Sustaining Desirable Practice Change

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Why is sustained practice change so difficult?

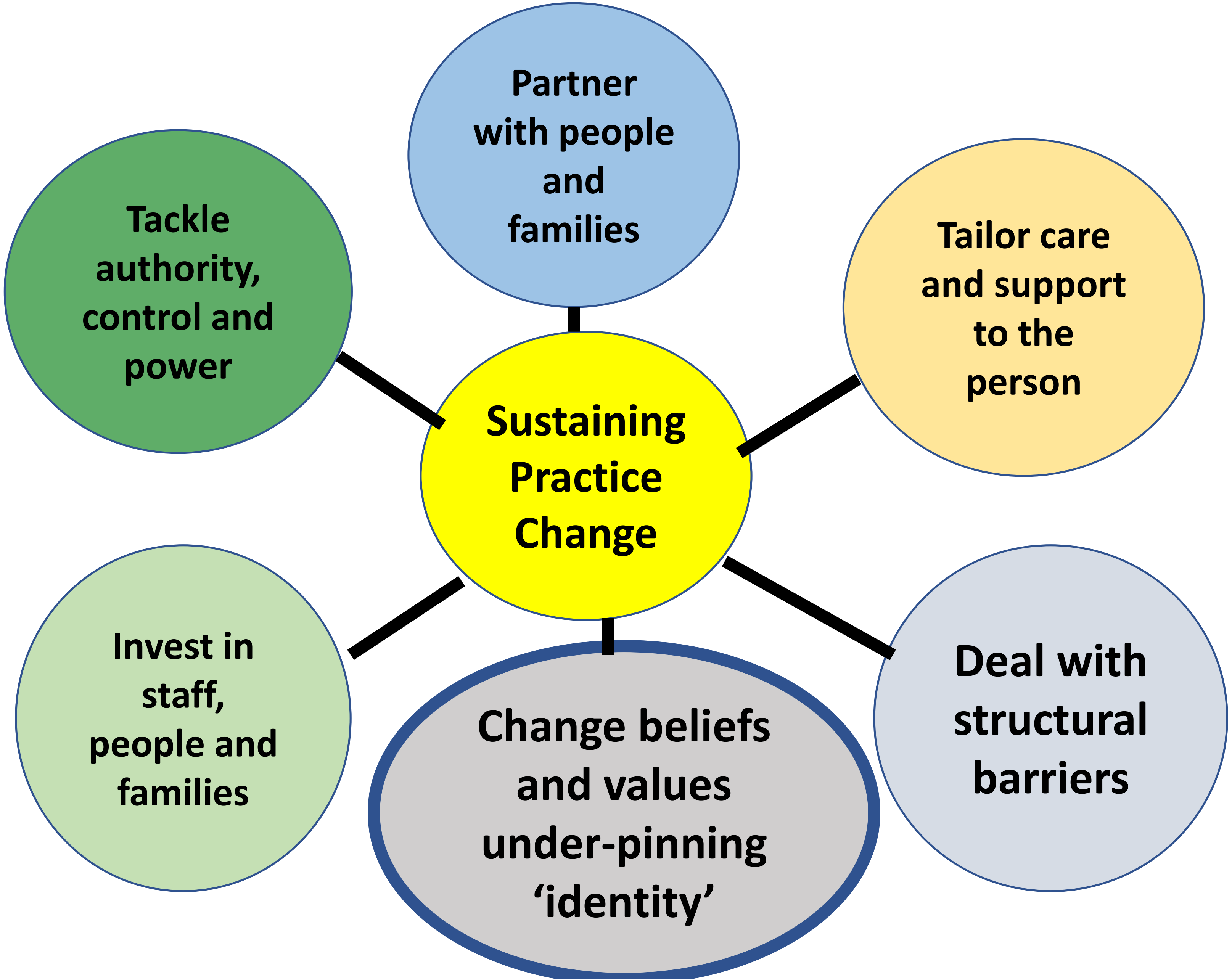
- **Belief that the change to organisational thinking and practice change can be made quickly and easily**
- **Top-down structure where management is far removed from people, families and direct care staff**
- **Reliance on predictability, group needs and service standardisation**
- **High levels of managerial control over staff actions and schedules, combined with inadequate mentoring and supervision**
- **Resistance by influential managers, staff and families**
- **Insufficient staff skills (at all levels of the organisation)**
- **Centralised organisational systems and poor local systems of support**
- **Belief that the organisation is the sole provider of services**

What is needed to sustain practice change ?

Sustaining Practice Change

- Partner with residents and families
- Tailor care and support to individuals
- Deal with structural barriers to change
- Establish core beliefs and values of service ‘identity’
- Invest time, support and education of managers and staff
- Tackle workplace authority, control and power

Reconfirm the vision for change



Sustaining Practice Change

Partner with people and families

Tailor care and support to the person

Deal with structural barriers

Change beliefs and values under-pinning 'identity'

Invest in staff, people and families

Tackle authority, control and power

Re-confirm the Vision for Change

Facilitate wide discussion with all stakeholders on agreed changes – inputs, processes and outcomes:

- **Reconfirm desirable and achievable care goals and desired outcomes**
- **Reconfirm agreement on the nature and process of change**
- **Communicate the vision and action plans frequently and widely**
- **Embed the vision in policies, procedures, job descriptions, work appraisals, education programs**
- **Allocate time and resources to embed and disseminate vision across services**
- **Engage in regular organisation renewal in discussion with residents, families and staff at all levels of the organisation**

Theme: Thinking differently

Getting rid of the noise in the system

"When you look at cultural change that we are facing [we] *want to get the noise out of the system."* (P. 1: line 321).

"... there's a lot of history, there's a lot of tradition in what we do. Many of the people that we employ are people that have got influence. They've been around for a long time. They've got their own ways of doing things. They've seen ways pass over them before ... so we're asking them to break out of that" (P. 1: lines, 138 – 43).

"... it's a journey ... a catalyst to make a certain change... pointing them [staff] in a completely different direction... away from the institution ... [to] improve the well-being and the life of the people ... rather than our own [and] on the needs of operating of our organisation." (P. 1: lines 50 – 66)

Theme: Thinking differently

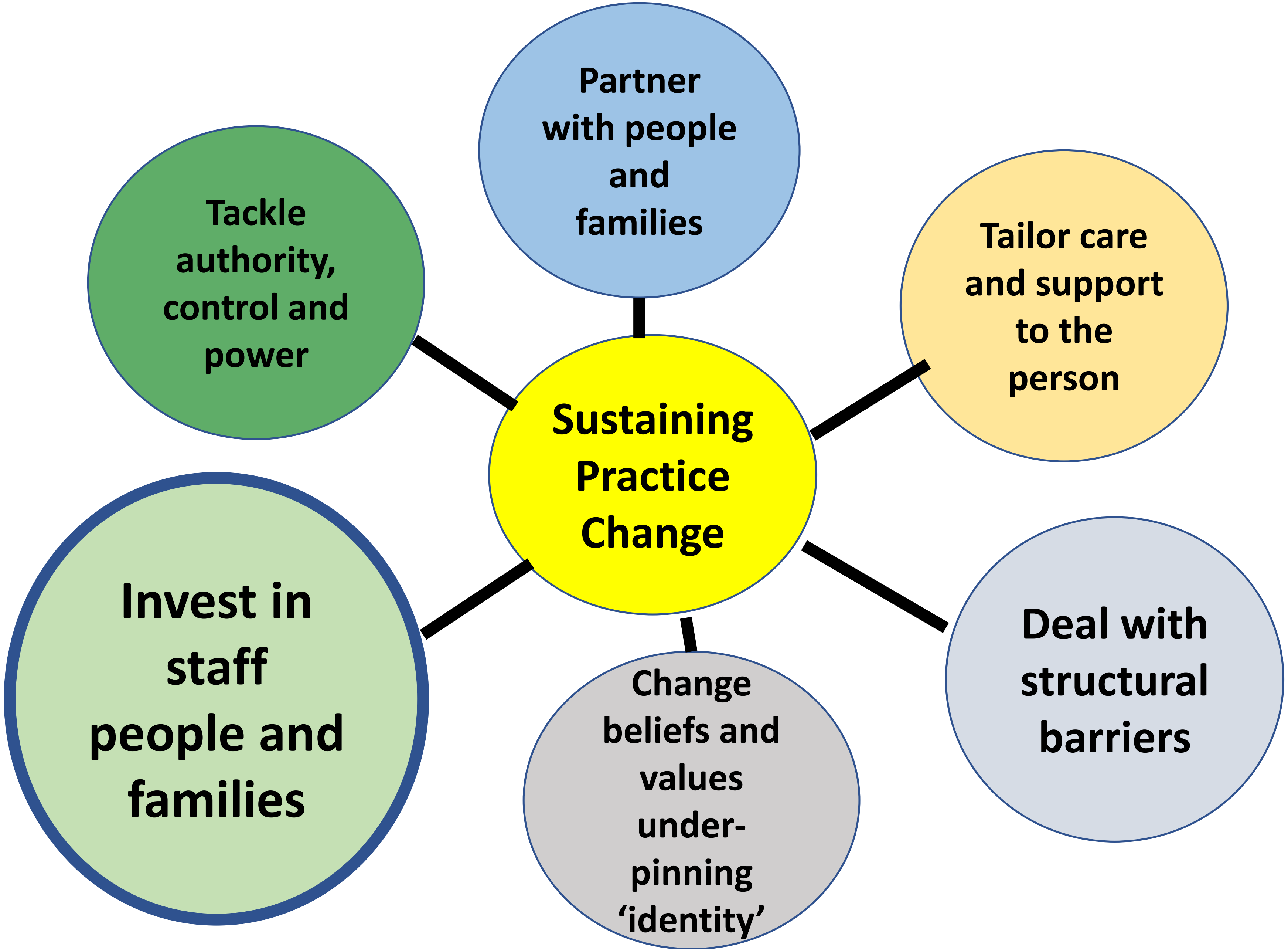
Changing systems

"... [Traditionally] *we've built things that the market might like but we haven't actually designed some of the work to enable PCC ... we've already had a shift in culture to acknowledge that care comes first ...* (P. 9; lines 21-22).

"... we've moved from compliance to outcome measures and clinical indicators, from satisfaction to the quality of life ... there's a lot of work to do in terms of culture at all levels..." (P. 2: lines 131 – 40).

"Its vision... it's fundamentally important to us; it's the biggest challenge that we have but we are tackling it ... how does the service we offer go forward?" (P. 1: lines 66 – 7).

Invest in Staff Skills for Practice change



Sustaining Practice Change

Partner with people and families

Tailor care and support to the person

Deal with structural barriers

Change beliefs and values under-pinning 'identity'

Invest in staff people and families

Tackle authority, control and power

Invest in / act on in staff knowledge and skills

Act on areas for knowledge and skill reinforcement and areas for improvement:

- **Ensure ongoing access to information and other resources for knowledge and skill development**
- **Support the ‘knowledge brokers’ among the team to guide the change process**
- **Prioritise staff teamwork, mentoring and supervision**
- **Regularly review practice policies, procedures and approaches**

Theme: Changing Peoples' Lives

Enabling the person to live the life they want to live.

"Training staff to ask the question 'What does the normal day look like for you? ... What can we do for you to help you come in here? ... How can we make it easier for you coming in here? ... The essence is the... THE person." (P. 6: lines 360 – 74)

"I feel like the changes we've made, a little bit, has been outrageously good ... you know now, through people's feedback" (P. 8: line 350).

"Staff now watch the expression on their face and know 'yes you've made them comfortable at that minute'... but you continue to ask 'yeah, but what do I do now? ... you're gauging what they want to talk about. So, you're responsive to what they are saying. You don't look as if you've changed that much but in reality you have, and you've made such a difference. So, whatever they want to focus on; every resident is different and every relative has a different concern." (P. 7: lines 211 – 232).

Theme: Changing Peoples' Lives

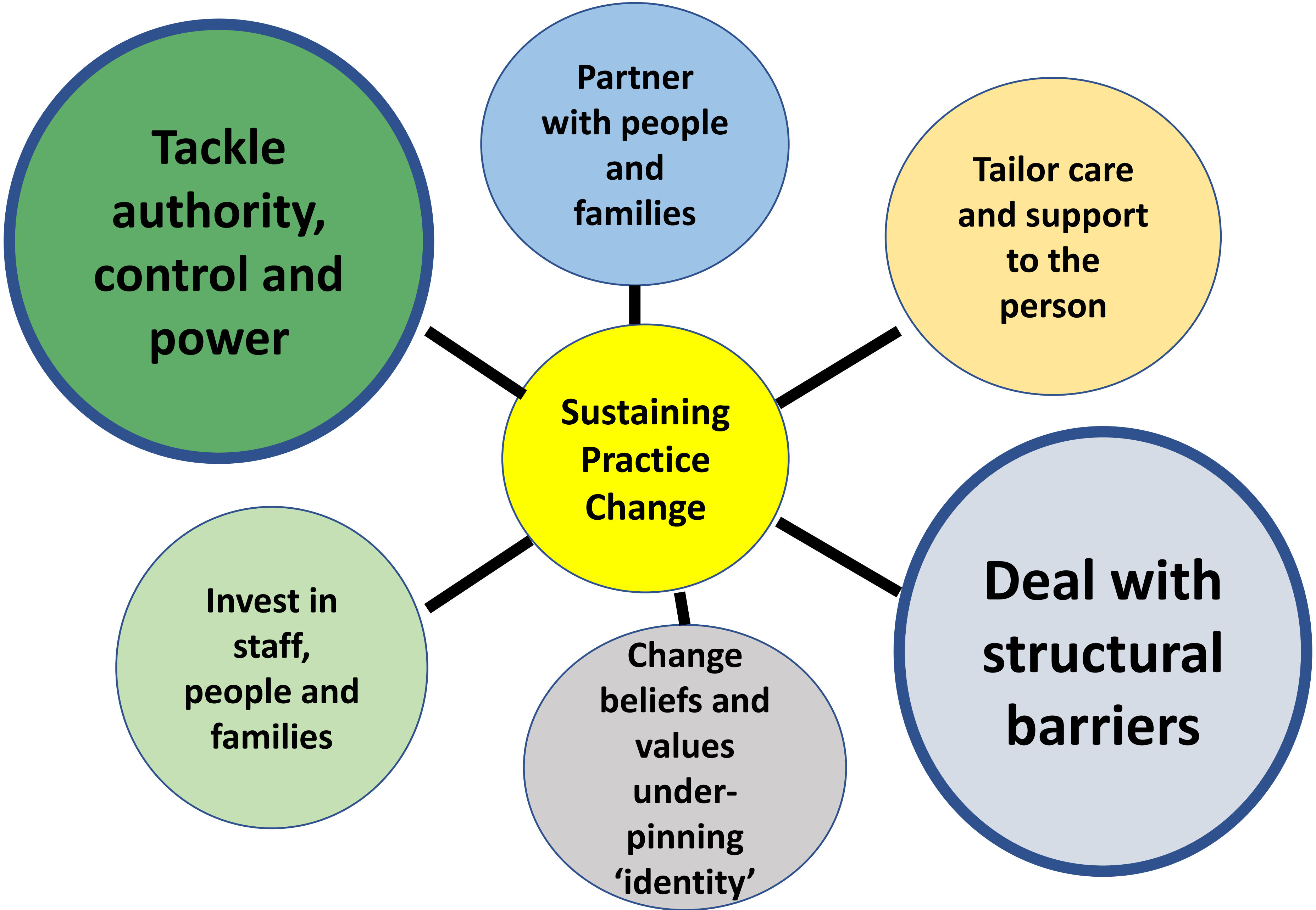
Encouraging friendships between residents and staff

" *We have continued a new role for staff to be friends with the new resident for the first week, eat with them in the first week…"* (P. 2: line 179).

