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LIVING WITH DISABILITY RESEARCH CENTRE

What does the Evidence say about Housing and Support for People with Intellectual Disabilities

Professor Christine Bigby

Quality of life

- Social Inclusion
- Interpersonal Relations
- Self-Determination
- Rights
- Personal Development
- Emotional Well-Being
- Physical Well-Being
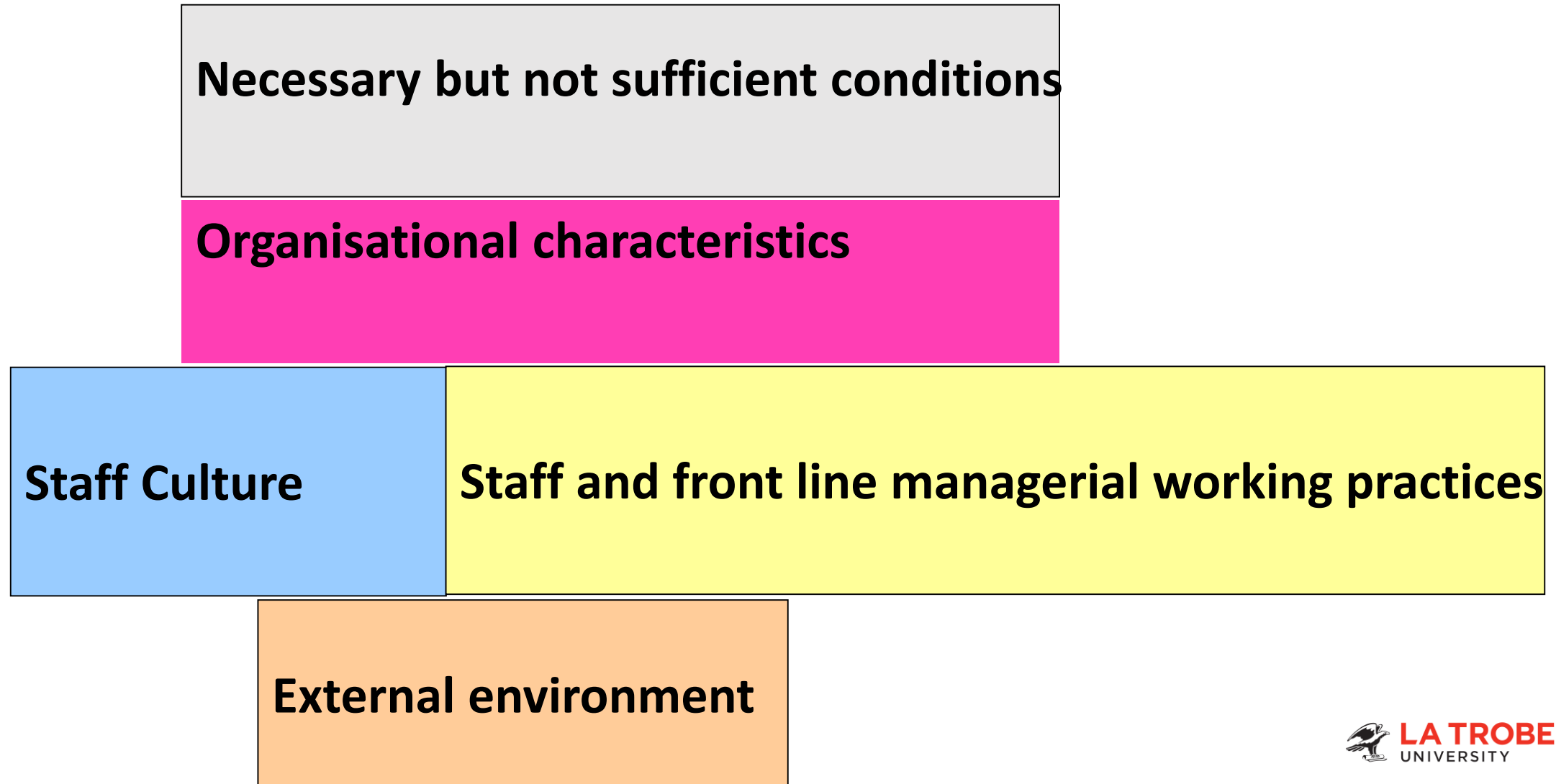- Material Well-Being

Subjective and Objective components

(Schalock, R., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., et al., 2002).

