

Delivering on its promise?

**Exploring Victoria's system of
individualised funding for people with
disabilities from a capabilities and rights
based perspective**

Christina David & Paul Ramcharan

RMIT University

Questions guiding the research

- * What is the relationship between the rights based rhetoric of IF and the everyday reality of individuals and families? Does it promote choice, self determination and inclusion and if so how and for whom?
- * What conditions and arrangements are required to promote self direction and who is responsible for creating these?
- * What are the constraints and enablers within this self directed approach?

A Study of Individualised Funding in Victoria

- * Small qualitative research
- * The experience of people using the ISP funding & service framework
- * Providers and planners experience
- * Funded by Victorian DHS
- * 2010 – amidst uncertainty about the NDIS and desire to learn about current models in ways which might inform future NDIS implementation

Victorian ISP Program 2008 -

- * Informed by Disability Act 2006 & State Disability Plan 2002-12
- * Human rights values - participation in community, self determination, transparency, accessibility, citizenship
- * Individual choice as key policy driver and flexible funding as key mechanism for this
- * Funding to be directly related to person's disability and support plan goals e.g. *independent living, social inclusion, skills and capabilities, support for carers, health and well being*

Key Elements of ISP Self direction

- * Self directed funding
- * Self directed planning
- * Self directed services

- * Emphasis on individuals being able to take up opportunities to *'achieve goals and pursue own lifestyle'*

International Context

- * Personalisation in social support and care an international trend - individual choice and control using individualised funding as a key policy mechanism for change
- * Promoted on basis of strong disability rights framework and narrative supported by the CRPD 2006 which:
 - * formalised disability as a human rights issue
 - * grounded in a social model understanding of disability
 - * informs national and state disability policy and strategy
- * Victoria's Charter of Rights and Responsibilities contributes to human rights awareness

Problematizing personalisation

- * Is personalisation reform and its neoliberal focus on individual choice and responsibility entirely consistent with disability rights principles around citizenship, equality and collective representation?
- * Will individualising payments also individualise and silo need and risk at the expense of collective voice and participation and the structural reforms required to address embedded disadvantage?
- * Rapid uptake but do we know enough about impact particularly in context of austerity measures, ageing population and increased competition for resources.

Research Questions

- * To what extent and in what ways does the Victorian model of individualised funding promote, protect and ensure the rights of people with disabilities, particularly in relation to choice and autonomy?
- * What are the tensions, risks, and opportunities for key stakeholders in this funding and service framework?

Sample and approach

- * 11 adults with an ISP; 5 family carers; 2 support workers; 2 ISP facilitators
- * 7 DSP CEOs or senior staff – peer recommended on basis of interest and skill in personalised service approaches; form of triangulation
- * Semi structured interviews asking about experience accessing and using funding and services, expectations, choices made, enablers and constraints, aspirations

Initial Findings Overview: Better but not good enough...

- * Consistent with previous studies regarding benefits, limitations, risks, and inconsistencies
- * A few exemplars but some still in a 'holding pattern' due to inadequate funding, weak or exhausted social supports, and constrained choices
- * Confirmed dichotomy in previous research but also highlighted the mixed, contingent, and diverse nature of experience with the ISP framework
- * The system produced winners and losers with no explanation of why
- * Individual experience of choice and rights shaped by multi-level social and contextual factors, many beyond the control of the person implying the need to better understand these factors

The ISP experience: Benefits

- * More choice & flexibility in the who, what, how, and when of everyday service provision e.g. banking hours, changing roster times
- * More influence in choice and continuity of staff – relationships, shared interests, skills: SWs as a relational, social, informational resource , not ‘a pair of hands’
- * Independent living; coming, leaving or staying at home
- * Opportunities for participation: e.g. TAFE, pub nights, art classes , maintaining social networks
- * Family carer benefits – flexible respite, supportive relationships with services, shared decision making and emotional support with ongoing staff

Constraints and risks to choice

- * **Inadequacy** – funding primarily for personal and practical supports failed to support longer term social goals and aspirations in personalised ways
- * **Rationing and ‘trade offs’** – a consequence of inadequate funding levels e.g. shower or go out
- * **Personalisation of risk** - unfunded costs of individualised arrangements absorbed by individuals, family carers, and services
- * **Inconsistency and inequity** - complex bureaucracy and service processes did not deal consistently with all participants or account for diverse capabilities.