"This (staff role) helps the resident to overcome the *daunting experience of walking into the dining room with a hundred and so people and you get sat in your spot*" (P. 7: lines 240 – 5).

" (residents) *can live their daily life the way they want to … looking beyond the clinical day-to-day stuff, focusing on their spiritual needs, their social needs* [and] *their relationship needs"* (P. 3: lines 85- 86).

Provide incentives to adopt change



Tackle authority, control and power

Partner with people and families

Tailor care and support to the person

Sustaining Practice Change

Invest in staff, people and families

Change beliefs and values under-pinning 'identity'

Deal with structural barriers

Continue to identify and address structural barriers

Place effort on a receptive context for change among managers and other key staff:

- **Continue to lead by example (both in commitment and application)**
- **Maintain systems to enable continued adoption of change across the organisation**
- **Reinforce agreed priorities and methods of staff selection, supervision, support and promotion**
- **Continue to reward cooperation, leadership, mentorship and supervision of change adoption**

Theme: Adopting a ‘yes’ Culture

Focusing away from compliance to the values and vision of PCC

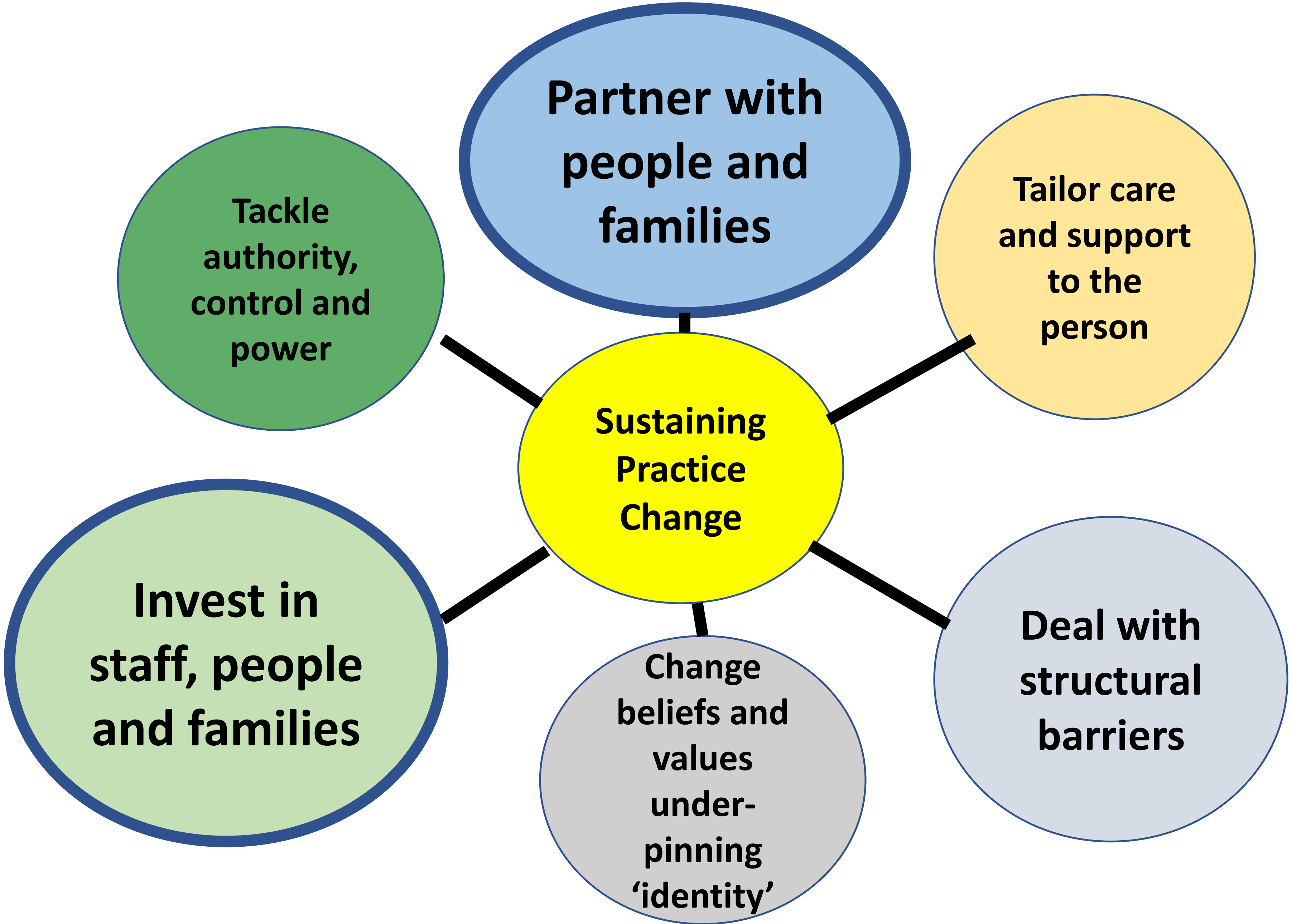
“ The process involves teaching people on the ground: this is how you make changes, sustainable changes and sensible changes”. (P. 2: line 233).

“When I walk away they [staff] should have that well and truly down pat” (P. 3: line 230).

“My role is to make the changes happen here; to help implement the practice change toolkit ongoing” (P. 5: line 365).

“The job design … the language and the expectations in the position descriptions actually align with practice change... [with] *more emphasis on the empathy, more emphasis on our values and a person-centred approach.”* (P. 1: lines 406 – 9).

Ensure adequate resourcing for change over time



Sustaining Practice Change

Partner with people and families

Tailor care and support to the person

Deal with structural barriers

Change beliefs and values under-pinning ‘identity’

Invest in staff, people and families

Tackle authority, control and power

Ensure adequate resources for change

Structure systems to enable continuation of desirable change practice outcomes:

- **Support work teams to lead change at the level of the care unit, the department and the whole facility**

- **Provide material and human resources to enable continued adoption of desired care practices, e.g. leisure, sensory and comfort objects for residents, technical aids for staff, individually-tailored equipment for resident care, family/resident friendship circles**

- **Continue enriching the care environment – personal and public spaces, leisure & creative events, positive relationships between managers and staff, residents, family members, volunteers and community visitors**

Theme: Adopting a 'yes' Culture

Working together in decision-making

"... our 'yes culture' is basically decentralised decision-making... We are looking to a future in which the people have got that ability to say, yes we can, okay let's do that, I'll stop what I'm doing; I used to make beds at 10 o'clock, okay why do I need to make the bed at 10 o'clock why don't we sit down have a chat with the residents." (P.2: lines 56-57).

"...It's a different management framework, which can be a bit confronting, at least challenging, personally to the managers..." (P.2: 235-6).

"... the role of management is to give voice to staff and allow them the ability to be autonomous...yes, that comes from bottom up and top down" (P. 6: lines 60 – 2).

Theme: Changing Systems

Harnessing staff attributes in skill development

“*…we focus on the right mix of staff*” (P. 7: line 450).

“*…the managers ensure that they’re* [staff members] *are okay with reallocation to roles, stating: ‘It’s your expertise that we need here’ … getting staff buy*-in. *”* (P. 6: lines 183 – 93).

“ *A registered nurse educator position is dedicated to the implementation of the person-centred approach, so that staff are able to understand all that we are doing conceptually and to develop a personal development plan for all the staff*” (P. 8: lines 286 – 6).

“…. employing the right person with the right attributes from the start…the people who are going to work like this ... whose attributes are ... discernment and judgement...” (P. 4: lines 135 – 55).

Operationalise the Action Plan

Maintain ongoing agreement from all key stakeholders on the process and timing of practice change as per the Action Plan:

- **Ensure all stakeholders have regular opportunities to revisit and suggest amendments to the Action Plan**
- **Regularly communicate updated details of the Action Plan and the timing of the change process**
- **Ensure all stakeholders have ongoing advice on how the planned changes are being evaluated and the role they play in that process**

Theme: Adopting a ‘yes’ Culture

All of us are accountable to the plan

“[This process] gives the managers visibility on what’s happening as soon as it happens so they can start to measure themselves against the data. To feed that information back ... to show how we’re progressing.” (P. 6: lines 7 – 28).

“... people come back to the table as a group and we work on, we discuss what we’re doing, we analyse that and we work out a plan going forward ... keep people accountable the whole way through.” (P. 5: lines 138 – 40).

“….the changes we are implementing include ... a bigger strategic platform for leadership, including transformational change and values driven practice...” (P. 2: lines 467 – 81).

“Good people management, good systems management, holding people to account reasonably and fairly, staying on top of things, procedures in place, systems in place, delegations happening, well educated, clear expectations are set, managers are looking at educating their own staff and recognising those needs, I think all those things have a play in managing PCC” (P. 4: lines 209 – 27).

Conclusion: REQUIREMENTS for sustained practice change

Vision + **Skills** + **Incentives** + **Resources** + **Action Plan** = ***CHANGE***

Skills + Incentives + Resources + Action Plan = ***CONFUSION***

Vision + Incentives + Resources + Action Plan = ***ANXIETY***

Vision + Skills + Resources + Action Plan = ***RESISTANCE***

Vision + Skills + Incentives + Action Plan = ***FRUSTRATION***

Vision + Skills + Incentives + Resources = ***TREADMILL***

(Knoster, T. (1991) TASH Conference, Washington, D.C.)

Living With Dementia

Stephen Bourne – 26.11.19

Note: Names and some details have been changed in examples to protect privacy.

The objective of this presentation is to examine some modern-day treatment approaches that have the potential to give new meaning to *living with* dementia.

Today we can often forestall the impacts of dementia for longer than has traditionally been thought possible.

We also recognise now that people with dementia are first and foremost our friends, family members, colleagues and heroes.

Paul: Psychosis initially misdiagnosed, later identified at about age 62 as younger onset dementia, fully dependent on carers within 3 years.

Janet: Now aged 87, significant change in memory function over past 5 years, only moderate change in other domains, diagnosis uncertain, husband reluctant to subject Janet to cognitive tests, no challenging behaviours.

Helen: Now aged 75, challenging behaviours in social contexts and at home, significant language barrier, Helen and her husband have withdrawn from social activities, no support network or family support.

These examples of Paul, Janet, and Helen illustrate the stark contrast between different manifestations of dementia. In each case there are daily impacts of dementia upon the person with dementia and those involved in his or her life.

In Paul's case, the rapid change in behaviour can only be described as extraordinary, but for Helen the change is just as real even if it is much slower.

In Janet's case, the prognosis may be regarded as less certain, but the impacts are no less real.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'Halting Antipsychotics in Long-Term Care' (HALT) withdrawal trial

- Aimed to achieve complete antipsychotic withdrawal in a cohort of 133 participants falling outside the exclusion criteria for the HALT trial (Aerts et al., 2019, p.1574).
- Goal not achieved for 39 participants. Failure to de-prescribe drugs, and re-prescribing following initial withdrawal of medication, mainly driven by nursing staff.

Other factors identified by Aerts et al. (2019)

- Inadequate staffing.
- Managerial expectations.
- A “prescribing culture” within a facility.
- GPs lacking confidence and skills to recommend non-pharmacological approaches.
- Residents’ substitute decision makers also common drivers of re-prescribing.

✓

Hargood et al. (2017, p.4) suggest that a person with dementia may be reluctant to engage socially due to a fear of becoming lost when away from home.

'Therapeutic Locative Interactive Fiction' (TLIF) may build confidence in leaving the confines of home.

TLIF combines activity-focused narrative with GPS technology to drive interest in stepping outdoors, in the company younger relative or carer, to re-connect with the local community and amenities.

The narratives of Paul, Janet and Helen speak to the diversity of dementia symptomology and decline.

It is essential to understand the barriers in each case and identify the best treatment and support options.

Even then, there is a danger that intended treatments are subverted in their delivery, even if not through any deliberate neglect on the part of the service provider.

Behind the barrier of dementia is a real person whose life can still have purpose, pleasure and dignity.

Thank You

Stephen Bourne

sb@psyc101.com

Designing research to support older adults living with dementia: do-able or doomed?

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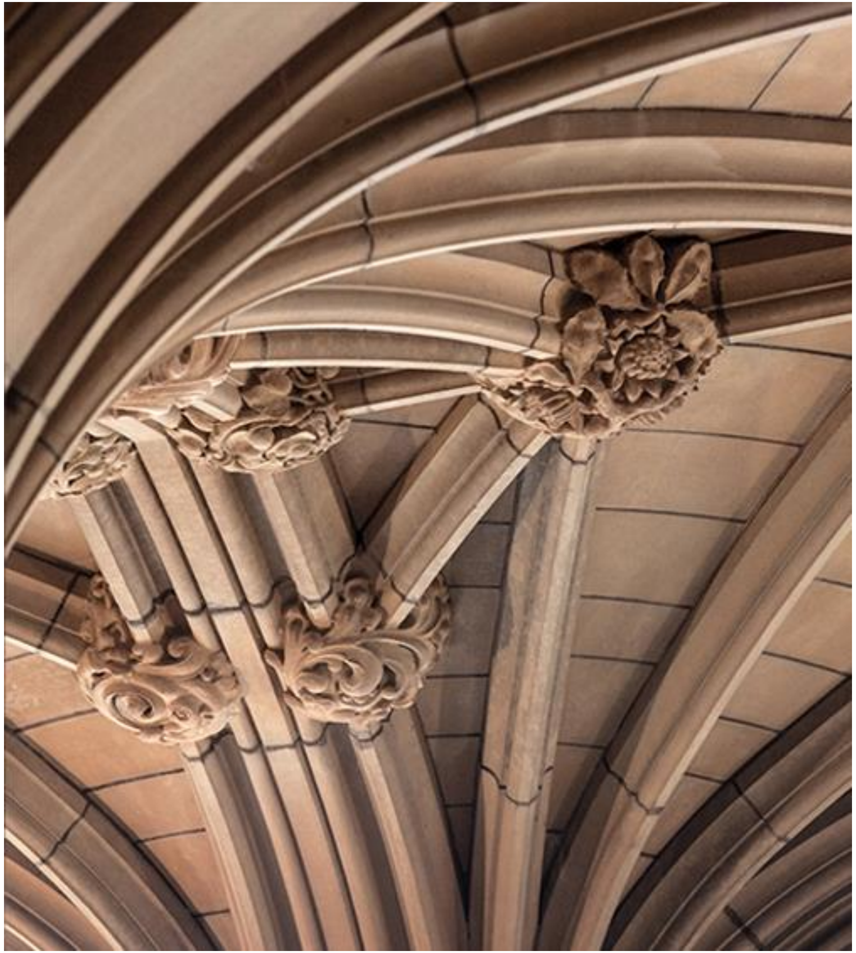
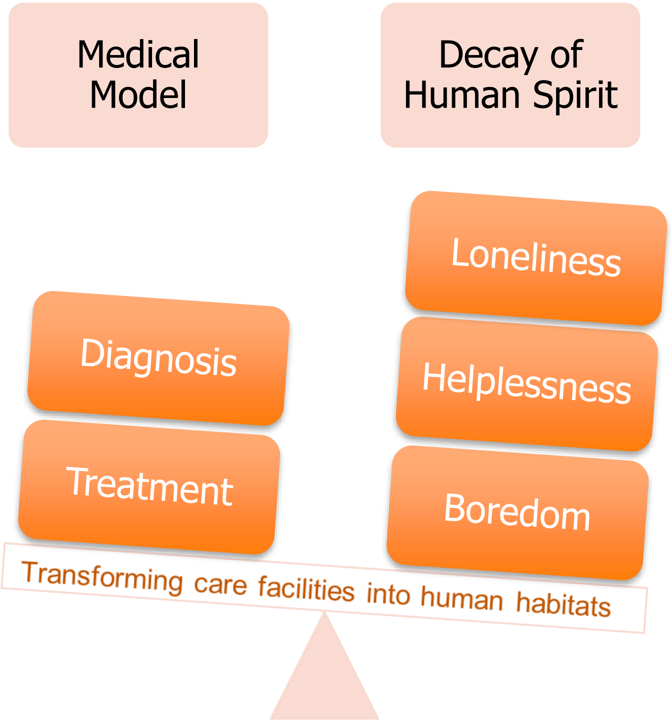
Faculty of Health Sciences,
Discipline of Occupational Therapy
sanet.dutoit@sydney.edu.au