Quality of life and engagement

Housing and Support for people with intellectual disabilities

What makes a difference?

Necessary but not sufficient conditions

Organisational characteristics

Staff Culture

Staff and front line managerial working practices

External environment

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Necessary but Not sufficient conditions

Sufficient Resources – Skilled support does not cost more (Beadle –Brown et al., 2016)

Over 3 months		Skilled support (n=18 of 50)	Less skilled support (n=32 of 50)
Accommodation and support cost adjusted for reported per person staff hours	Mean Range	£21,640 £7,430 – £67,020	£16,580 £7,430 – £29,950
Total care package cost per person, including external services	Mean Range	£22,420 £7,430 – £67,640	£17,060 £7,430 – £30,990

More staff is not necessarily better

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Necessary but Not sufficient conditions

Housing Design and Size

Large v small supported settings

"No doubt, that people with an intellectual disability benefited from deinstitutionalisation"
(Mansell & Ericsson, 1996).

- No more than 6 people living together

- Stepped rather than gradual impact

- Ordinary streets

- Dispersed rather than clustered

    (Bigby et a., 2019; Emerson et al.; Janssen et al., 1999; Mansell & Beadle Brown, 2009; Tossebro, 1995, Mansell & Beadle Brown, 2009; Young, 2006)

- Clustered poorer outcomes - social inclusion - material well-being -self-determination - Personal development – rights.

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Design – supported living v group homes

- Much less evidence
- Supported living (usually drop in, 1 or 2 people tenancy or owner)

Better outcomes

- greater sense of choice, frequency and range of community activities,
- cheaper (Stancliffe, 1997, Stancliiffe & Keene, 2000; Howe et al., 1998, Emerson et al, 2001, Perry et al., 2012; Bigby et al., XXX)

Poorer outcomes

- exploitation, scheduled activities, health, money management (Felce et al., 2008; Perry et al., 2012; Emerson et al., 2001)

Few differences – except choice and control (Stainton et al., 201; Bigby et al., 2017; 2018;)

- People in both group homes groups and supported living had mediocre Quality of Life

Who lives where?

- Group homes have been the only option for many years

- Group homes have a wider range of people in terms of severity of disability than supported living

- Significant overlap between the two groups between 30 - 35 %

Supported Living
239
(166 – 282)

31%
(166 – 263)

Group Home
148
(22 – 263)
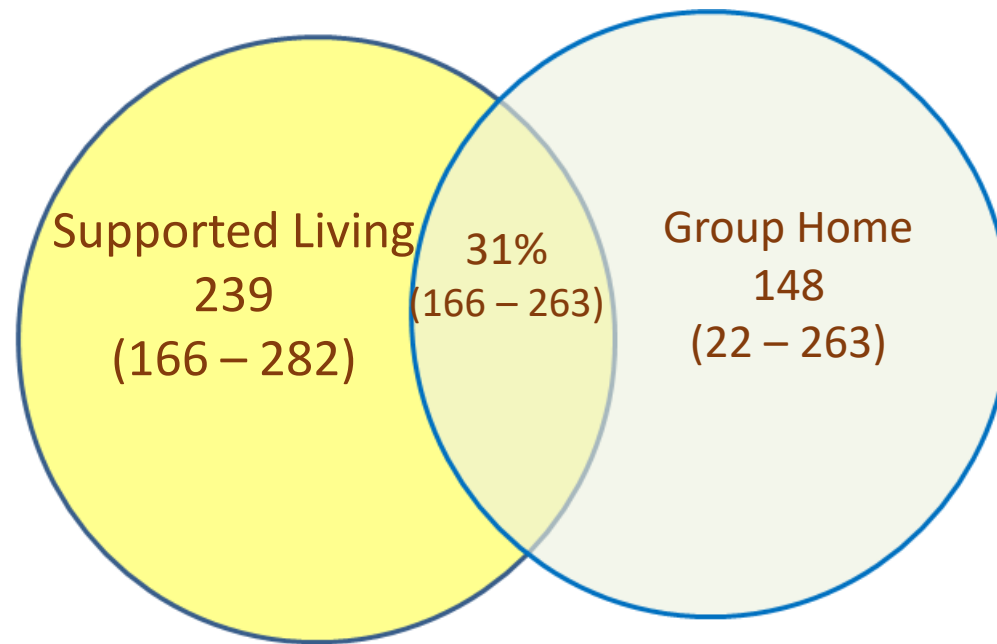
- As funding changes maybe characteristics of service users will change

