paper will draw on the stories of mothers of children with Down syndrome to examine how they have confronted societally devalued roles imposed on people with disability in order to forge reciprocal family relationships and reclaim their family member as a valued and contributing family member.

1b Tom Doody
Accidental? Integration in a Church Youth Group

Churches of all denominations espouse values that call for the respectful treatment—the positive valuation—of all people. However, the potential for genuine integration is often undermined by societal stereotypes and expectations. What makes the difference? Why are some churches so much more welcoming and inclusive than others?

1c Rob Nicholls
Acceptance, Belonging vs Fear/Rejection: Old New Directions for People with Disabilities and the Church

An important claim of the church that it is a place of community where acceptance and belonging can be found as a central part of the teaching of Jesus Christ. Therefore it is crucial that such a claim can be validated by the experience of people who are isolated and excluded. This paper will examine the importance of belonging in church communities for people with disabilities and their families.

2a Bob Jackson
Building Belonging in the Curriculum

This paper will demonstrate that students can be included in the same curriculum, regardless of impairment. In so doing, the whole class benefits both academically and socially and the foundations of an ordinary life are strengthened.

2b Glenys Mann
Schools and Belonging. The Queensland Education System and Students with Disabilities

This paper will reflect on the links between educational inclusion, personal social integration, valued social participation, and belonging.

11c Judy Dickson & Judie Bounds
First Steps

This paper documents the first steps in the journey of transformation from the provision of traditional centre based services to facilitation services aimed at enabling people with a disability to explore, learn, participate, contribute and engage with a rural community.

12a Peter Symonds
Congregation and Segregation in Employment

This paper will look at how community based employment supports the themes of SRV and rebuilds engagement with the community through relationships and contribution.

12b Caroline Arcand
Beyond Profit

This presentation demonstrates 12 keys for success, that will enable people, regardless of intellectual capacity, to contribute to the business and that will allow the business to become a recognized economic engine.

12c Sally Richards & Philippe Mornincome
Jack

Through his employment Jackson has maintained relationships, a legitimate place in the ACT business community and is delivering a valued service.

4.30pm Summary Session
Michael Kendrick

5.00pm End

7.00pm Wolf Wolfensberger Tribute Dinner

Friday 23rd September 2011

9.00am Plenary Session
Susan Thomas
Situating SRV in the Larger Context of Human Service Developments, Including Societal Dynamics

This presentation underlies the universality of applicability and relevance of SRV, its ability to deal with critical issues that impact on the human service scene and the importance of not discarding SRV simply because it is not sufficient to solve all human service problems.

Storyteller
Meg and Annie Boman
Growing up with Jack

10.10am Morning Tea

Sponsor

10a

Guy Caruso
Helping People to get the
Good Things in Life:
Independent Monitoring for
Quality Program

Since 1990, the USA state of Pennsylvania's office for intellectual disabilities has funded 30+ non-profit, board governed, Independent Monitoring for Quality Programs (IM4Q) that have adults with disabilities, family members, and interested non-conflicted others interview yearly over 6000 children/adults with intellectual disabilities, who live in a variety of residential settings. The impact of the IM4Q program will be discussed as it pertains to the valued roles it helps create for its interviewers and people interviewed.

10b

Julie Johnson
Contribution Through
Reciprocity: Families & an
Organisation Working
Together

Children and adults with a disability have a crucial natural safeguard when they are embedded in the life of their family. The challenge though, is to provide support in ways that enable the family to craft a life that allows their son or daughter to have valued roles through which to contribute, to have meaningful/reciprocal relationships and to have a full sense of belonging and self worth.

10c

Anne Heard &
Lenore de la Perrelle
Walk for Life

For many, a diagnosis of dementia marks the withdrawal from active participation in community groups. Yet this is a time when physical and social activities can be crucial to maintaining cognitive abilities and general well being. The Walk for Life project seeks to develop a model of peer support to keep people with dementia engaged in community groups.

11a

Rhonda Held &
Joylene Thomas
Valued Roles for Older
People: The Keys to
Belonging and Contribution

This paper will illustrate how social roles are crucial to both belonging and contribution of older people.

11b

Deb Rouget
Personal Lifestyle
Assistance

Over the years, we have witnessed the transforming of not only people's thinking but in the lives of individuals with disabilities. This presentation shares personal stories and reflects on the investments and learning.

