

Establishing a research agenda for intellectual disability & challenging behaviour:

A Template for Research

Clare Townsend PhD.

Centre of Excellence for Behaviour Support

The University of Queensland

44th ASSID CONFERENCE

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HOBART, AUSTRALIA



INTRODUCTION

PREMISE

Intellectual disability policy & practice should be firmly underpinned by a strong evidence base.

Article 31- Convention for the Rights of Persons with Disabilities 2006 mandates :

The collection & dissemination of statistical & research data that will ensure the implementation of the Convention and identify and address barriers faced by persons with disabilities in exercising their rights.

INTRODUCTION

This paper presents a template to assist in the conceptualization of a comprehensive research agenda for Intellectual Disability, including the area of challenging behaviour.

BACKGROUND

Prevalence rates for intellectual disability have been variously estimated for UK & Nth America - 5-15% (Qurseshi, 1994; Borthwick-Duffy , 1994)•

In 2003 the Australian Institute of Health & Welfare estimated prevalence rates = 3%

Prevalence rates are expected to rise (United Nations , 2007).

50% of people with an intellectual disability have at least one other significant disability (5; 6).

Many have an array of complex needs.

INTELLECTUAL DISABILITY & CHALLENGING BEHAVIOUR

7%-15% of people with intellectual disability exhibit challenging behaviour (10-12).

“Behaviour of such intensity, frequency or duration that the physical safety of the person or other people is likely to be placed in serious jeopardy; or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities”(Emerson, 2001,p. 7).

Severe challenging behaviour is thought to persist into middle age (Emerson et al, 2000; Lowe et al, 1998) .

People frequently exhibit multiple behaviours of concern (Emerson et al, 2000; Lowe et al, 1998) .

INTELLECTUAL DISABILITY & CHALLENGING BEHAVIOUR

Quality of life is lower for people with ID, especially for those who exhibit challenging behaviour (Cummins, 2005; United Nations, 2007).

Community and service responses have frequently been crisis driven and ad hoc.

Human rights abuses have been evidenced e.g. restrictive practices, resulting in adverse physical & psychological effects for consumers & carers (Deveau 2009; Sanders, 2009).

DEVELOPING THE RESEARCH AGENDA

Within a human rights framework service users are entitled to expect and receive effective services.

A complex and infinite array of research issues exist to meet this expectation.

Innovative research is occurring but frequently occurs in separate research organizations & there is an absence of comprehensive frameworks .

DEVELOPING THE RESEARCH AGENDA

There is increasing recognition that a diverse research agenda is required to inform evidence based policy and service development and reform.

CONCEPTUAL FRAMEWORKS

Conceptual frameworks have been developed to facilitate comprehensive social policy.

They delineate the domains and elements of comprehensive policy and services.

A Mental Health Policy Template was developed as a generic tool for comprehensive mental health policy development (Townsend et al, 2004).

The model has been adapted to organize the huge array of research topics surrounding intellectual disability and challenging behaviour within a human rights framework.

FEATURES OF A TEMPLATE

Townsend et al 2004

It should identify the essential domains and elements that need to be considered when formulating a research agenda.