Variability of outcomes - all designs

Residential settings in England and Wales service user engagement in meaningful activity
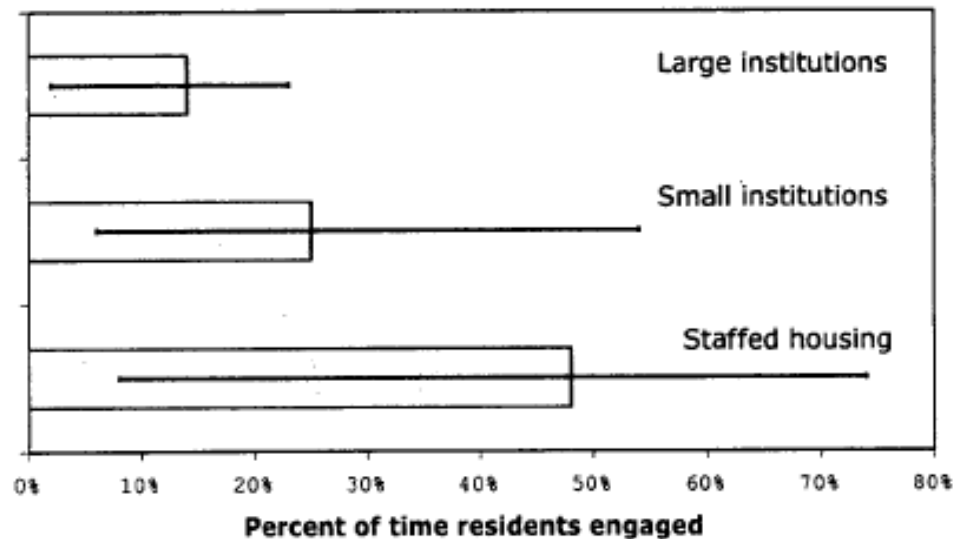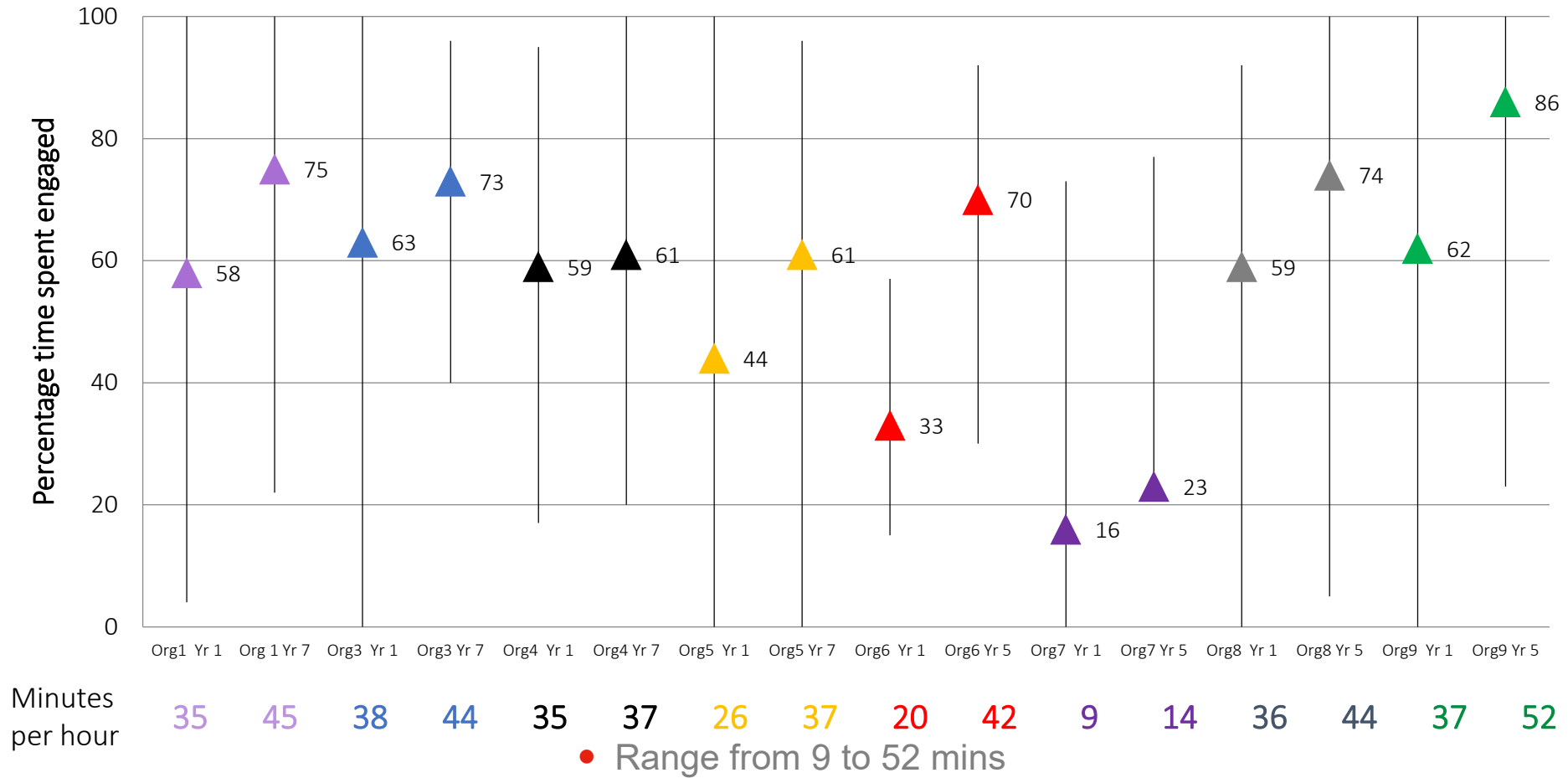