THE UNIVERSITY OF SYDNEY



Issues associated Well-being & Institutionalisation



Medical Model

Decay of Human Spirit

Loneliness

Helplessness

Boredom

Diagnosis

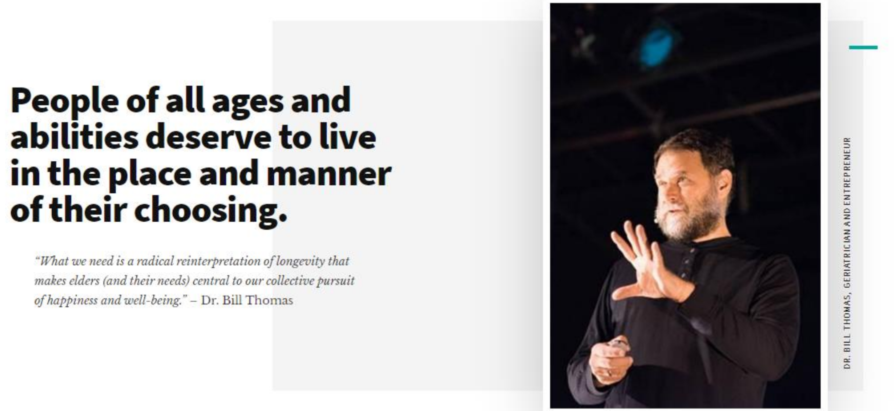
Treatment

Transforming care facilities into human habitats

BEING A NON-CITIZEN

Ref: Google Images

Reframing Ageing



People of all ages and abilities deserve to live in the place and manner of their choosing.

"What we need is a radical reinterpretation of longevity that makes elders (and their needs) central to our collective pursuit of happiness and well-being." – Dr. Bill Thomas

DR. BILL THOMAS, GERIATRICIAN AND ENTREPRENEUR

AS FEATURED IN:

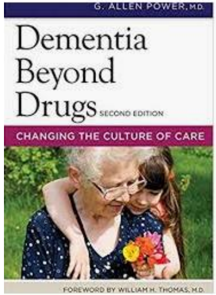
The Washington Post The New York Times TED Ideas worth spreading

Pioneer Network

Changing the culture of aging in the 21st century

Kate Swaffer / August 13, 2018

#BanBPSD

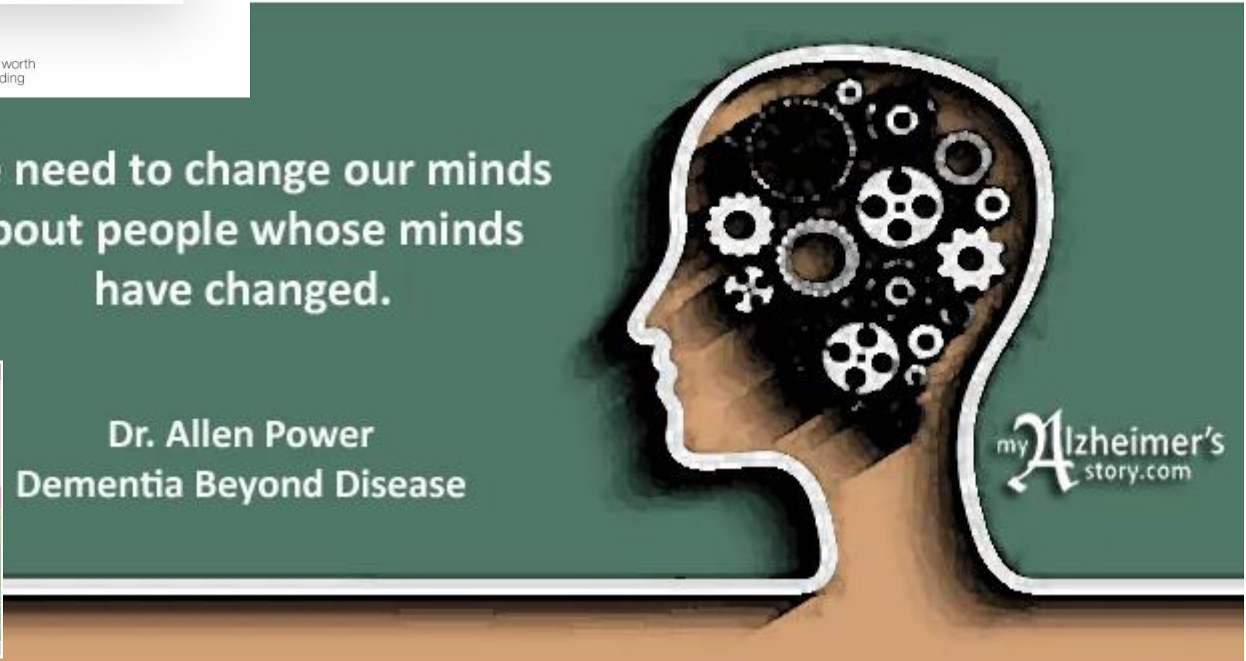


G. ALLEN POWER, M.D.

Dementia Beyond Drugs SECOND EDITION

CHANGING THE CULTURE OF CARE

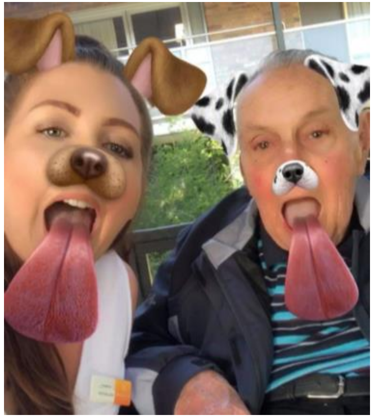
FOREWORD BY WILLIAM H. THOMAS, M.D.



We need to change our minds about people whose minds have changed.

Dr. Allen Power
Dementia Beyond Disease

A Social Approach to Aged Care



Free rent and meals offered by nursing home to students in companionship program

ABC Radio Sydney By Harriet Tatham

Updated 30 Sep 2019, 8:54am

Resident-directed care ↔ Rondomised control trials

The electronic toilet top bidet in residential aged care

Dr Meredith Gresham

BPSD Workshop, Sydney: Tues 26th Nov 2019

UNSW SYDNEY

Australian Government

NHMRC National Institute for Dementia Research

DCRC
Dementia Centre for
Research Collaboration


The BIDET SHOP

NSW Health Extreme BPSD Policy Project

Kate Jackson

Director, Older People's Mental Health

Mental Health Branch, NSW Ministry of Health

BPSD workshop

November 2019

NSW GOVERNMENT Health

Project aims

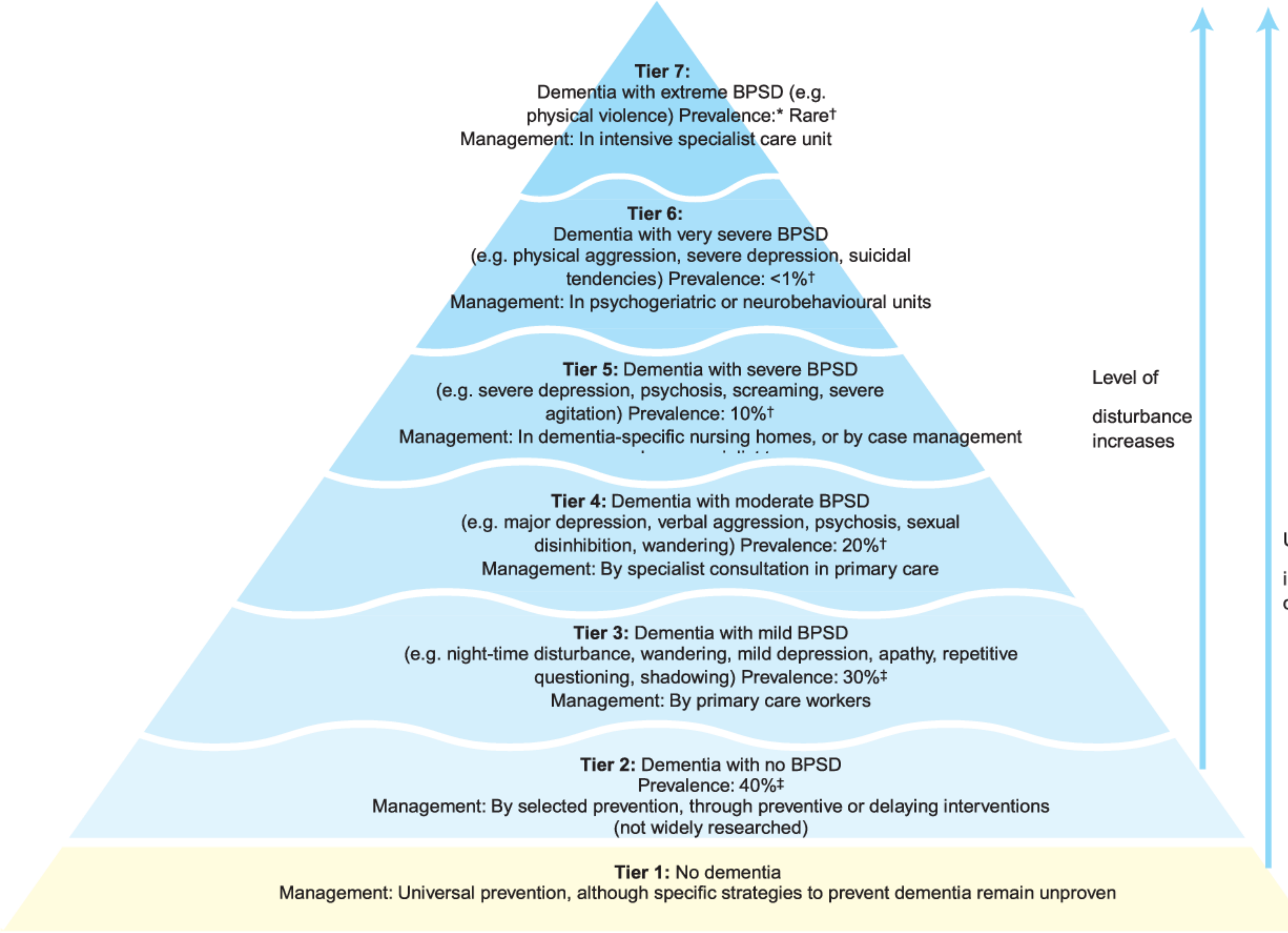
To explore the numbers, characteristics and needs of people with extreme BPSD

To inform policy and service planning

To improve care and service responses

NSW GOVERNMENT | Health

Who are we talking about?
Brodaty et al triangle model (2003)



Tier 7:
Dementia with extreme BPSD (e.g. physical violence) Prevalence:* Rare†
Management: In intensive specialist care unit

Tier 6:
Dementia with very severe BPSD
(e.g. physical aggression, severe depression, suicidal tendencies) Prevalence: <1%†
Management: In psychogeriatric or neurobehavioural units

Tier 5: Dementia with severe BPSD
(e.g. severe depression, psychosis, screaming, severe agitation) Prevalence: 10%†
Management: In dementia-specific nursing homes, or by case management

Tier 4: Dementia with moderate BPSD
(e.g. major depression, verbal aggression, psychosis, sexual disinhibition, wandering) Prevalence: 20%†
Management: By specialist consultation in primary care

Tier 3: Dementia with mild BPSD
(e.g. night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing) Prevalence: 30%‡
Management: By primary care workers

Tier 2: Dementia with no BPSD
Prevalence: 40%‡
Management: By selected prevention, through preventive or delaying interventions (not widely researched)

Tier 1: No dementia
Management: Universal prevention, although specific strategies to prevent dementia remain unproven

Level of disturbance increases

Use of interventions is cumulative

Who are we talking about? (cont.)

Characteristics may include:

- cognitively impaired
- persistently very severely behaviourally disturbed OR
- have episodic and **unpredictable** periods of **very extreme behavioural disturbance**
- **physically robust**, ambulant, often strong
- extremely **physically aggressive**
- significant communication or language problems
- severe **sexually disinhibited** behaviour
- **high risk of serious harm** or death to others and self
- multiple co-existing conditions and a high level of complexity
- medically stable (ie not post-acute delirium)
- at risk of premature death due to iatrogenic causes such as over sedation and restraint
- often male, often of younger age (i.e. under 65 years) but have early ageing issues (eg cognitive impairment)
- psychosocial and environmental strategies have resulted in minimal change in presentation
- trials of psychotropic medication have been unsuccessful

The person is likely to have experienced

- a **long inpatient stay** of over three to six months, or
- a shorter inpatient stay with **significant risk or safety issues** or incidents apparent quickly
- inability to secure a residential aged care placement, and/or
- multiple **unsuccessful hospital admissions or residential aged placements**

Project context

Currently, people with extreme BPSD may be cared for a variety of services environments in NSW, which vary in their capacity and approach.

- OPMH Acute Inpatient Units
- Geriatric and acute medical units
- MH-RACF partnership services
- Non-acute OPMH inpatient units (BPSD-focussed)
- State Government nursing homes
- Adult MH high dependency/intensive care/ acute inpatient units
- Forensic mental health system
- Corrective services

Project approach

- Small project team for expert advice
- Consultation with key groups and individuals, as well as groups in key locations across NSW
- Interviews with key stakeholders and informants within NSW and other jurisdictions
- Literature scan of relevant service models (limited)
- Reviewing of available data
- Draft report for feedback, then a final project report - intended to inform improved care for people with extreme BPSD, and guide NSW Health policy and planning
- Also hoping to add to the published literature in this space

BPSD workshop – Partnering with Government, November 2019

Policy

The dementia policy and program settings are underpinned by the **National Framework for Action on Dementia 2015-19**. Agreed to by the Council of Australian Governments (COAG) Health Council, it **guides ongoing action in dementia care** for governments, service providers, peak bodies and the broader community.

The Australian Health Ministers' Advisory Council (AHMAC) has initiated a **review** of the Framework, being coordinated by the WA Government, out for consultation.

The current Framework has informed policy and program design across all levels of government, but has not included clear accountabilities, performance targets or ongoing monitoring of outcomes.