Constraints to choice

- * **Resistance to innovation** and change in more personalised and transformative funding use, service centric approaches resisted transfer of choice and control, traditional power relationships and boundaries maintained
- * **Lack of market diversity and depth**
- * **Variable information and knowledge** – patchy planning and information provision a risk to informed choice

Service providers – risks and challenges

- Empowerment versus business interests and viability?
- Real costs of self- direction not funded by ISP - the ‘thinking, linking and bridging’ work of connecting people to the community e.g. unpaid casem’ent
- New rhetoric, same services – a risk averse, slow to change sector ... ‘*client capture*’ culture unchallenged
- Lack of necessary leadership, exemplars and sector expertise in self direction to propel real change

Reimagining the role of services

- * **Working at the edge, 'above and beyond'** – push boundaries to move beyond what has been done or known
- * **Building social capital and connection using IF as a tool** -but split on whether funding should be known first or not
- * **Community Development focus** – building diverse and tailored pathways & opportunities
- * **From client land to person land:** from object to service; from welfare to rights, from special to ordinary pathways
- * **Beyond the 'tools' and jargon** – about real embedded person centred cultural, values, and practice based change

Findings after the first analysis

- Consistent with previous studies regarding general benefits, limitations and barriers.
- * But findings were mixed and often contradictory – choice co-existed with compromise, social exclusion and lack of opportunity i.e. individualised funding did not always convert to the better lives people wanted
- * Did not adequately resolve the tensions outlined in earlier debates or offer a more nuanced way forward.

Questions remained

- * Why did some participants do so well whilst others continued to struggle on the margins?*
- * What framework could assist to develop greater meaning from the findings and offer a more equitable way forward?*
- * What framework could better explain the dynamic relationship between resources, opportunities, and lives of greater choice?*

Re-analysis from a capabilities based understanding of rights

A social justice framework based on core values of **diversity, freedom, and agency** – aligns with and extends human rights based approach

An alternative measure of justice and well being, arguing that a focus on equality of resources or normative outcomes does not measure well being or account for diversity within pluralistic populations – diverse hopes, needs and contexts or diverse capacities to convert resources into valued *doings and beings*

Primarily concerned with people as ends in an of themselves rather than a means of production

Relevance to this study

- Concerned with how policy and programs create the freedoms and ***‘effective opportunities people have to lead the lives they have reason to value’*** (Robeyns, 2006) and the factors which expand or limit these
- * Distinction between what people achieve (*functionings/outcomes*) and the freedoms or opportunities they require to make choices of value and meaning to them (*capabilities/opportunities*)

Relevance to the Study

- Shifts analytic gaze from equality of inputs and outcome measures to instead critically examine how the individualised funding and service framework expands the **real opportunities people with disabilities require to make choices about how they want to live**

Capabilities and human rights

- Human rights as claims to valued capabilities thus more explicitly highlights correlate obligations of duty bearers , particularly social, economic, and cultural positive rights claims (Sen,2012; Nussbaum 2012)
- What are the different responsibilities of the state and the market in ensuring these freedoms and what is the relationship therein?

The concept of conversion

- * Acknowledges pluralism and diverse needs, contexts and abilities to convert otherwise latent resources and processes into manifest and valued opportunities, capabilities, and choices
- * Describes resource and process characteristics which enabled or constrained this process of conversion e.g. adequacy of funding, diversity of service offerings, empathy of support worker, supports for co-production of services

The Concept of Conversion

- * Useful for explaining the multi level factors contributing to the mixed findings i.e. why some people were able to optimise and convert resources into real opportunities and others were not?

Diversity & Conversion not consistently acknowledged

- * Many core conversion factors central to expanding substantive opportunities and self determination were unacknowledged and unfunded e.g. building relationships, knowing the person, co-ordination, helping people think through options, sourcing local knowledge, time to develop trust, creating social opportunities and pathways
- * The ISP and service framework did not consistently respond well to diverse needs and abilities e.g. deficit based, standardised, inflexible and inconsistent features disadvantaged those least able to manage these

Foundational Conversion Factors

- * **Relationships and relational approaches** – social capital role of services and natural supports, knowing each other, trust, reciprocity, mutual concerns, ethic of care
- * **Thinking, linking and bridging to community** – services, informal advocacy, natural supports
- * **Collaboration, participation, dialogue** – embedded processes for participation and dialogue key to managing risks, opportunities, innovation in uncertain environment

Foundational Conversion Factors

- * **Capability based funding and support** - informed by person's potentials and goals and the opportunities and freedoms required for self determination
- * **Streamlined, enabling and person centred** administrative and funding processes
- * **Market diversity and depth**
- * **Accessible, timely, and tailored information systems**

Conversion factors for choice and change

Conversion Factors:

- Resource and process characteristics
- Personal, – history, attributes, resources
- Socio- cultural, Environmental & Institutional