Mean = 13.7% Range = 2 - 23%

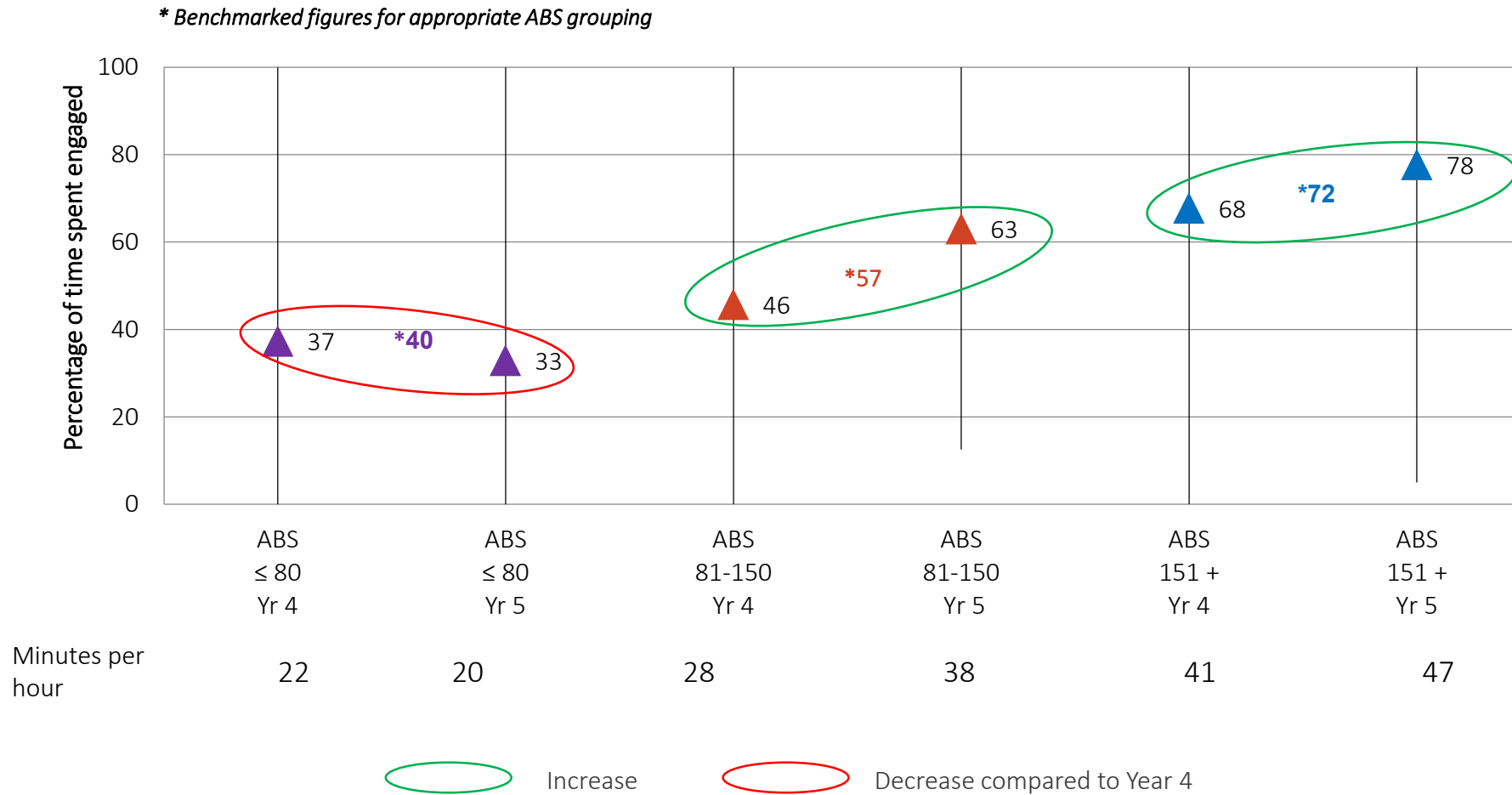Mean = 24.7% Range = 6 - 54%

Mean = 47.7% Range = 8 - 74%

The poorest group homes are not as good as the best institutions (Mansell, 2006)

Australian data – variability over time, within and between organisations

Percentage time spent engaged

| Org1 Yr 1 | Org 1 Yr 7 | Org3 Yr 1 | Org3 Yr 7 | Org4 Yr 1 | Org4 Yr 7 | Org5 Yr 1 | Org5 Yr 7 | Org6 Yr 1 | Org6 Yr 5 | Org7 Yr 1 | Org7 Yr 5 | Org8 Yr 1 | Org8 Yr 5 | Org9 Yr 1 | Org9 Yr 5 |

Data points: 58, 75, 63, 73, 59, 61, 44, 61, 33, 70, 16, 23, 59, 74, 62, 86

Minutes per hour: 35 45 38 44 35 37 26 37 20 42 9 14 36 44 37 52