Research

There have been significant advances in **dementia research** in prevention, clinical treatment and care, and understanding disease mechanisms.

From 2019, a further $185 million over 10 years will fund the Medical Research Futures Fund **Ageing, Aged Care and Dementia Mission,** to support dementia research beyond the end of the Boosting Dementia Research Initiative, including in the priority areas of diagnosis, treatment and prevention, consistent with the NNIDR Strategic Roadmap for Dementia Research and Translation.

Guided by an Expert Advisory Panel, and administered by the NHMRC with the Minister approving research priorities. Areas of research focus:

- improving timeliness of dementia diagnosis and early post-diagnostic treatments
- prevention and risk reduction
- prolonging quality of life
- developing innovative care models and technologies to improve health outcomes; and
- compressing the period of intense morbidity in later years.

Contributions from philanthropic organisations, governments, industry, and the private sector will be sought to increase the impact of the Mission.

Aged Care Centre for Growth and Translation Research (CGTR)

The government has also committed $34m to the formation of an **Aged Care Centre for Growth and Translation**. The Centre will examine new ways to deliver care for older Australians and training and education for aged care providers, through:

- **research seed funding** – for innovations such as assistive technologies, models of care, best practice guidelines, and strategies to improve care at the interface of health and aged care;
- **knowledge translation** – this will include online training modules, courses and tailored on-site training; and
- **advisory groups** and a survey to guide funding priorities.

The Dementia and Aged Care Services (DACS) fund targets support for emerging priorities and challenges in aged care, focusing on dementia care, and projects to support Aboriginal and Torres Strait Islander people, CALD and LGBTI.

DACS funded projects will often provide tools or an evidence base to support on-the-ground practice changes in aged care – major challenge is **how to share tools and knowledge** across the aged care and health sectors, to scale best practice or embed it in such a way that it is sustainable.

How can we translate dementia research into better dementia care?

We're constantly looking at how we can better translate research into practice; embed research outcomes into policy development; and leverage across government to improve the outcomes for those living with dementia as they navigate across the health, disability, community and aged care sectors to have their needs met.

In the design of the new **MRFF Ageing, Aged Care and Dementia Mission** we are considering how to use **unique funding models** to drive partnerships for translation. Such models are already applied through the MRFF fund including the Rapid Applied Research Translation (RART) project and Frontier Health and Medical Research Initiative. MRFF Mission approach of increasing impact through philanthropic and private co-contributions is an opportunity to consider how **community interest** can reflect in dementia research.

We are also trialling new ways to take a human-centred design approach to policy formation through the **Dementia in the Community.** This project has involved ethnographic research and brought policy makers and program managers from within government together with those living with dementia, their carers, health professionals, aged care workers, specialist dementia services and researchers to **identify current gaps** in dementia understanding and **co-design a set of policy opportunities.**

Programs

The government invests more than $50m each year in dementia support programs, such as the National Dementia Support Program, the DBMAS and SBRT. In addition, the **SDCP** is a new Australian Government initiative for people exhibiting very severe BPSD, who are unable to be appropriately cared for by mainstream aged care services.

These national programs present an opportunity to **embed funded research outcomes** into practice through well established awareness and information distribution channels, such as the Dementia Training Program.

Conclusion

We continue to look for opportunities to make program improvements based on contemporary research. Where we often fall short is in tackling issues that are not neatly addressed from within a program or a particular area of policy responsibility – e.g alleviating social isolation, assisting people to move between the aged care and health care systems, or overcoming the stigma associated with dementia and ageing.

I look forward to engaging with you further on how we can create partnerships through research, and shape future policy and program improvements to increase the quality of life for those with dementia and their carers.

University of
South Australia

Beyond BPSD

Kate Swaffer

Author and Activist
PhD Candidate, University of South Australia
Chair, CEO co-founder, Dementia Alliance International

BPSD

- Wandering (normal desire to walk)
- Sundowning (normal tiredness)
- Anxiety or agitation (communication, sensory or other disability not being supported; unmet need e.g. pain; bored and lonely; lack of attention due to low staffing levels, etc.)
- Aggression (all of the above; dislike the staff; distress from unknown source, e.g. a care leaver who was abused as a child)
- Hallucinations
- False ideas (confabulation – or a desire to fit in?)
- Disinhibited behaviour

Normal human responses

- Walking (wandering)
- Tiredness (sundowning)
- Anger (anxiety, aggression, tiredness, unmet needs)
- Apathy (fear, grief, sadness, loss of agency and self determination, etc.)
- Frustration (anxiety and/or agitation, fear, grief, sadness, loss of agency and self determination, etc.)
- Fear (grief, apathy, fear, grief, sadness, loss of agency and self determination, etc.)
- Excitement (agitation)

The problem with BPSD

- Relegates people’s expressions to brain disease
- Ignores environmental, relational and historical factors
- Pathologises normal expressions
- Uses flawed systems of categorisation
- Creates a slippery slope to drug use
- Does not explain how drug use has been successfully eliminated in many care homes
- Misapplies psychiatric labels, such as psychosis, delusions and hallucinations

(Power, 2019)

University of
South Australia

In the case of those living with dementia why has the Pharmaceutical Industry been one of the primary "stakeholders" in "educating" the caring profession? "BPSD" was a term coined by industry rather than reality, let alone science.

This is why I want to see "BPSD" go into the dustbin. Alas, at least in the UK, my profession continues to receive significant amounts of "education" from vested interest

(Pearce: 2018)

Thank you

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@KateSwaffer

University of South Australia

2018 PhD Candidate
2008 Bachelor of Psychology
University Merit Award

High Level Meeting Steering Committee
Civil Society Working Group

FINANCIAL REVIEW women of influence

2018 Winner, Global Leader category

Australian of the Year Awards

2017 Australian of the year SA

UNIVERSITY OF WOLLONGONG AUSTRALIA

2016 Alumni Award Social Impact Award, Winner

National Disability Awards

2015 Emerging Leader in Disability Awareness, Winner

UNIVERSITY of STIRLING

2015 International Dementia Leader

HOPE

NOT DESPAIR

THE YAHTONG APPROACH TO DEMENTIA

Dr Carmelo Aquilina

VMO Staff Specialist Yathong Lodge T-BASIS unit,
Wagga Wagga Base Hospital

Yathong Lodge - orientation

- T-BASIS unit @ Wagga Wagga Hospital
- 8 beds
- Multidisciplinary team - input from geriatrics
- RMO and 1 day VMO consultant
- Take tier 5 & 6 patients mainly with agitation, aggression

Yathong Lodge -challenges

- Cannot be managed elsewhere
- What are we treating ?
- What is happening ?
- Need time to see what’s happening
- “My shift” syndrome
- Limited medical time

Yathong Lodge - HOPE

- Holistic
- Outcomes oriented
- Person-centred
- Experience

Yathong Lodge - HOPE

- Holistic
  - *Assess everything*
    - *Life story*
    - *Likes and dislikes (top 5)*
    - *Medical history and physical examination and tests*
    - *Behavioural symptoms*
- Outcomes oriented
- Person-centred
- Experience

Yathong Lodge - HOPE

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  - *Assess everything*
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- Outcomes oriented
  - *Measure the behaviour to figure out if your treatment is working*
  - *Focused on resolution of main problems*
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Yathong Lodge - HOPE

- Holistic
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  - *Treatment is tailored for each person*
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Yathong Lodge - HOPE

- Holistic
  - *Assess everything*
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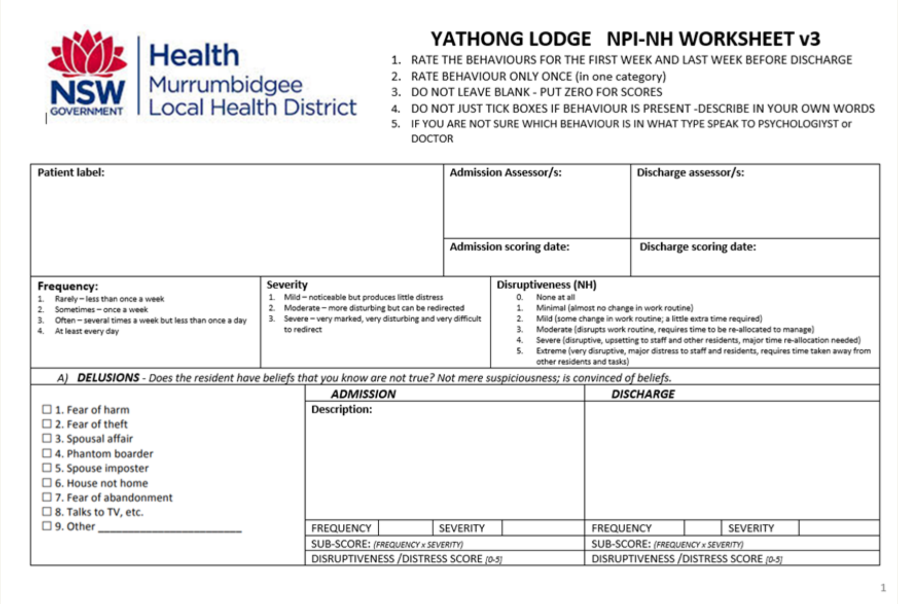
    - *Medical history and physical examination and tests*
    - *Behavioural symptoms*
- Outcomes oriented
  - *Measure the behaviour to figure out if your treatment is working*
  - *Focused on resolution of main problems*
- Person-centred
  - *Treatment is tailored for each person*
- Experience
  - *The patient and their carers have a positive experience of admission*

Behavioural

- Use of standard instrument – NPI-NH* (short nursing home version)
- Done one week after admission to allow for effects of new environment
- Measure frequency, severity and impact on unit
- Allows most significant behaviours to be prioritised
- Done on discharge to gauge effects of admission



NSW GOVERNMENT | Health Murrumbidgee Local Health District

YATHONG LODGE   NPI-NH WORKSHEET v3

1. RATE THE BEHAVIOURS FOR THE FIRST WEEK AND LAST WEEK BEFORE DISCHARGE
2. RATE BEHAVIOUR ONLY ONCE (in one category)
3. DO NOT LEAVE BLANK - PUT ZERO FOR SCORES
4. DO NOT JUST TICK BOXES IF BEHAVIOUR IS PRESENT -DESCRIBE IN YOUR OWN WORDS
5. IF YOU ARE NOT SURE WHICH BEHAVIOUR IS IN WHAT TYPE SPEAK TO PSYCHOLOGIYST or DOCTOR

Patient label:	**Admission Assessor/s:**	**Discharge assessor/s:**
	Admission scoring date:	**Discharge scoring date:**

Frequency:
1. Rarely – less than once a week
2. Sometimes – once a week
3. Often – several times a week but less than once a day
4. At least every day

Severity
1. Mild – noticeable but produces little distress
2. Moderate – more disturbing but can be redirected
3. Severe – very marked, very disturbing and very difficult to redirect

Disruptiveness (NH)
0. None at all
1. Minimal (almost no change in work routine)
2. Mild (some change in work routine; a little extra time required)
3. Moderate (disrupts work routine, requires time to be re-allocated to manage)
4. Severe (disruptive, upsetting to staff and other residents, major time re-allocation needed)
5. Extreme (very disruptive, major distress to staff and residents, requires time taken away from other residents and tasks)

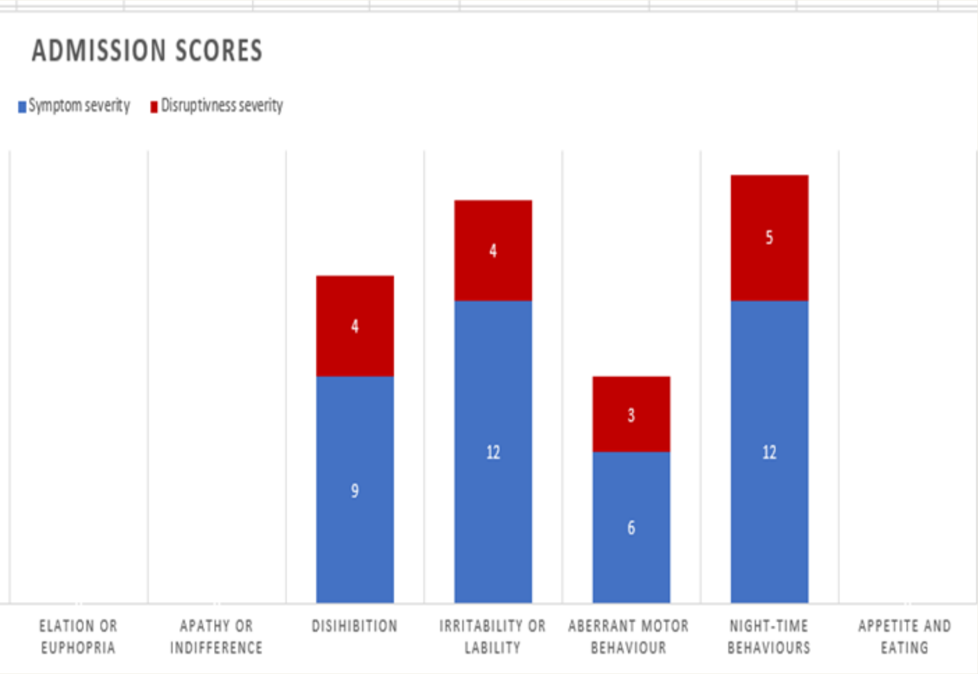
A) **DELUSIONS** - *Does the resident have beliefs that you know are not true? Not mere suspiciousness; is convinced of beliefs.*

☐ 1. Fear of harm
☐ 2. Fear of theft
☐ 3. Spousal affair
☐ 4. Phantom boarder
☐ 5. Spouse imposter
☐ 6. House not home
☐ 7. Fear of abandonment
☐ 8. Talks to TV, etc.
☐ 9. Other ______________________

ADMISSION				***DISCHARGE***			
Description:							
FREQUENCY		SEVERITY		FREQUENCY		SEVERITY	
SUB-SCORE: *(FREQUENCY x SEVERITY)*				SUB-SCORE: *(FREQUENCY x SEVERITY)*			
DISRUPTIVENESS /DISTRESS SCORE *[0-5]*				DISRUPTIVENESS /DISTRESS SCORE *[0-5]*			

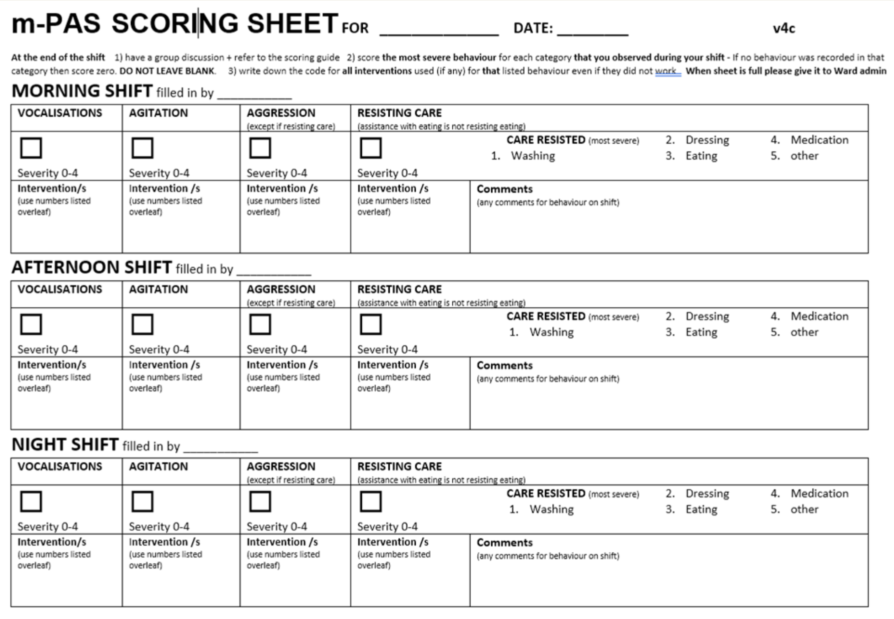
Wood, S et al (2000) *The use of the neuropsychiatric Inventory in Nursing Home residents: characterisation and measurement* . **Am J Geriatr Psychiatry.** Winter 8(1)75-83