Agency - adapted preferences, history, expectations



Resources

Formal and informal

e.g. funding, services, social supports, community resources



Opportunities, freedoms and capabilities

What a person can be and do

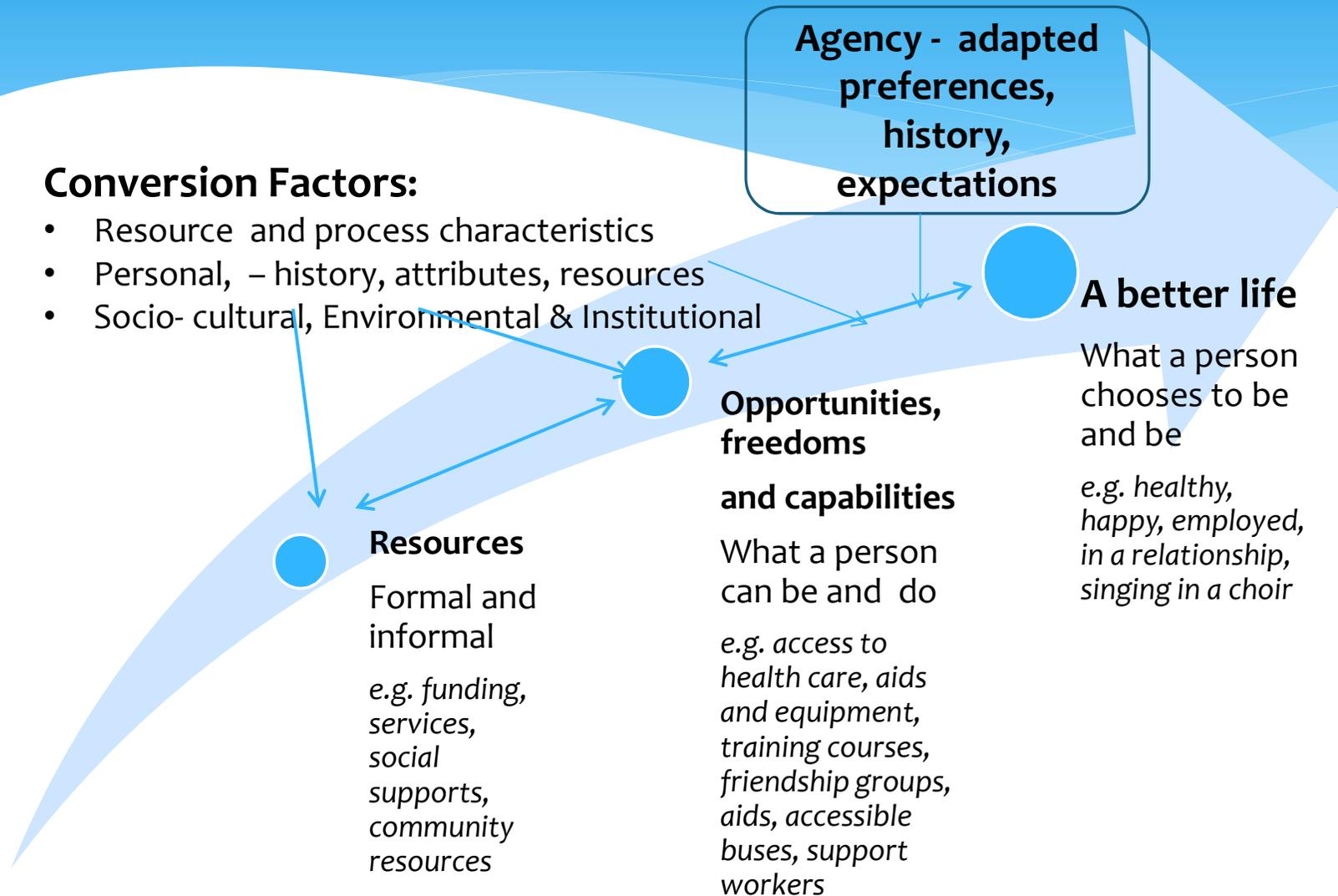
e.g. access to health care, aids and equipment, training courses, friendship groups, aids, accessible buses, support workers



A better life

What a person chooses to be and be

e.g. healthy, happy, employed, in a relationship, singing in a choir



Answering the research questions

- * Empirical data analysis identified the benefits, risks, and opportunities of the individualised funding program from multiple stakeholder perspectives – (Question 1)
- * Applying a capabilities perspective extended the human rights lens by elaborating the role of opportunities and capabilities in the choice process; and, explained in more detail the role of often overlooked variables in converting latent resources into opportunities of meaning and value. (Questions 2 & 3)
- * By elaborating the relationship between resources, capabilities, and choice, the analysis also highlights the role of the state in ensuring conditions and opportunities for people with disabilities such that choice and self determination can be realised. This cannot be left to the market alone. (Questions 2 & 3)



Thank you and
questions