● Range from 9 to 52 mins

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People with higher support needs consistently have poorer outcomes

*Benchmarked figures for appropriate ABS grouping

Average Time Spent Disengaged

Whole Sample Average
Disengagement 38%

ABS ≤150
Disengagement 49%

ABS ≥151
Disengagement 29%
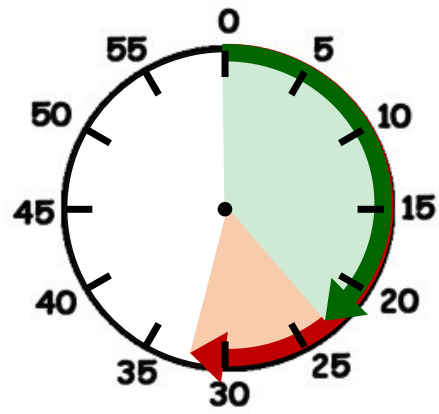
23 mins per hour (Year 6)
32 mins per hour (Year 1)
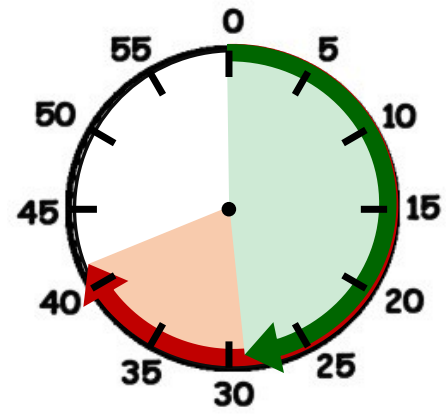
29 mins per hour (Year 6)
41 mins per hour (Year 1)
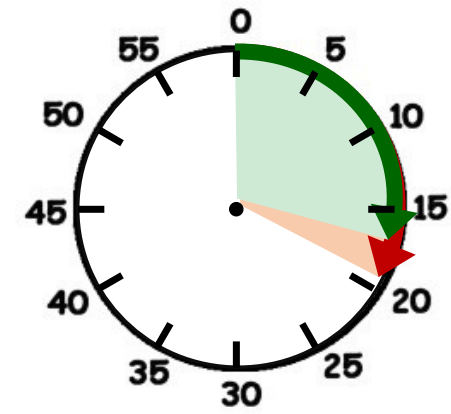
17 mins per hour (Year 6)
19 mins per hour (Year 1)