NPI-NH -form


ADMISSION SCORES
Symptom severity
Disruptivness severity
4
9
4
12
3
6
5
12
ELATION OR EUPHOPRIA
APATHY OR INDIFFERENCE
DISIHIBITION
IRRITABILITY OR LABILITY
ABERRANT MOTOR BEHAVIOUR
NIGHT-TIME BEHAVIOURS
APPETITE AND EATING

Behavioural - mPAS

- Use of modified Pittsburgh Agitation Scale* to measure 'big four' challenges: agitation, aggression, vocalisation
- 1-2 minutes per person per shift
- Done every shift -3 times a day throughout admission
- Allows colour coded behaviour by time
- changes by behaviour, by time and overall score



m-PAS SCORING SHEET FOR ____________ **DATE:** ________ **v4c**

At the end of the shift 1) have a group discussion + refer to the scoring guide 2) score **the most severe behaviour** for each category **that you observed during your shift -** If no behaviour was recorded in that category then score zero. **DO NOT LEAVE BLANK.** 3) write down the code for **all interventions** used (if any) for **that** listed behaviour even if they did not work. **When sheet is full please give it to Ward admin**

MORNING SHIFT filled in by ___________

VOCALISATIONS	**AGITATION**	**AGGRESSION** (except if resisting care)	**RESISTING CARE** (assistance with eating is not resisting eating)	
☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	**CARE RESISTED** (most severe) 1. Washing 2. Dressing 3. Eating 4. Medication 5. other
Intervention/s (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Comments** (any comments for behaviour on shift)

AFTERNOON SHIFT filled in by ___________

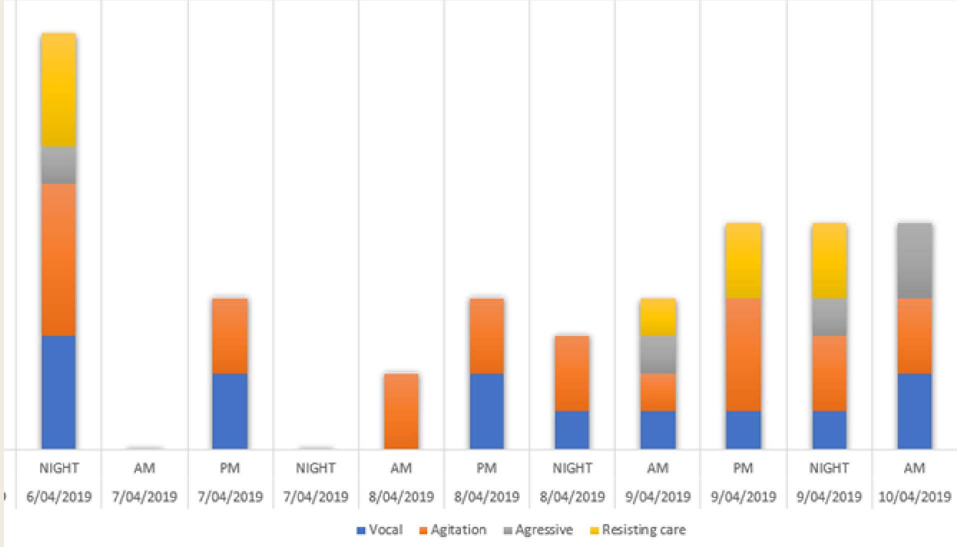
VOCALISATIONS	**AGITATION**	**AGGRESSION** (except if resisting care)	**RESISTING CARE** (assistance with eating is not resisting eating)	
☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	**CARE RESISTED** (most severe) 1. Washing 2. Dressing 3. Eating 4. Medication 5. other
Intervention/s (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Comments** (any comments for behaviour on shift)

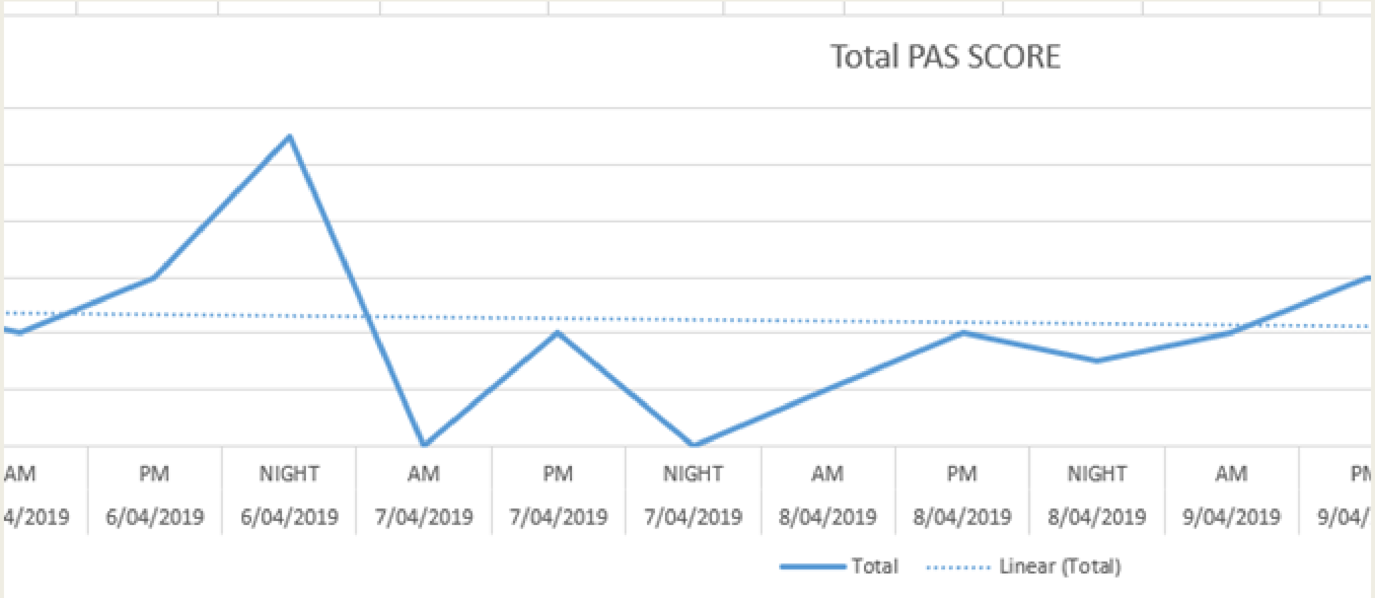
NIGHT SHIFT filled in by ___________

VOCALISATIONS	**AGITATION**	**AGGRESSION** (except if resisting care)	**RESISTING CARE** (assistance with eating is not resisting eating)	
☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	☐ Severity 0-4	**CARE RESISTED** (most severe) 1. Washing 2. Dressing 3. Eating 4. Medication 5. other
Intervention/s (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Intervention /s** (use numbers listed overleaf)	**Comments** (any comments for behaviour on shift)

(Rosen et al (1994) *The Pittsburgh Agitation Scale: A User-Friendly Instrument for Rating Agitation in Dementia Patients*. **Am J Geriatr Psychiatry.** 1994 Winter;2(1):52-59)

mPAS form

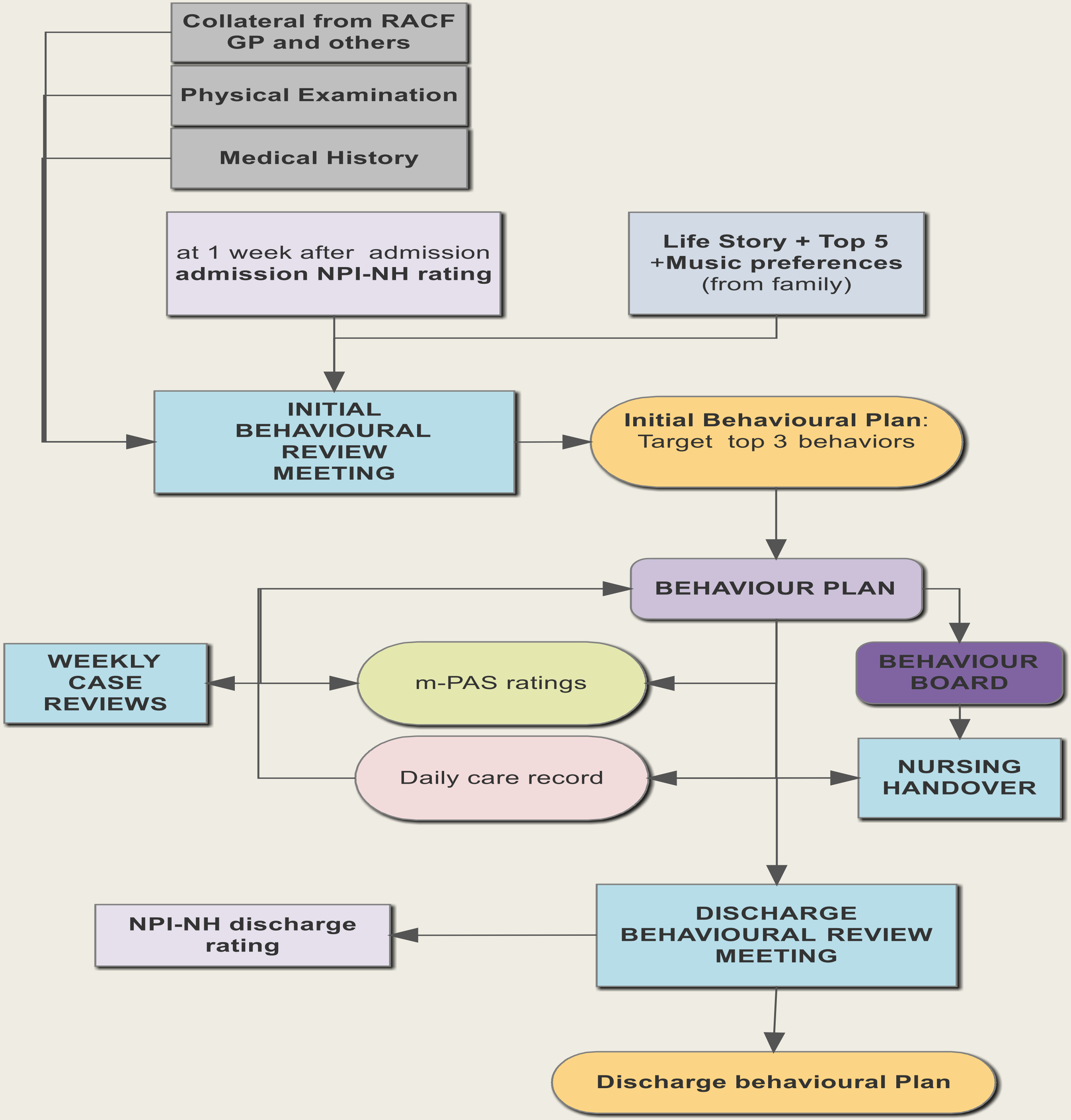

NIGHT
6/04/2019
AM
7/04/2019
PM
7/04/2019
NIGHT
7/04/2019
AM
8/04/2019
PM
8/04/2019
NIGHT
8/04/2019
AM
9/04/2019
PM
9/04/2019
NIGHT
9/04/2019
AM
10/04/2019
Vocal
Agitation
Agressive
Resisting care


Total PAS SCORE
AM
4/2019
PM
6/04/2019
NIGHT
6/04/2019
AM
7/04/2019
PM
7/04/2019
NIGHT
7/04/2019
AM
8/04/2019
PM
8/04/2019
NIGHT
8/04/2019
AM
9/04/2019
9/04/
Total
Linear (Total)

INITIAL NPI SCORE

WEEKLY UPDATES

ORE



Collateral from RACF GP and others

Physical Examination

Medical History

at 1 week after admission
admission NPI-NH rating

Life Story + Top 5 +Music preferences
(from family)

INITIAL BEHAVIOURAL REVIEW MEETING

Initial Behavioural Plan:
Target top 3 behaviors

BEHAVIOUR PLAN

BEHAVIOUR BOARD

WEEKLY CASE REVIEWS

m-PAS ratings

Daily care record

NURSING HANDOVER

DISCHARGE BEHAVIOURAL REVIEW MEETING

NPI-NH discharge rating

Discharge behavioural Plan

Advantages

- NPI-NH Allows identification of key intervention areas
- M-PAS give quick assessment of behaviour and when it happens and the trends without having to read all eMR notes
- Allows staff to recognise and acknowledge improvement
- Cue for discharge timing
- NPI-NH and m-PAS scores support suitability for transfer to RACF

mPAS issues

- Paper entry and then data entry into Excel by admin is time-consuming
- Inconsistent quality of form filling and transcription errors
- Only last complete week of m-PAS data shown at any time
- Not supported by IT

Seeking help for HOPE

- We are looking to develop
  - *a database version of both instruments to allow direct data entry*
  - *methods to include interventions (drug and non-drugs)*
  - *Standard reports from our data*
- We are interested in
  - *developing the databases and approach for other interested services*
  - *Teaming up with researchers interested in ‘real world’ data*
  - *Offering our unit/data to allow for evaluation of interventions (including whole of ward interventions)*

HOPE

THANK YOU FOR LISTENING

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AUSTRALIA
CREATE CHANGE

MHICare Project

Mental Health Benchmarking Industry Specific Tool for Residential Aged Care

Dr Nadeeka Dissanayaka, PhD

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Head, Dementia & Neuro Mental Health Unit
The University of Queensland Centre for Clinical Research
Faculty of Medicine
Affiliate: Neurology, RBWH; Psychology, UQ

@NadeekaDissa

OUTLINE

- Why do we need an industry specific tool?
- What is a balanced score card?
- Development of an aged care industry specific benchmarking tool.

Why MHICare?

1. Over half of residents in aged care are living with dementia

2. Mental health is poorly managed

3. There is a clear need to evaluate industry specific standards of mental health care in RAC

4. However, there is no specific tool to evaluate mental health care practices in RAC industry

Why MHICare?