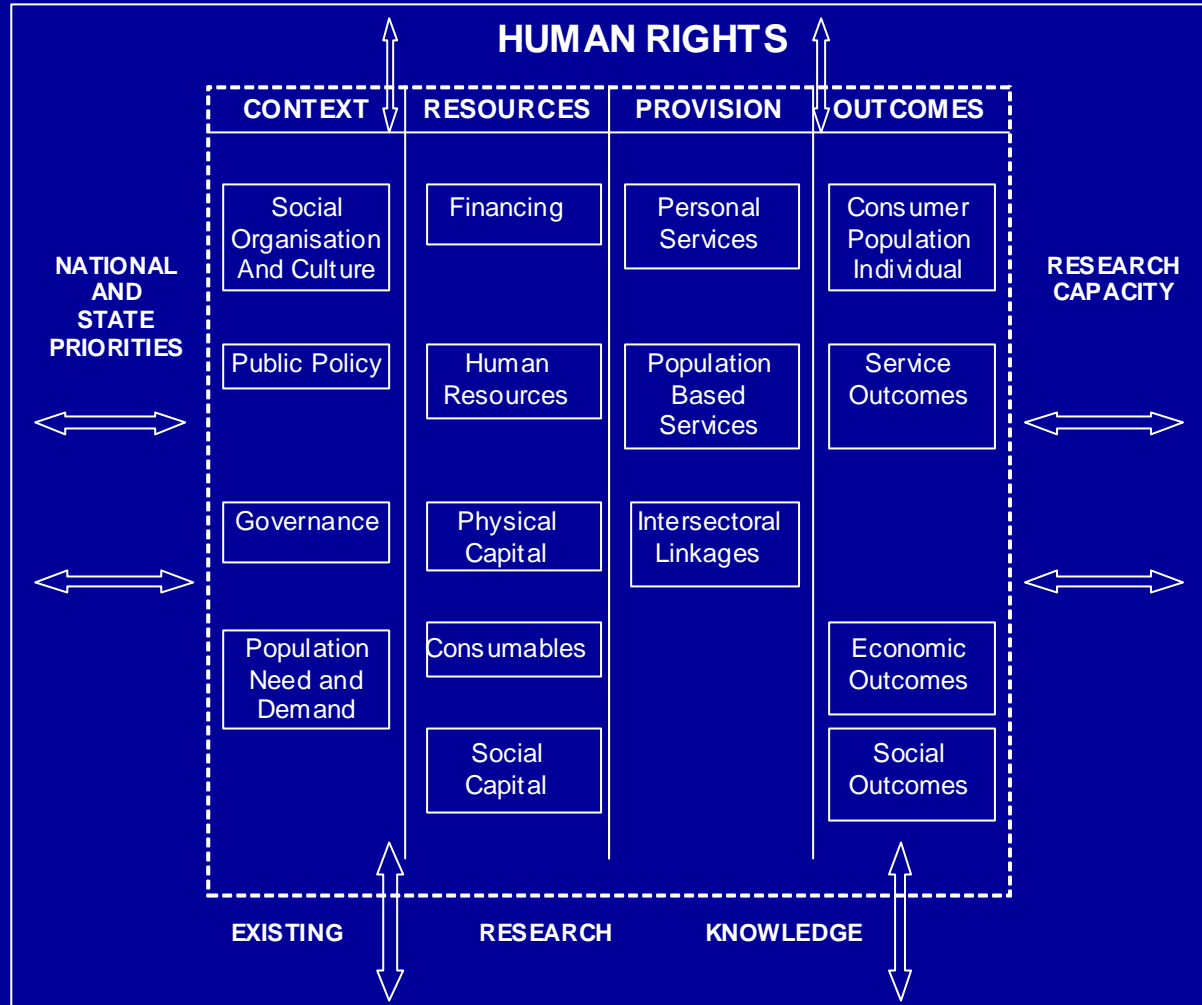
It should be applicable to country, region, province or community levels

It should use language, concepts and terminology consistent with mainstream social and health sector reform.

It should be sustainable over time and transcend the government & research fashion of the day.

The Intellectual Disability and Challenging Behaviour Research Template

DOMAINS FOR RESEARCH AGENDA FORMATION



EXTERNAL PARAMETERS

- The four external parameters are realities which exist within the policy environment.
- They may operate as filters, drivers or impediments to the research endeavor.
- They should also be influenced by research.

EXTERNAL PARAMETERS OF THE TEMPLATE

(i) HUMAN RIGHTS PARAMETER

The Convention for the Rights of Persons with Disabilities (2006) demands that research “promotes social entitlement, economic opportunity and human rights for people with **disability** (Wolbring, 2004; Fry, 2004).”

(i) HUMAN RIGHTS PARAMETER

The Human Rights Parameter should be applied to each research domain and element in terms of:

- Nature of the research
- Methodology
- Dissemination
- Utilization.