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Staff and front line managerial working practices that

- **Reflect active support**

- **Strong front line practice leadership**

- **Compensates for difference**

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Consistent use of Active support
More Engagement, skills, choice and control and Less challenging behavior (Mansell & Beadle-Brown 2012)
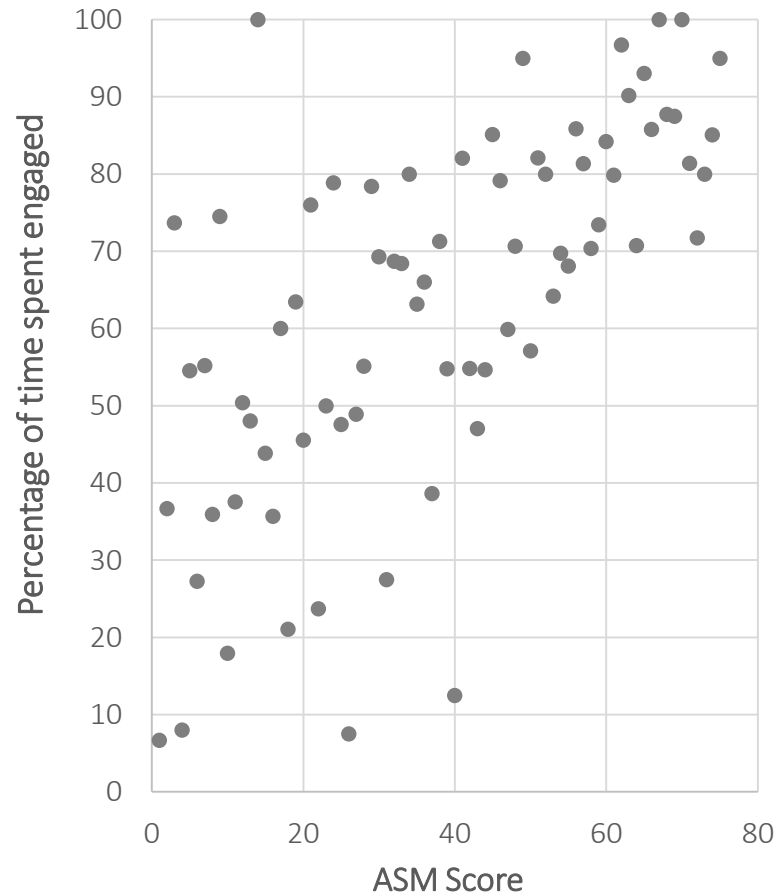
r = 0.513, n =307, p =0.0001
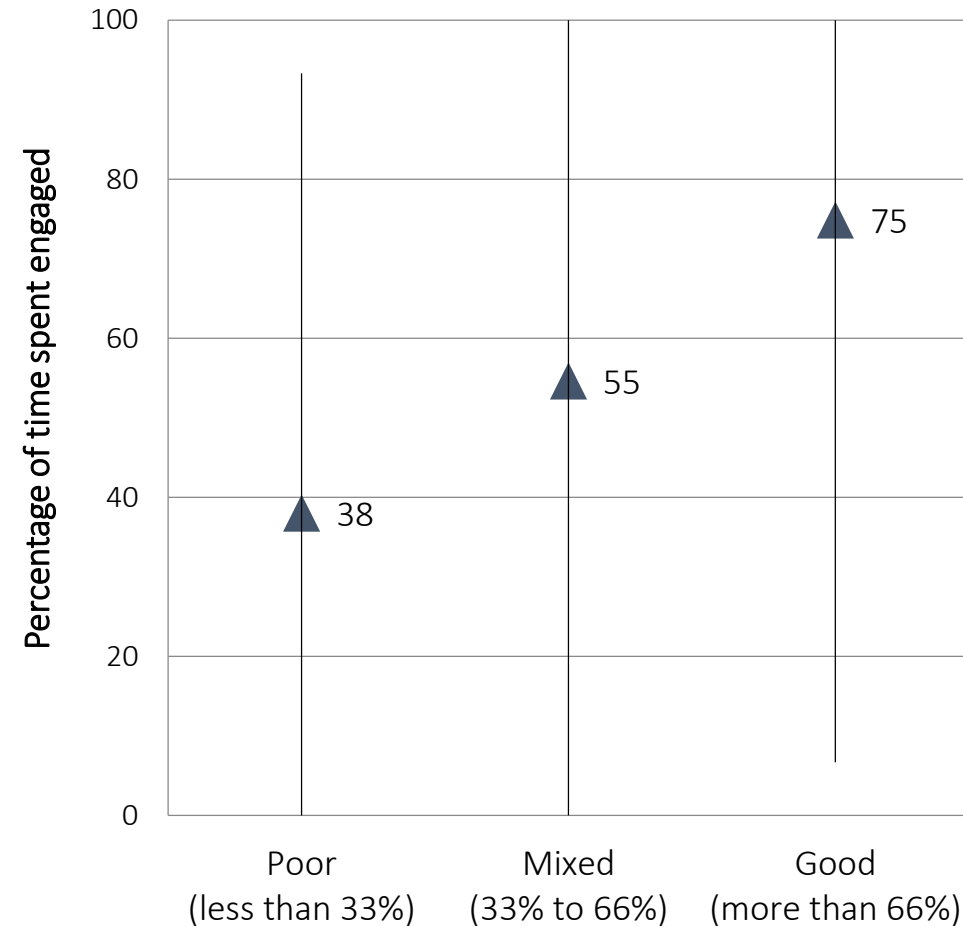
Person-Centred Active Support is…