- Psychotropics
- Depression
- Behaviours

Psychotropic Drug Use in RAC

N=779

Psychotropic medication with indicators

N=441

56.6% with dementia

N=220

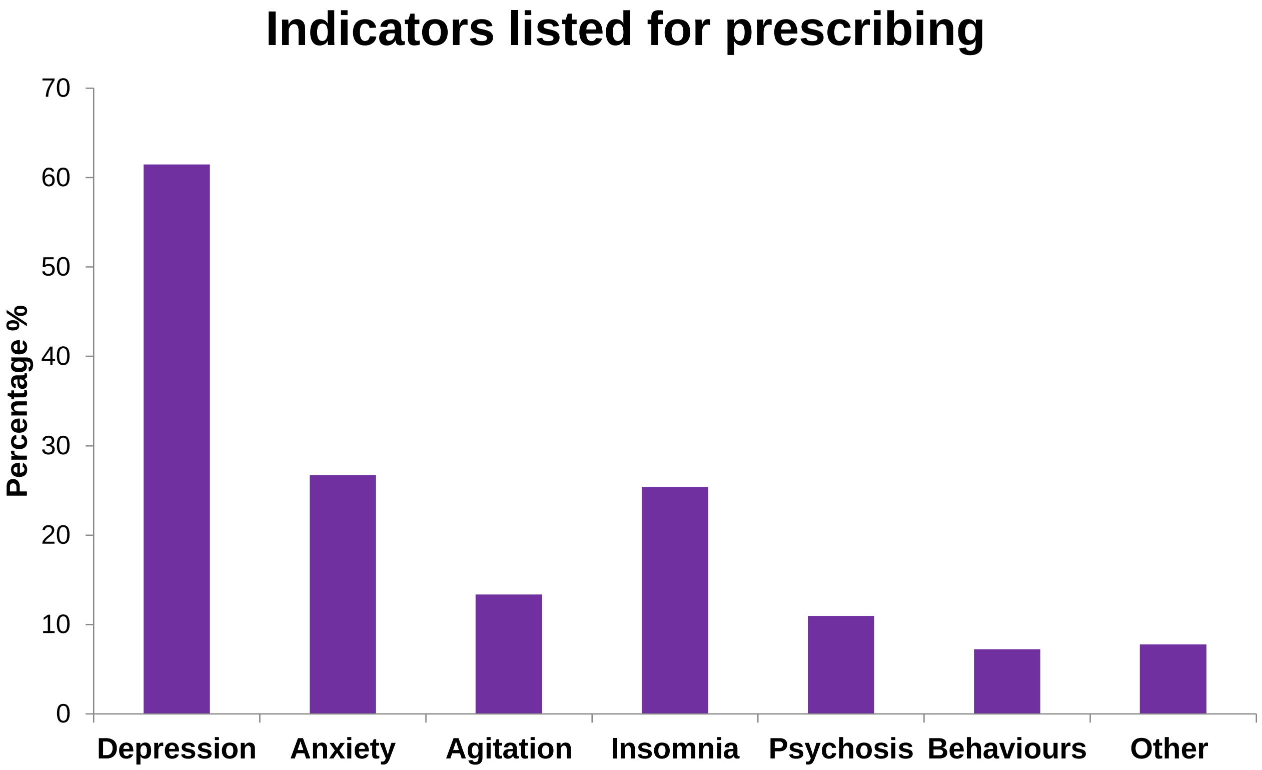
49.9% Prescribed with any psychotropic

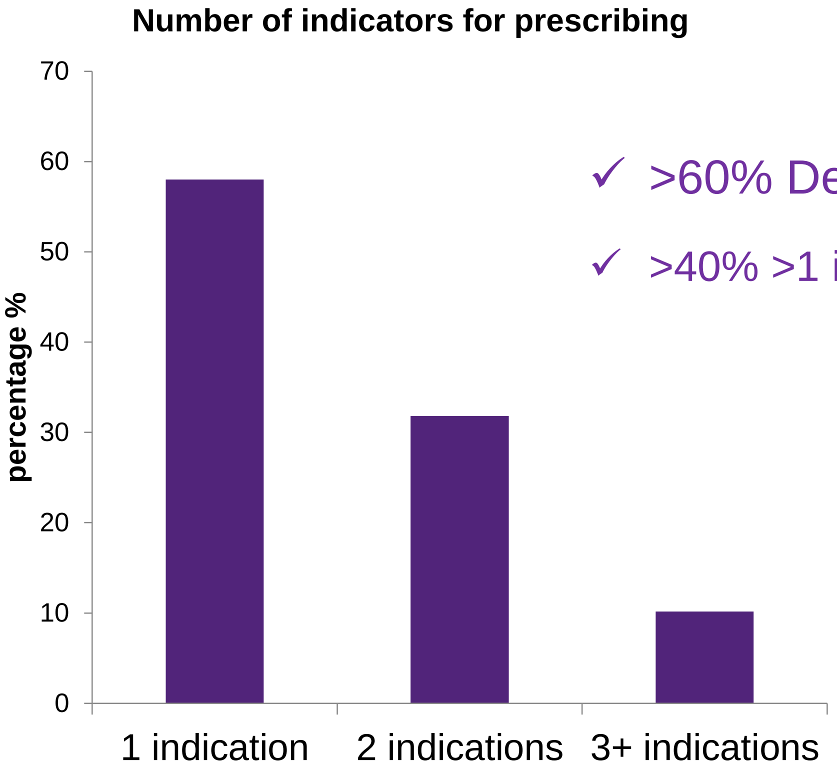
53.4% of Prescriptions were Potentially Inappropriate (Beers criteria)

	No Dementia N=338	**With Dementia N=441**	**Odds Ratio (95% CI)**
Any Psychotropic	154 (45.6%)	220 (49.9%)	1.26 (0.93-1.7)
Anti-depressants	92 (27.2%)	152 (34.5%)	1.50 (1.08-2.08)*
Benzodiazepines	82 (24.3%)	74 (16.8%)	0.63 (0.44-0.90)*
Anti-Psychotics	37 (10.9%)	79 (17.9%)	1.88 (1.23-2.87)**
Significant at *p <0.05, **p<0.01			

Brimelow, Wollin, Byrne, Dissanayaka Int Psychogeriatrics 2019, 31 (6), p837-847

Reasons for Psychotropic Prescriptions





- ✓ >60% Depression
- ✓ >40% >1 indicators

Brimelow, Wollin, Byrne, Dissanayaka Int Psychogeriatrics 2019, 31 (6), p837-847

Variable Rates of Depression Evaluation and Treatment in Residential Aged Care

- ✓ Cornell Scale for Depression (CSD): 78% completion rate (N=604/779)
- ✓ However there was large variation between homes, from 43.3% to 98.2%
- ✓ Age, gender and cognitive capacity did not influence completion rates
- ✓ High completion of the Cornell Scale for Depression in homes with high prescription rates for depression.

Brimelow, Wollin, Byrne, Dissanayaka 2019- under submission

Frequency of Behaviour Recorded over 2 Months Period in 25 Residents & Response

- ✓ Total of 395 behaviours
- ✓ Average number of 15 behaviours reported per resident (range 0-240)

Brimelow, Beattie, Byrne, Dissanayaka 2019- under submission

Psychotropics

Depression

Behaviours

MHICare

A Balanced scorecard to allow quality reporting in RAC facilities to inform future policy and planning at the individual facility level and nationally

OUTLINE

- Why do we need an industry specific tool?
- What is a balanced score card?
- Development of an aged care industry specific benchmarking tool.

A Balanced Mental Health Score Card

- ✓ First proposed by Kaplan and Norton in 1992 as a strategic management tool.
- ✓ Works to provide information on areas of strategic importance to assess current system performance and to guide future planning.
- ✓ Used by management and employees to facilitate discussions, knowledge creation, information dissemination, follow-up and reporting processes.
- ✓ Original motivation for four perspectives consideration of non-financial aspects of performance during the selection of measures for the BSC.

Kaplan & Norton 1992, 1996

A Balanced Mental Health Score Card: Our Model

Adapted and Modified from Kaplan & Norton 1992, 1996

OUTLINE

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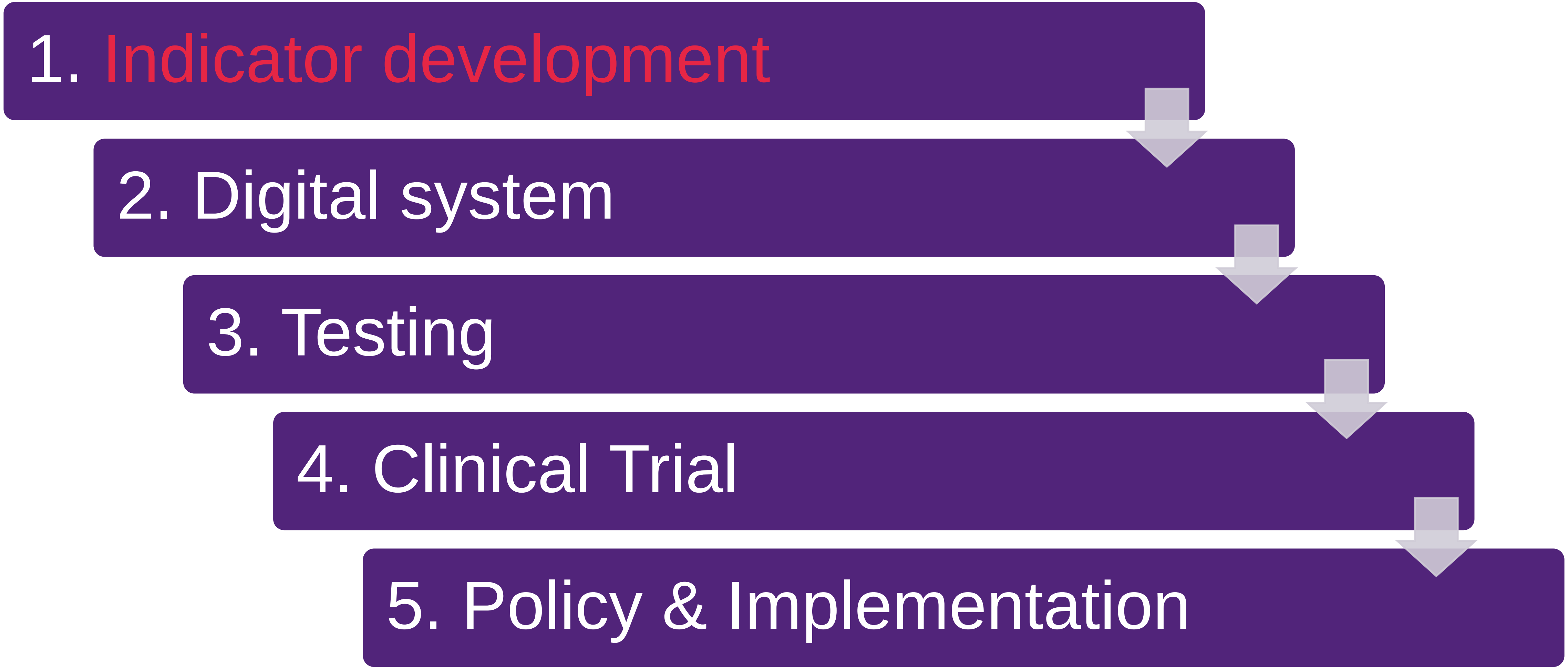
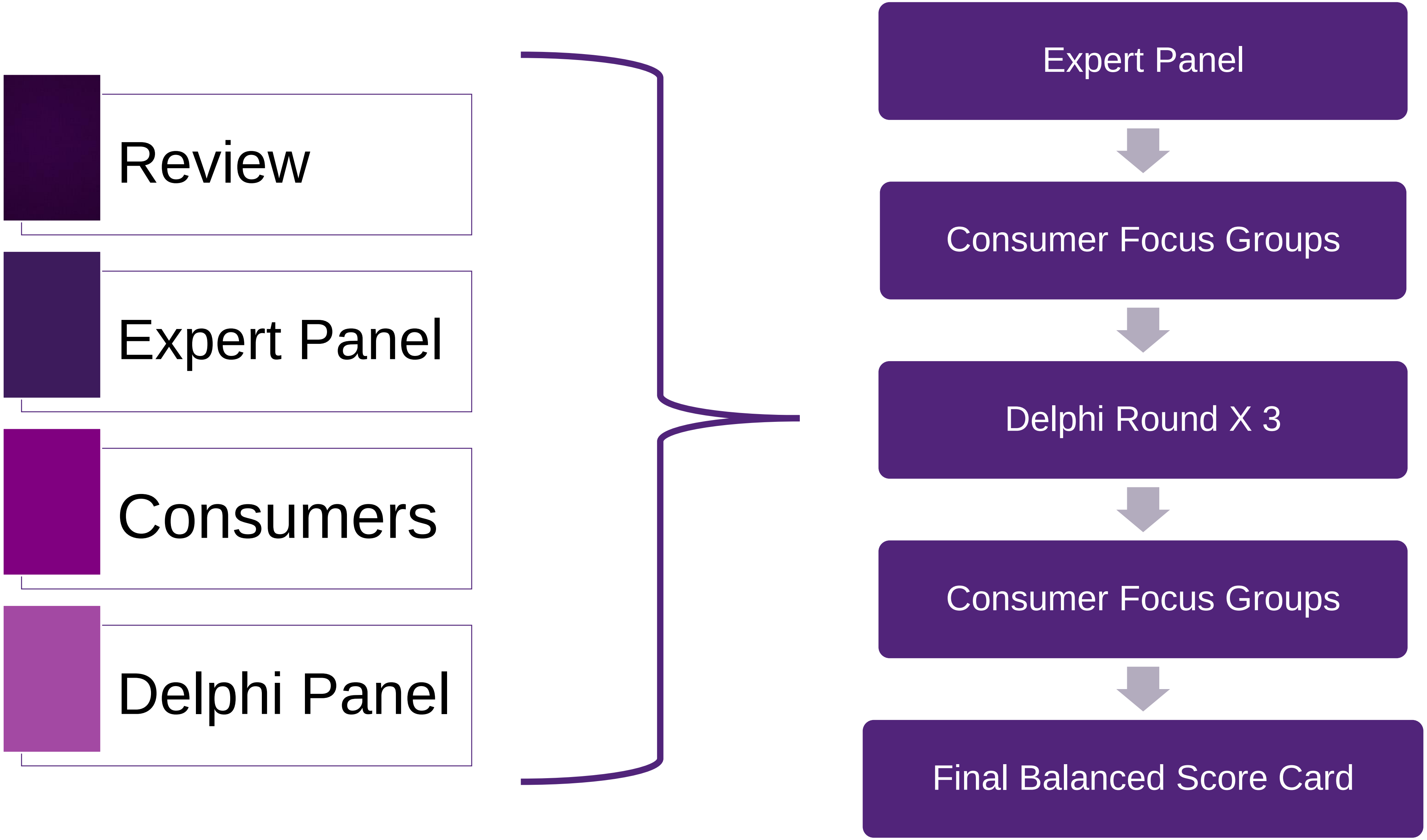
Process Levels: MHICare Project



1. Indicator development
2. Digital system
3. Testing
4. Clinical Trial
5. Policy & Implementation

Indicator Development: MHICare Project



- Review
- Expert Panel
- Consumers
- Delphi Panel

Expert Panel

Consumer Focus Groups

Delphi Round X 3

Consumer Focus Groups

Final Balanced Score Card

Invitation to Participate: MHICare Project

Consumers

Delphi Panel

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AUSTRALIA
CREATE CHANGE

Virtual Reality Assisted Interventions to Reduce BPSD

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Faculty of Medicine
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Virtual Reality Research Program

Systematic Review: VR in dementia

Alzheimer's and Dementia: Translational Research & Clinical Interventions (In press)

VR in Cognitive Impairment: 10 mins session

Cyberpsychology, Behavior & Social Networking (In press)