Issues of research focus will include:

- Dignity, autonomy, independence;
- Non-discrimination
- Community living ;
- Full and effective social participation and inclusion
- Liberty
- Equal protection of the law
- Standard of living
- Education; Work
- Health issues

(ii) NATIONAL AND STATE PRIORITIES PARAMETER

National and state policies and priorities also inform the research agenda.

- 1. The National Disability Strategy 2008**
- 2. The Qld Disability Services Act 2006 & Amendments to the Act 2008; & the Victorian Charter of Human Rights and Responsibilities Act 2006.**
- 3. The DS, Disability Service Plan 2007-2010**

NATIONAL AND STATE PRIORITIES PARAMETER

National Disability Strategy 2008	Queensland Disability Act 2006	Queensland Disability Service Plan 2007-2010
Better measurement of need Population Benchmarking Access for Aboriginal & Torres Strait Islanders	Least restrictive way to ensure safety Equality of human rights Regular review and monitoring Transparency, accountability Increased participation & inclusion Promotion of rights & safety Improved quality of services.	Early intervention strategies Increased access Cross-governmental linkages Specialist disability services Accountability, performance reporting and quality.

PARAMETERS

(iii) RESEARCH KNOWLEDGE & (iv) RESEARCH CAPACITY

The capacity of researchers to respond to and prioritize research options will also be determined by:

- Existing research knowledge
- Research expertise and capacity
- The support of other researchers, including consumer researchers and researchers from other sectors.

INTERNAL DOMAINS AND ELEMENTS

The template has 4 internal domains.
Each domain contains sub-domains or elements.

“What research is required to inform this element sufficiently so that human rights, evidence-based policy and services can be developed and/or evaluated?”

For each element there may be a variety of research tasks which need to be undertaken.