- Way of **providing just the right amount of assistance**, to enable a person with intellectual disability to **successfully take part in meaningful activities and social relationships**.

- a way of working that you can apply at all times, with all people.

- ….not something that you schedule for set times, or with particular people, or when extra staff are working.

[EMHP composite]

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Active Support - What do you See

For People you support

- **Engagement in meaningful activities and relationships**

  - **doing something constructive with materials**; vacuum cleaning a floor, laying a table, cutting a hedge, loading a washing machine, listening to a radio.

  - **interacting with people**; talking or listening to them or paying attention to what they do - holding a conversation, watching someone show how to do something.

  - **taking part in a group activity**; watching the ball and running after it in football.

For Staff

- Providing enough help to enable people to participate successfully in meaningful activities and relationships -irrespective of degree of intellectual disability

- Graded assistance

- Every moment has potential

- Little and often

- Choice and control

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Person-Centred Planning and Person-Centred Action

Person-centred planning

Informs about longer-term direction, the bigger picture

Informs about individual strengths, possible directions and aspirations, grounded in reality

Person-centred action
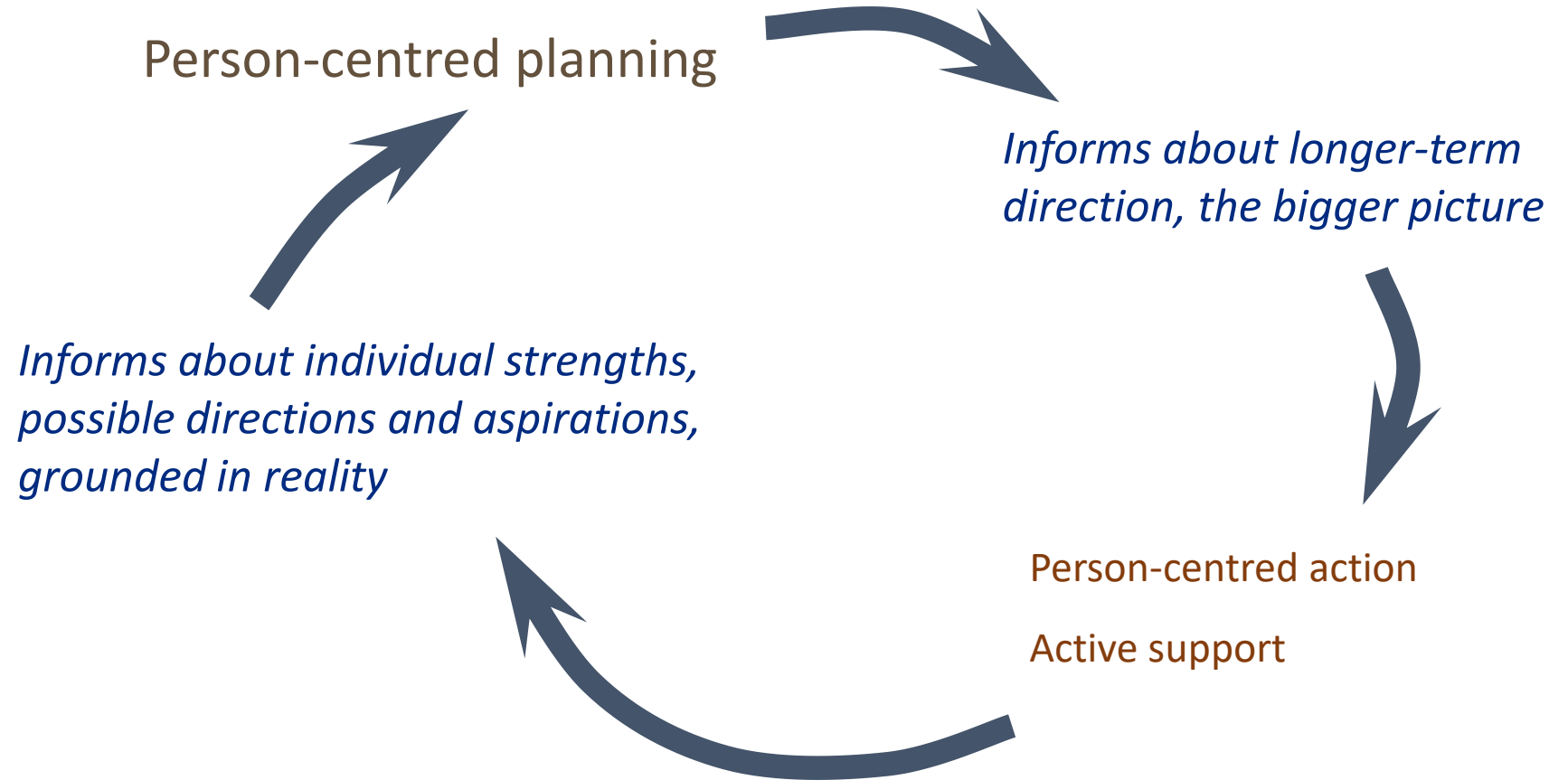
Active support

Active Support proxy for other person-centred approaches – PCP, Spell, PSB, Effective communication

- One of a family of person centred approaches. Research evidence for the impact of the other approaches on quality of life is currently very weak

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Strong front line Practice Leadership

Focus on Quality of life outcomes

Team meetings

Practice Leadership