2c

Ric Thompson &
Fiona Sanders
From Community Tourist To
Citizen – Disability,
Community and Inclusion

Participants will be introduced to the relevance and importance of SRV in the development and maintenance of successful community inclusion outcomes for individuals with a disability and how this may be reflected in the presence of meaningful and sustainable relationships, having a strong sense of belonging through the opportunity to contribute.

3a

Jeremy Ward &
Catherine Raju
Planning for the Good Life:
Pave the Way Experience

Families need time, energy, inspiration, support and resources to move from a position of panic and paralysis to the positive approach of visioning and planning. This presentation will outline some strategies Pave the Way has taken to support families, as well as the values and principles guiding its work.

3b

Cindy Treanor
U + Me + US

A group of people with and without intellectual disability from L'Arche around Australia will present various ways in which members with disability induct Assistants and new friends into L'Arche Community life.

3c

Marc Tumeinski
Small Really is Beautiful

This presentation will tell the story of a 12 person residential agency which for the past 30 years has been providing support to people living in their own homes. This agency has stayed small in a service environment that pushes for larger organizations.

4a

Jo Massarelli, Ann Flynn &
Carolyn Brennan
SRV as a Medical
Safeguarding Strategy

The Medical Safeguards Project, a medical advocacy effort involving physicians and nurses working to insure excellent care for people with impairments, are two entities that implement Social Role Valorization in the context of medicine. The projects are inspired by SRV, and they apply the notion of "heightened vulnerability" to medicine, using the Conservatism Corollary to address issues of devaluation particularly in hospital.

4b

Pierre Rosenberg
From Community to
Nursing Home and Back to
Community

This presentation will share some of my life experience of living with Cerebral Palsy, how I ended up in an Aged Care Nursing Home and how I managed to now be living back in my local community again.

4c **Lenore de la Perrelle & Anne Heard**
Banners on My Parade

'Banners on My Parade' project demonstrated the sense of belonging, inclusion, and the sheer enjoyment which comes from sharing stories of significance, discovering connections and being part of a community art project. It reinforced the role that art can play in promoting health and providing meaningful creative and purposeful activity for older people.

3.45pm **Afternoon Tea**

4.15pm **Michael Kendrick**
Summary Session

4.45pm **End**

Thursday 22nd September 2011

9.00am **Plenary Session**
George Durner
Relationship and Transformation

We live in a world filled with insecurity and fear. We are taught to be afraid of people who are different and in the end, we can have a very limited, very narrow vision of what it means to be a human being. We create barriers around ourselves to keep out those that we have been taught to; they prevent us from entering into relationships that could transform us, that could be the beginning of creating peace in our society.

Storyteller

Person or family member speaking to their experience of Relationship

10.10am **Morning Tea**

10.45am **WORKSHOP STREAMS**
(Please choose two workshop groupings)

5a **Richard Long**
Warmth and Solidarity

Finding the right support and making the right connection is a fundamental part of how services can develop opportunities for greater inclusion. But this is not about dry, emotionless models of support. This is about putting the emotion back into services. Not just meeting outcomes but truly investing in people and making a real commitment to support people to have an even better life.

5b **David Race**
'Hearts or Minds' - The Mythos and Logos of Teaching and Implementing SRV in Achieving the Good Life for People.'

This paper is a reflection on the relative importance of key components of teaching and implementing SRV, and what their underlying power has meant in terms of striving for the good life for people. It is based on thirty five years experience of normalization and SRV.

12.30pm

Lunch

1.30pm

Plenary Session
Janet Klees
Contribution...By Accident, or Design?
Making Contribution-Being Contribution:
Using SRV Framework to Deepen the Shared Experience of Contribution

Through stories and thinking anchored in 18 years continuous experience with one family group in Canada (Deohaeko Support Network) Janet will talk about Contribution. The common thread being that valued contribution is deepened, made meaningful and safeguarded by the intentional use of SRV thinking to anchor the shared human experiences of contribution.

Storyteller
Mark Grantham
Dream it, Live it. I did, I Do.

2.30pm **Afternoon Tea**

3.00pm **WORKSHOP STREAMS**
(Please choose two workshop groupings)

9a **Mike Steer**
The Baleful Tale of Blind Freddy

'Blind Freddy could see that' is an expression widely used throughout Australian society and often heard in the media. This expression should cease to exist. The challenge of promoting 'people-first' language as its replacement should lie primarily with Australians who are blind or significantly vision impaired.