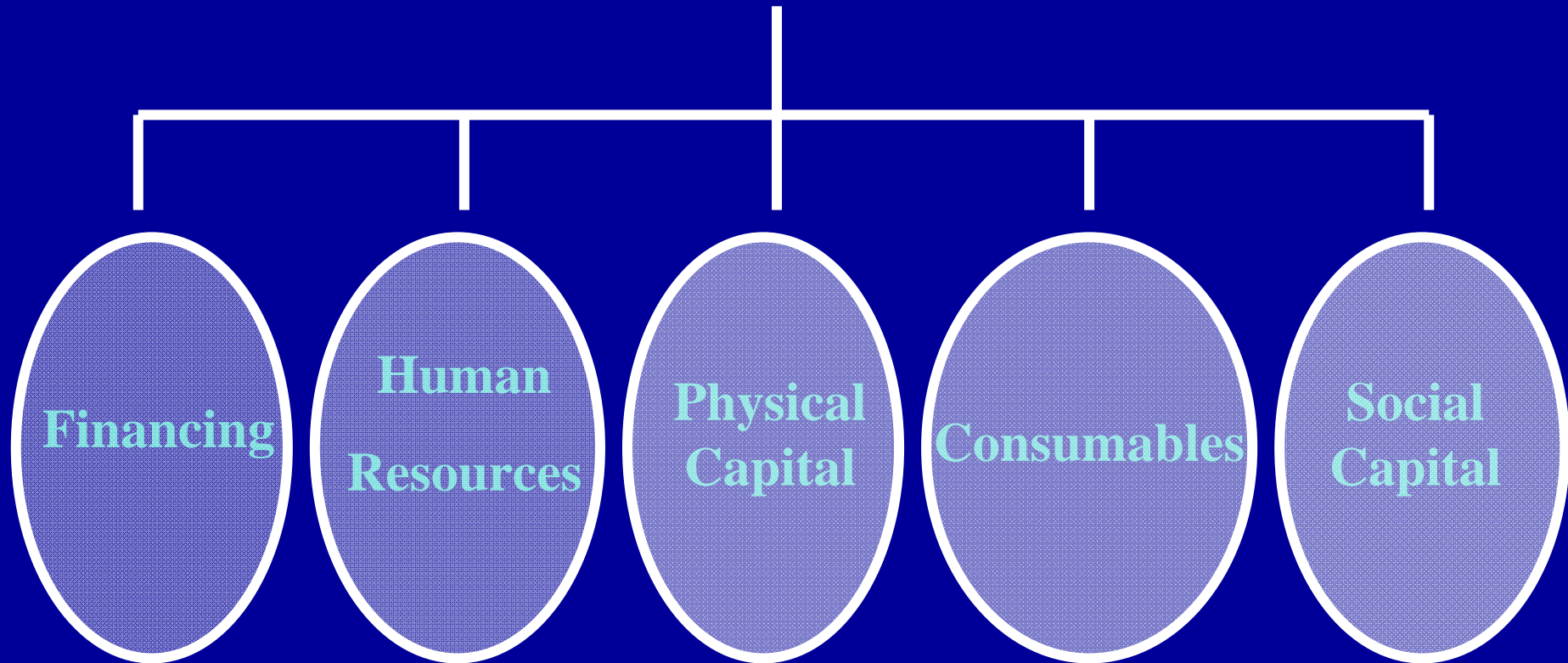
1. CONTEXT



Context : Research Issues

- **Stigma and discrimination**
- **Establishing prevalence rates: Prevalence estimates are limited & vary so much in some countries that it is impossible to use them for policy and service planning & development.**
- **Articulating the research imperative and defining the research agenda.**

2. RESOURCES



This domain can generate research in areas such as:

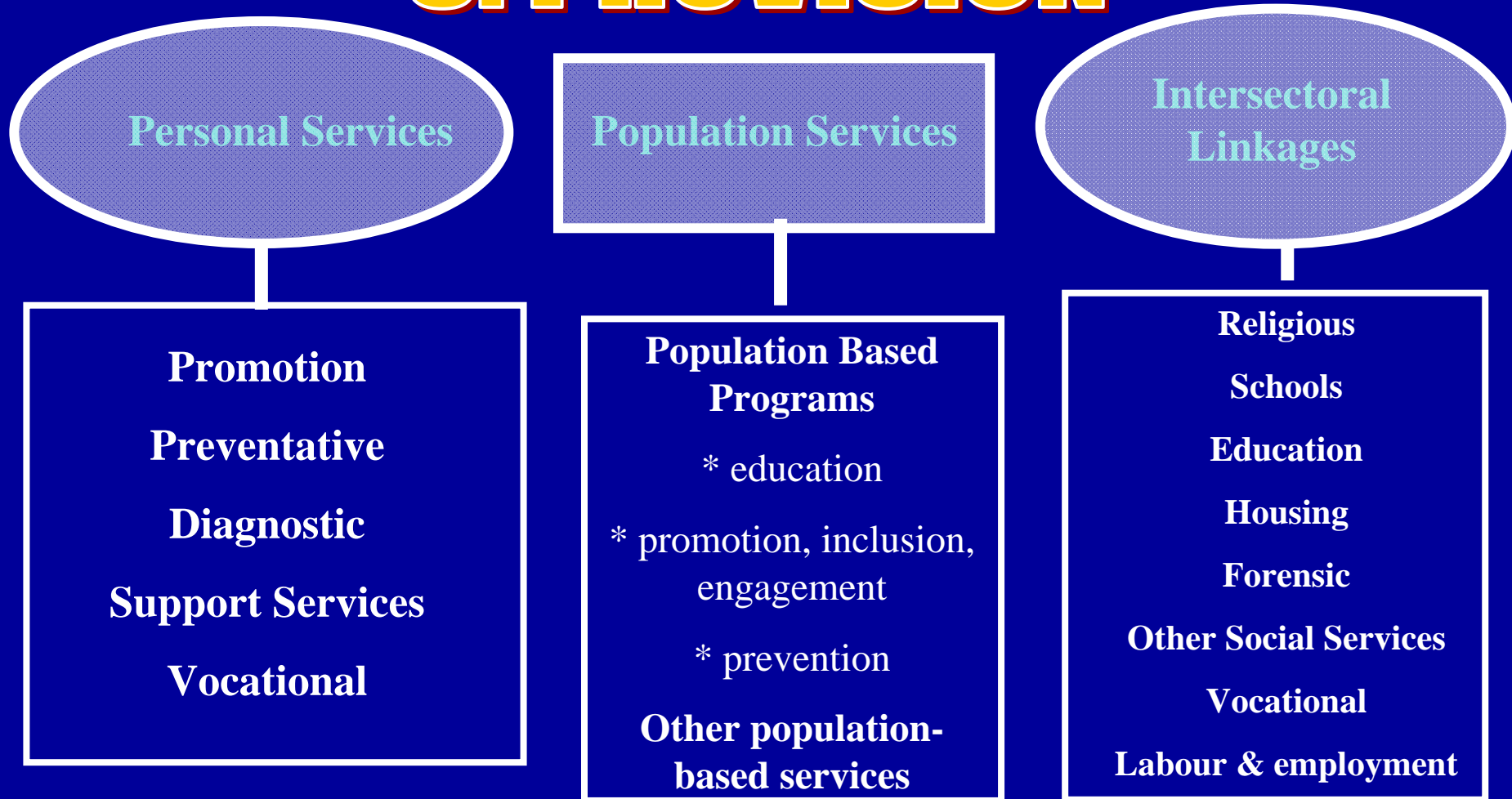
Funding models for service users

Economic analysis and modelling.

Workforce research into best practice models for training and development.

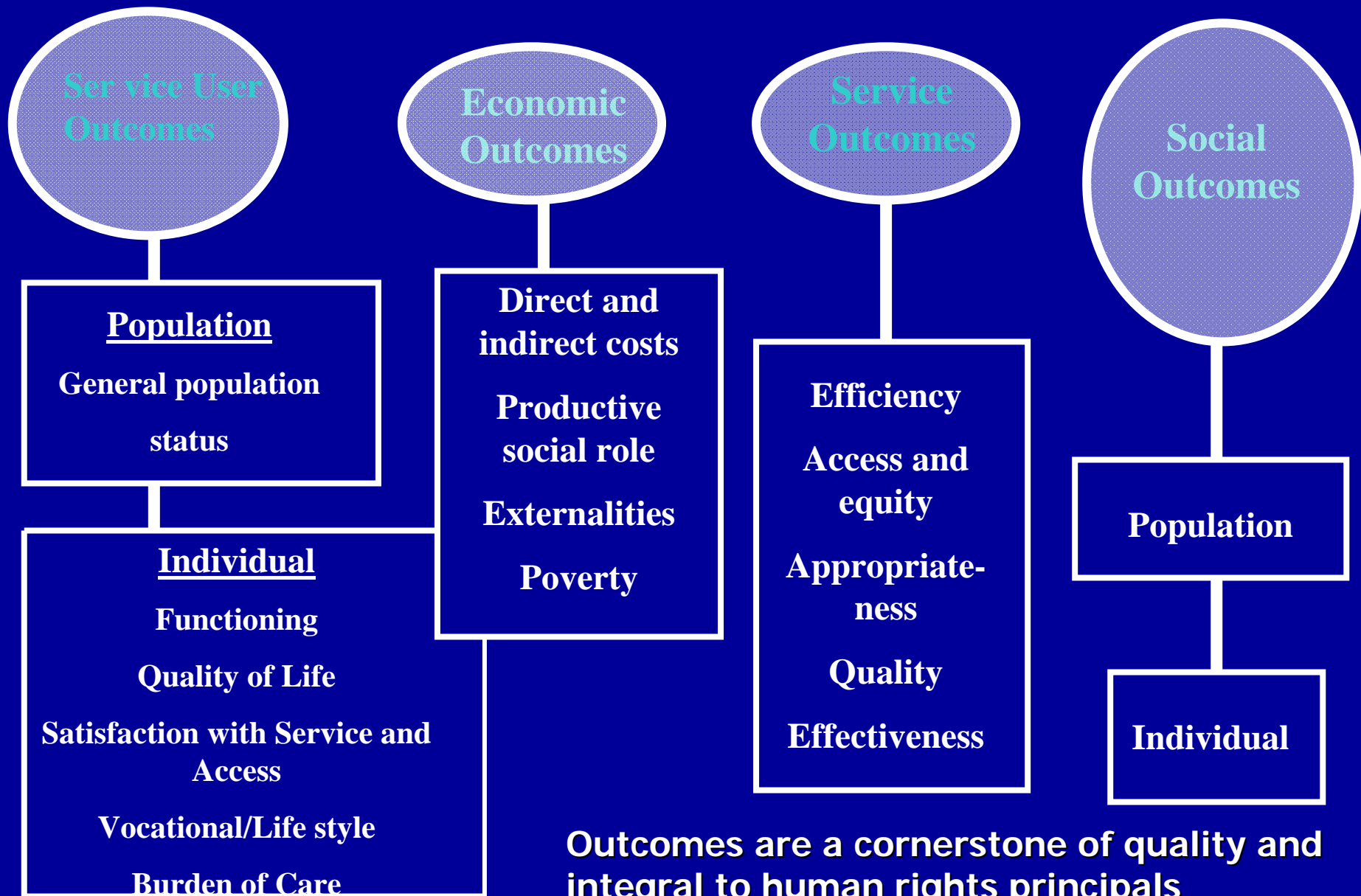
Technologies that support and facilitate communication and mobility and the measurement of their effectiveness.