VR in Cognitive Impairment

6 sessions over 3 weeks

VR assisted Cognitive Behaviour Therapy

New Package of 8 weeks therapy

Aims to develop a suite of virtual reality applications to increase engagement, provide pleasurable immersive experiences and assist psychotherapy

VR in Persons with Cognitive Impairment: 1 VR Session for 10 minutes

The development of a suite of virtual reality applications to increase engagement, provide pleasurable immersive experiences and assist psychotherapy

Evaluate effectiveness of VR concepts on engagement & apathy in residents with and without dementia

Pre

Observed Emotion Rating Scale (OERS)

Person–Environment Apathy Rating Scale (PEAR)

Intervention

13 Residents

1 VR session

Post

OERS

PEAR

Qualitative interview

Brimelow, Dissanayaka. Cyberpsychology, Behaviour and Social Networking (In press)

VIRTUAL REALITY EXPOSURE VIDEO EXAMPLE

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Australian Government
NHMRC National Institute for Dementia Research

UNSW SYDNEY
Australia's Global University

Time to invest in better care for people living with dementia

Dr Claire Burley

BPSD Workshop, Sydney: Tues 26th Nov 2019

UNSW SYDNEY

Australian Government
NHMRC National Institute for Dementia Research

DCRC
Dementia Centre for Research Collaboration

Background

- **Dementia** is defined as **cognitive decline leading to functional impairment**
- **However, agitation, apathy, depression,** and other behaviours and psychological symptoms, can be more distressing for people living with dementia and their families
- Account for up to **44% total costs** (e.g., agitation; Panca 2019; see Lancet commission: Livingston et al., 2017)
- Affect **≤ 90%** of people living with dementia (Cerejeira 2012) and correlate with functional and cognitive impairment

Cost of agitation: longitudinal studies

Authors, year, country	Setting, number of people with dementia (N)	Cost ($ per unit or predictor %)
Hermann et al. 2006 USA	Community N=500	1-point = 2.3% increase in total costs
Jönsson et al. 2006 Sweden, Finland and Denmark	Community N=272 (Costs analysis, N= 208)	1-point = 8% increase in total costs
Gustavsson et al. 2011 Sweden	Community and residential N=1,222	1-SD increase = 8% increase in costs (community setting)
Lacey et al. 2013, ADNI study Ireland & USA	Community N=138	1-point = 1.62% increase in total costs
Rattinger et al., 2015 USA	Community N=287	1-point = 2% increase in informal costs
Wübker et al., 2015 Spain, Germany & France	Community and residential N=2,014 (community: N=1,048)	1-SD increase = 8.8% increase in costs (community setting)
Costa et al. 2018 8 European countries	Community (homecare) and residential care Cross-sectional study, N=1,997 (community, N=1,217)	17% increase in informal care costs (community setting)

Evidence-based non-pharmacological approaches

1. Person-centred care (Fossey et al., 2006, Chenoweth et al., 2009 & 2014; Tay et al., 2018)

2. Educational training (Ballard et al., 2017; Henskens et al., 2018)

3. Therapeutic approaches (e.g. activities/ games, CBT, Mindfulness, plush animal, doll therapy) (Cheng et al., 2012; Paller et al., 2015; Shin et al., 2015; Jøranson et al., 2015; Mervin et al., 2018)

4. Reminiscence-based approaches (Davison et al., 2016; Duru Aşiret and Kapucu, 2016)

5. Cognitive stimulation therapy (CST) (Capotosto et al., 2017; Paddick et al., 2017)

6. Aerobic and resistance exercise, dance movement therapy (Cancela et al., 2016; Chen et al., 2017; Ho et al., 2018)

7. Music-based approaches (Chu et al., 2014; Cheung et al., 2018; Schroeder et al., 2018)

8. Multicomponent/ other approaches (Luttenberger et al., 2012; Schiffczyk et al., 2013; Menne et al., 2017)

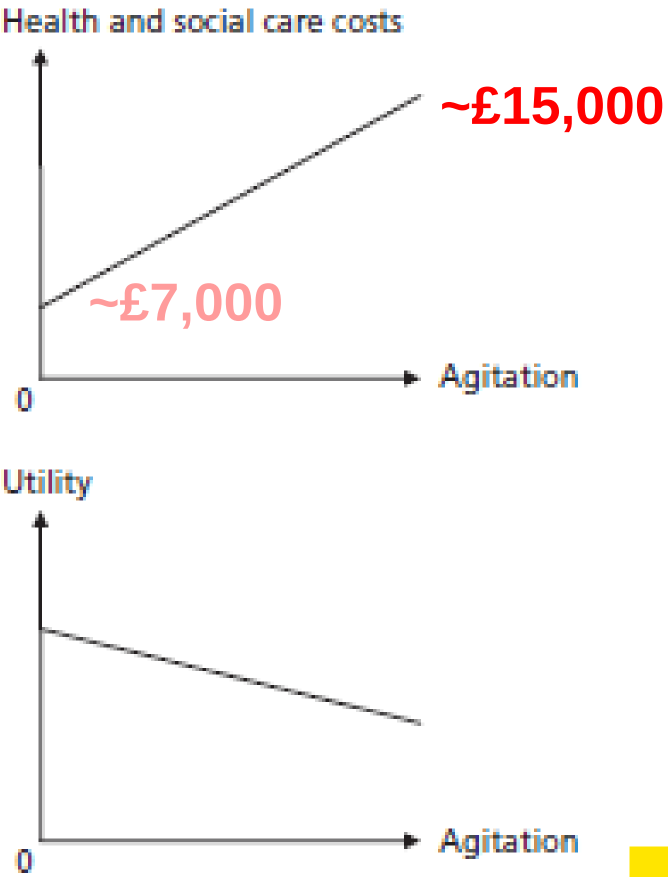
Cost of agitation: intervention studies

Authors, year, country	Setting, study type, N	measure	Cost analysis
Mintzer et al. 1997 USA	Residential setting, 21-day Inpatient Programme (IP) & Continuum of Care (CC) (21- vs. 7-days hospitalisation), N=178 (N=68 & 110 respectively)	CMAI	Change in CMAI score per US $1,000: CC: 0.89 IP: 0.27 (CC > 3 times more cost-effective)
Chenoweth et al. 2009 Australia	Residential setting, Person-Centred Care (PCC), Dementia Care Mapping (DCM) and usual care Cluster RCT, N=289 (N=95, 77 and 64 respectively)	CMAI	Incremental cost per 1-point decrease in CMAI: **PCC: AU $8, $6 at follow-up** DCC: AU $49, AU$ 47 at follow-up
D'Amico et al. 2016 United Kingdom	Community, 2 conditions: exercise and treatment as usual, RCT, N=52 (N=30 and 22 respectively)	NPI	Intervention cost: £284 (range: £190-£320). CEAC: willingness to pay £500 per increment improvement, cost effective with a probability >80%
Mervin et al. 2018 Australia	Residential setting: therapeutic robotic seal (PARO) v soft seal v usual care. Cluster RCT, N=415 (N=138, 140 & 137)	CMAI	Incremental cost per 1-point decrease in CMAI: **AU $13**

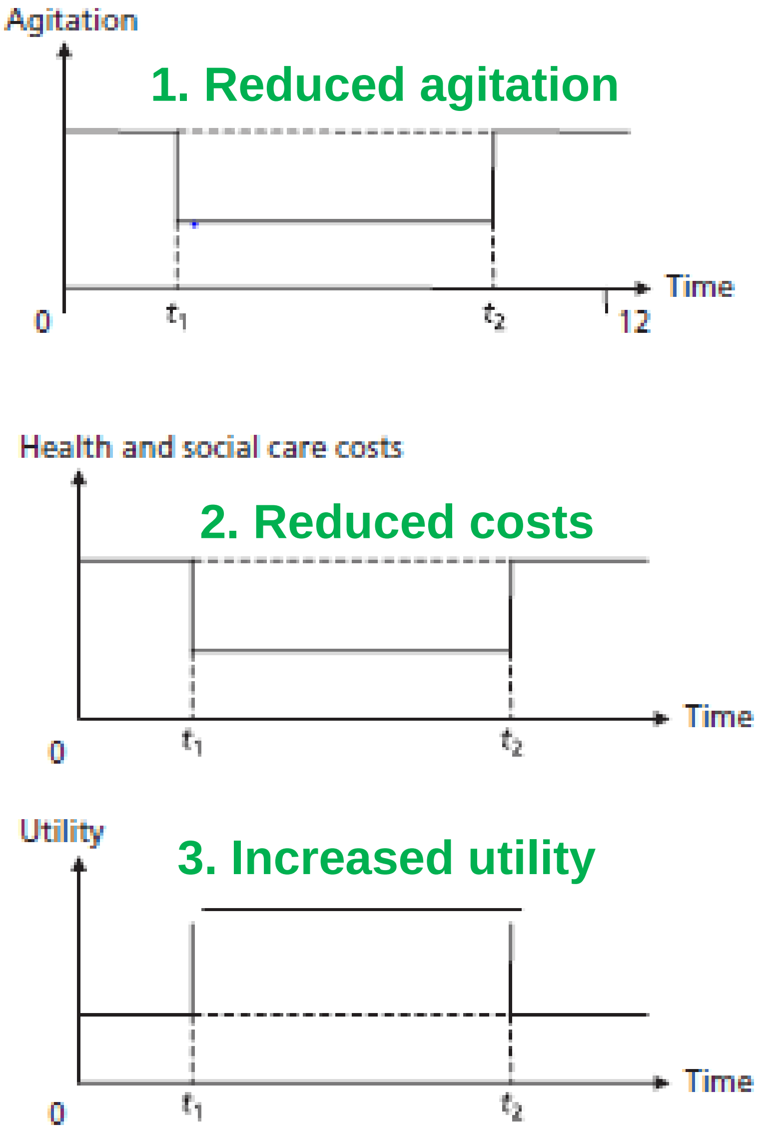
Cost of agitation: systematic review

Livingston et al., Lancet 2014

- **Worldwide studies**
- **Total health and social care costs over 3 months**



Nonpharmacological approaches:



Cost of agitation: systematic review

Cost per unit ↓ in agitation (CMAI):

£4 ($6), £42, £62 Training paid caregivers in person-centred care or communication skills

(Chenoweth et al., 2009; McCallion et al., 1999; Deudon et al., 2009 respectively)

£4 Music Therapy

(Lin et al., 2011)

£24/ £143 Sensory approaches/ acupressure

(Yang et al., 2007; Lin et al., 2009)

£162 Montessori-based activities

(Lin et al., 2009)

£3,480 Highly structured sensorimotor activities

(Buettner and Ferrario, 1997)

The challenge of change

Barriers to achieving better value for money in dementia care

- Evidence is not implemented
- Poor coordination of health and social care provision and poor financing (Knapp et al. 2013)

Here we demonstrate the **economic feasibility** of **adopting evidence-based non-pharmacological approaches into everyday practice**

However, **implementation (the real challenge!)** requires **change** in **care practice** and **change** in **care culture**

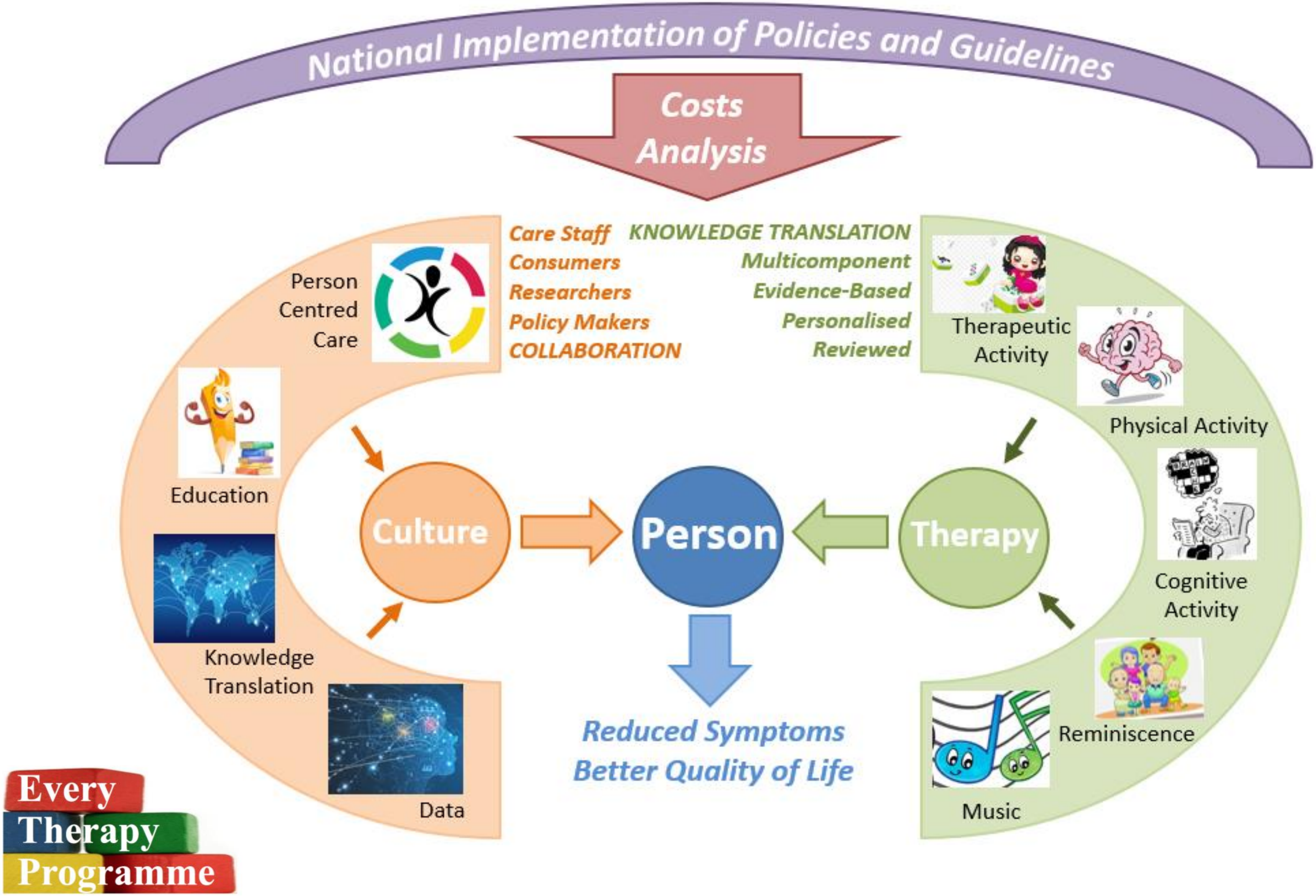


Figure. *The Every Therapy Programme*: Includes all effective approaches from the evidence-base and their implementation into the care environment. Particular focus of this implementation model is on: providing choice and personalisation for the person living with dementia, improving care culture through family/ carer training and support, and ongoing collaboration and review between government and policy makers, clinical/ research professionals and consumers (people living with dementia, and families and carers), whilst demonstrating cost-effectiveness

Mrs Val Fell:
How do we implement best practice?

A special unit for assistance in caring for people living with dementia and how will it be funded?

In recent years, through carers in my support group, I have come across a number of instances where the behaviour of a person living with dementia has created difficulties.

Two instances in-home settings:

1. The carer was being physically attacked by her husband and a neighbor called the police. It was regarded as a domestic violence incident.