9b **Jan Doody**
Our Values Follow Us

This presentation will describe how the Polus Center has applied lessons learned from 30 years of providing shared living and vocational services for people with disabilities in Massachusetts to its international work in developing countries.

9c **Sarah Forbes**
Collecting the Wisdom of our Elders and Passing it On

This presentation charts the reasons why services and families struggle to believe in community belonging for all despite there being many examples of success, and how those who have led the way have managed to do it in the face of significant opposition.

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7b

Gillian, Kerrie & Therasa Chernets
Expectation, Possibility, Reality & What is at the Heart of the Matter

Through pictures and story telling my two daughters will tell their individual stories of what is important in ensuring they have a life that is meaningful, participatory and offers a contribution to society.

7c

Peter Millier
Living in a Parallel Universe

The lives of people who are devalued and vulnerable have been characterised as 'being on a different set of train tracks' or a 'different world'. This paper will examine some of the ways in which one might challenge the notion that a parallel universe is somehow superior to a typical valued life in a regular community.

8a

Ray Lemay
Crafting VSR: From Dependence to Relationship

Using examples and research, this presentation will review how SRVs concept of Social Roles may be the basis of social integration and how the crafting of valued social roles can lead to a different way of providing human service, including professional services.

8b

Prue Gorman & Julie Edwards
Stepping Stones to Inclusion

The vision of families in the Community Living Project: that their sons and daughters with an intellectual disability will have the opportunity to secure a 'good life' in a home of their own choice, surrounded by people who love them, living lives that offer inclusion and opportunity. CLP works in partnership where each person and their family are encouraged to take active control over the decisions that affect their future.

8c

Jayne Barrett, Renee Stanley & Kingsley Fidd
Finding, Holding & Sustaining Freely Given Relationships

This presentation will share what was learnt from an Action Learning Project focused on building and strengthening the freely given relationship in the life of a person who lives with disability.

8d

Fiona Campbell & Silvana Gant
The Role of Social Advocacy in Getting the Good Life

This presentation describes the role of social advocacy in Getting the Good Life, based on our experience in advocating for vulnerable individuals with intellectual disability within a relationship based, values driven framework underpinned by Wolfensburger/SRV theory and principles.

5c

Fiona Cameron-McGill
Developing Friendships and Social Connections

This paper deals extensively with issues pertaining to Social Integration, as expounded in SRV theory. It examines efforts to secure the 'good life' as it relates to relationships, friendships and social connection.

6a

Rosey Olbrycht
Beyond Theory

Citizen Advocacy as a means to establishing and nurturing meaningful and sustainable relationships of support which can get people who are vulnerable 'the good life' or at the very least 'a better life'.

6b

Tom Doody
Citizen Advocacy in Rural New England

Citizen Advocacy programs initiate and support freely-given relationships between people with mental disabilities and their neighbors. After 25 years of inviting support from a significant percentage of our local population, an unanswered question is the impact of the work on the heart of our community.

6c

Deborah Espiner, Frances Hartnett & Ana Maria de Vos
"Stand by Me": Can Citizen Advocacy Promote Reciprocal Relationships?

This presentation will explore the challenges faced in implementing a Citizen Advocacy programme and remaining true to the core principles underlying Citizen Advocacy.

6d

Mitchel Peters
Role Call: Citizen Advocacy: Relationships as a Source of Valued Social Roles

This presentation examines how Citizen Advocacy relationships can provide a source of valued social roles for people with disabilities.

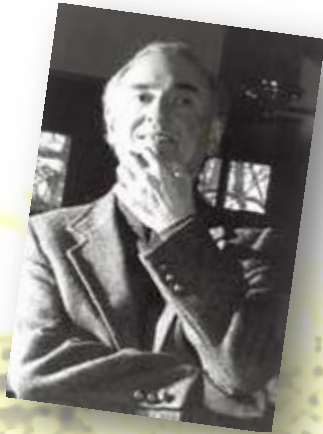
7a

Debbie & Adam Race
Learning from Sibling Relationships

This presentation will explore the power and benefits of positive sibling relationships and the opportunities such an exploration offers to consider what is important in long term relationships.

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