3. PROVISION



This domain will include research into areas such as:
positive behavior support;
positive behavior support plans;
housing models ;
cross sector linkages

4. OUTCOMES



OUTCOMES

Innovative research in this area will include the development of valid & reliable outcome measures that ascertain:

- Quality of life;
- Measures of quality care
- Efficacy
- Efficiency & costs of care
- Increased human rights compliance
- Consequent impacts on social capital

APPLYING THE TEMPLATE

The internal domains & elements constitute a 'finite' map of research topics.

Questions are asked for each internal domain and element

- What is prevailing situation in relation to this domain or element?
- What research exists?
- What research is required to inform this area?

A research proposal is drafted

The external parameters are applied.

- Is the area of research consistent with human rights instruments and Conventions?
- Does the research promote human rights?
- Does the research fit with existing policy directions and research priorities?
- Should this be promoted as a research priority?
- What resources are available?

YES

Research is undertaken

NO

Research proposal is revised.

Research proposal is rejected

TASKS TO DEVELOP THE RESEARCH AGENDA TEMPLATE

- **Inventory of research activities in Australia and internationally;**
- **A search of the international literature;**
- **Experience of countries that have developed comprehensive research & policy agendas in the area of intellectual disability and challenging behaviour;**
- **Consultation and collaboration with a range of key stakeholders in Queensland, nationally and internationally as to the applicability of the template and its constituent parts.**

DISCUSSION

Involvement of all stakeholders

Within a human rights framework all human beings have the right to participate in the scientific enterprise.

There is a need to open scientific matters to public debate and democratic participation so as to arrive at consensus and concerted action.

Such involvement entails a systematic revision of science and demands recognition of the increasingly diverse actors entering the social tissue of science (World Conference on Science, 1999).

DISCUSSION

RESEARCH UTILISATION

- The development of a research agenda will not automatically mean that researchers will directly influence human rights based policy or service development or reform.
- The utilization of research will be impacted upon by a web of multi-dimensional causal variables:
 - complex power relationships;
 - political expediency;
 - fiscal stringency;
 - shifts in ideology and values;
 - intellectual fashion

SUMMARY

- Research is needed to improve the quality of life & outcomes for people with intellectual disability & challenging behaviour.
- Research should be undertaken within a human rights framework.
- There are a plethora of research issues to be considered.

SUMMARY

- **The Intellectual Disability Research Template can assist in the rationalization and prioritization of the research agenda within a human rights structure.**
- **It has application at local, state and national levels.**
- **It can serve the purpose of drawing attention to an issue, support advocacy and pressure.**
- **In a system of finite resources it can rationalize the research critical mass to ensure real effectiveness.**
- **However we must ensure that our research efforts are adequately understood and represented by the range of stakeholders who will contribute to the service system.**

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Centre of Excellence for Behaviour Support
The University of Queensland
c.townsendwhite@uq.edu.au

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