Mrs Val Fell:
How do we implement best practice?

2. The carer was waiting for her husband to come home from his short walk and was surprised when he arrived in an aggressive mood (up to then he had been a very quiet man). He did not recognize her and ordered her out of his house. Although she was frightened, she rang for an ambulance saying her husband had had a “turn”. After a short stay in hospital he was admitted to a residential facility where she visits daily. Though he does not recognize her. He is quite calm.

These facts demonstrate that with an increasing number of people wanting to remain at home there is an increasing need for informal carers to have training in DEMENTIA CARE.

Mrs Val Fell:
How do we implement best practice?

Two instances in a facility:

1. The person’s behaviour became aggressive and the facility decided they could no longer care for him. He was transferred to a special unit just out of the area. It was not an elaborate place, in fact it was a very old place originally built as an isolation ward in the old TB days. But the carer will not have a harsh word said about the place -the care was excellent -everybody knew what they were doing - in addition they cared for the carer. The man passed away while in the facility.

Mrs Val Fell:
How do we implement best practice?

2. A carer found it too difficult to care for her husband at home and he moved to a facility. One evening he attacked another resident with fatal results. The person on duty was not trained beyond certificate 3, yet it was a dementia specific locked ward. The person responsible for the attack was transferred to a special ward at the hospital. He passed away shortly afterwards.

Should there be a mandatory protocol where facilities must call a response team or ask for help if they know THEY can't handle the situation?

With regard to funding, if the new units are to be for short term stays, will the "bed" be available after a system for caring for him/her has been established by the staff at the special unit?

Will the in-home carers in other cases be given specific training in dementia care?

UNSW SYDNEY | Australia's Global University

How do people living with a diagnosis of dementia feel?

Dr Claire Burley

BPSD workshop, Sydney

Tuesday 26th November 2019

Health South Eastern Sydney Local Health District NSW GOVERNMENT

Australian Government NHMRC National Institute for Dementia Research

Step Up for Dementia Research

DCRC Dementia Centre for Research Collaboration

Introduction

- Major decisions regarding healthcare are often made by families and healthcare professionals
- Rarely, the person living with dementia is asked what *they* would like to happen
- Qualitative study aims to find out the views and concerns of:
    1. People living with a diagnosis of dementia
    2. Family members, friends or carer partners
    3. Healthcare professionals (clinician or carer)

Hypotheses

- Views may differ between these three groups
- Views may be different for different behaviours and/ or psychological symptoms
- Views may highlight individual preferences

Methodology

Separate semi-structured interviews

? **Experience of behaviours and/ or symptoms (e.g. depression, sleep disruption, agitation)**

‘Have you experienced this?’

*‘What do **you** think should happen?’*

*‘What would **you** like to happen?’*

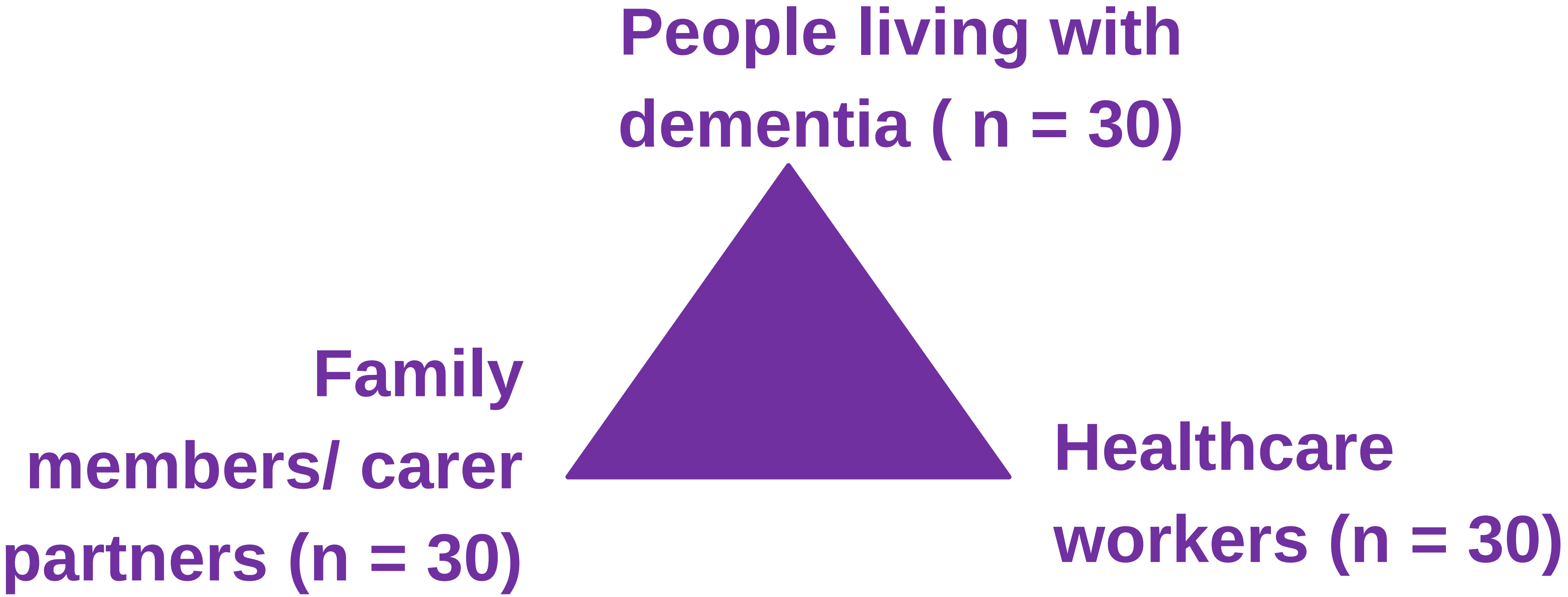
? **Appropriate terminology**

? **Other views or concerns**

Methodology

- Data will be coded using NVivo software to identify themes until theoretical saturation is reached
- Estimated 30 triads (5 for a pilot study)

  = 90 interviews in total (15 for pilot study)



People living with dementia (n = 30)

Family members/ carer partners (n = 30)

Healthcare workers (n = 30)

Key points

- Listening to people living with dementia and recognising them as experts in their experience
- Involving people with dementia with research and decision making around policy, guidance and expectations
- Post study focus group – people can share their views with peers to stimulate discussion

What next…?

- Get results and present in a language to suit all stake holders

  1) Consumers & general public (e.g. media, newspaper article, radio)
  2) Researchers & health care professionals (e.g. conference and scientific journals, ADF 2020, Adelaide)
  3) Government and policy makers (e.g. report, meeting)

- Collaboration and Implementation

More information

Changed behaviours associated with memory and cognitive decline: The views and concerns of people living with a diagnosis of dementia, family members and/or carer partners, and healthcare professionals

Step Up for Dementia Research

https://stepupfordementiaresearch.org.au

CHeBA Healthy Brains Positive Ageing

https://cheba.unsw.edu.au/join-a-trial

c.burley@unsw.edu.au

UNSW SYDNEY
Australia's Global University

School of Psychiatry \ UNSW Medicine

Perceptions of social relationships and BPSD

Anne-Nicole Casey PhD, Centre for Healthy Brain Ageing (CHeBA)

CHeBA
Healthy Brains Positive Ageing

Social connections count

Individual health outcomes are influenced by how people perceive social relationships[1,2,3]

Robust, supportive engagement decreases dementia risk; poor engagement, small networks increase risk [4]

People living with dementia feel socially supported or isolated based on how they perceive the quality of their relationships with others [5,6,7]

[1] Dunbar 2018 *Trends Cogn Sci*; [2] Cacioppo et al 2015 *Annu Rev Psychol*; [3] Antonucci et al 2002 *J Soc Issues*; [4] Penninkilampi, Casey, Fiatarone-Singh, Brodaty 2018 *J Alzheimers Dis;* [5] Casey et al 2015 *Gerontologist;* [6] Mitchell et al 2016 *JAMDA;* [7] Casey & Mitchell 2016 *AJDC*

Individual psychological factors

- Social interaction style amplifiers[1]
  - Attachment
    - Insecure attachment style (affect)[2,3]
  - Mental health
    - History of affective disorder (affect, sleep)[4]
  - Personality
    - Pre-morbid neuroticism (affect, apathy, appetite, sleep)[5,6,7]
  - Social Cognition
    - Disruptions in social cognition neural networks[8]

[1]Casey et al. 2019; [2]Perren et al 2007 *Attach Hum Dev*; [3]Browne et al 2006 *Aging Ment Health* [4]Savva et al 2009 *BJPsych*; [5]Rouch et al 2019 *J Alzheimers Dis*; [6]Tible et al 2017 *Ther Adv Neurol Diso;* [7]Low, Brodaty, Draper 2002 *Int J Geriatr Psychiatry*; [8]Amodio 2019 *Trends Cogn Sci*

Social environmental factors

Community settings

- Social integration[1]
- Relationship(s) with caregiver(s)[2]
- Cultural context, stigma[3]

Institutional settings

- Communal living vs privacy[4]
- Staff training and experience[5]
- Person-centred care[6]

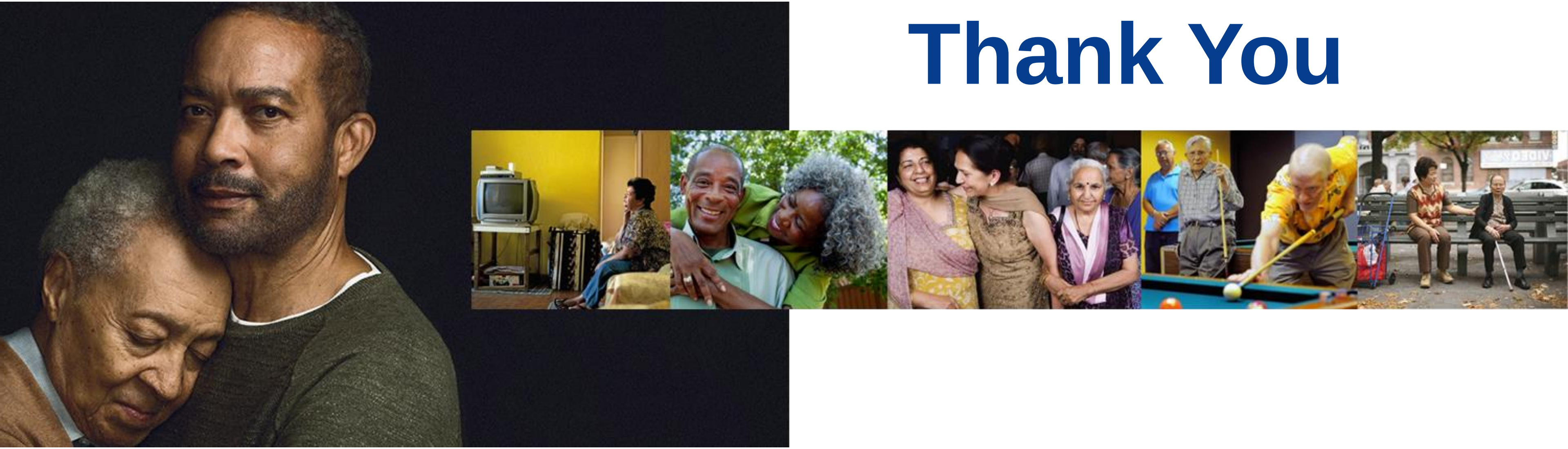
[1]Miranda-Castillo et al 2010 *Health Qual Life Outcomes*; [2]Edwards et al 2016 *BMJ Open*; [3]Baharudin et al 2019 *BMC Pub Health*; [4]Inventor et al 2018 *J Psychosoc Nurs Ment Health Serv*; [5]Abraha et al 2016 *BMJ Open*; [6]Chenoweth et al 2009 *Lancet Neurol*

Biological + Psychological
+ Social environmental
(interpersonal, broader context)
+ time (lifespan, carespan, in the moment)

= Complex, dynamic systems and outcomes for each individual[1,2,3]

[1] Spector & Orrell 2010 *Int Psychogeriatr*; [2] Lehman, David, & Gruber 2017 *Soc Personal Psychol Compass*; [3] Innui 2003 *Ann Intern Med*

Thank You



CHeBA
Healthy Brains Positive Ageing

This research was supported by funds from the Thomas Foundation through the Centre for Healthy Brain Ageing, UNSW Sydney.

Preventing dementia and enhancing brain health

Henry Brodaty

Appropriate Language

Dr Jacqueline Wesson
Dementia Specialist & Research Coordinator

BPSD Forum
26 December 2019

Montefiore

Behaviours and dementia

- **Problem behaviours**
- **Challenging behaviours**
- **Behavioural and psychological symptoms of dementia (BPSD)**
- **Behaviours of concern**
- **Expressions of unmet need**
- **Responsive behaviours**
- **Changed behaviours**

What is it?

NBN

DBMAS

BPSD

LOL

MAC

NSW

ABC

PHN

NOF

OPMH

CHSP

Appropriate

- *Suitable or proper in the circumstances*

Language

- *Method of human communication*

BPSD

PCC

“confused”

“wandering”

“interfering with care”

“verbally demanding & inappropriate”

“nil behaviour issues noted”

“resistant to care”

Ban BPSD shone a light on …..

- Systematic labelling, particularly in aged care environments eg wanderer, screamer
- Pejorative label → more likely to be perceived as a “burden” or “problem” that must be managed or controlled
- Staff less likely to seek to understand a person with dementia who has been labelled

#BanBPSD

- Overmedication, systematic prejudicial labelling and ‘human rights breaches’
- Less likely to be afforded understanding
- Physicians prescribe medications for ‘behaviours of concern’ that generally are a result of a person’s responses to unmet needs, or the challenges of living with changing cognition within environments that reflect an inadequate understanding of, and accommodation for, those changes
- Essential needs of people with dementia are being ignored
- Labelling → people feel devalued

Why the behaviours?

Bio-psycho-social framework

Socio-environmental

Interpersonal

Biological

Psychological

- DSA review Jan-July 2018 (n=3566)
- > 50 different contributing factors - biological, psychological, social and environmental
- Three most common: pain (47%), carer approach (34%) and over- or under-stimulation (27%)
- Each person had average of five contributing factors

Positives about the debate

- the negative impacts of systematic labelling
- need to acknowledge the broad range of contributory factors
- consistent inappropriate use of medication, particularly for people living in residential aged care.
- inadequate efforts to understand:
  - the person with dementia;
  - why they behave the way they do
  - their personal and cultural history
  - the environmental, social & biological adjustments that can be made to ease distress & promote quality of life

The way forward

- Problem behaviours X
- Challenging behaviours X
- Behavioural and psychological symptoms of dementia (BPSD)
- Behaviours of concern ?
- Expressions of unmet need X
- Responsive behaviours X
- Changed behaviours ?
- Behaviours and psychological symptoms associated with dementia (BPSD) √

The way forward

- Avoid labels as full description, BPSD is not a diagnosis
- Need clear description Antecedent, Behaviour and Consequence (ABC) as well as context and person
- Whatever term becomes current may → pejorative
- Focus needs to shift to prevention, care and understanding

www.dementiaresearch.org.au

Time for new words

- ✓ Inclusive
- ✓ Co-designed
- ✓ Strengths-based
- ✓ Transparent
- ✓ Straightforward

www.dementiaresearch.org.au

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