Allocating and organising staff

One-to-one Supervision

Observation, Feedback Modelling Coaching

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"Managers stop spending almost all of their time in the office doing paperwork, problem-solving on the telephone or in meetings. Now they become 'practice-leaders' teaching, guiding and leading their staff in providing person-centred active support to the people they serve. This means they spend most of their time with their staff, coaching them to provide good support". ~

Mansell et.al., 2004, p.123

Staff and managerial working practice that Compensates for difference

- Adapting support and the environment to the unique needs off the individual
- Based on knowledge about the individual – knowing the person
- Based on knowledge about the various sub groups to which they might belong based on
  - Age
  - Syndrome
  - Autism
  - Complex communication needs
  - Culture – ethnicity
  - Sexuality
  - Gender
  - Challenging behaviour
  - Health conditions

Staff Culture

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Culture that is Coherent, Enabling, Motivating, Respectful

Dimensions from ethnographic work (Bigby et al.,2012, 2015, 2016)

Dimension	Underperforming Group Homes	Better Performing Group Homes
1. Alignment of power-holders' values	Misalignment of power holders' values with the organisation's espoused values	Alignment of power holder and staff values with the organisation's values
2. Regard for residents	Otherness	Positive regard, as part of the same diverse humanity
3. Perceived purpose	Doing for	Making the life each person wanted it to be
4. Working practices	Staff-centred	Person-centred
5. Orientation to change and new ideas	Resistance	Openness to ideas and outsiders

E

Group Home Culture Scale

Translated into 7 dimensions – staff survey to measure culture – valid and reliable tool

(Humphreys 2018)

1. *Supporting well being

2. Factional

3. Effective team leadership

4. Collaboration within the organisation

5. Social distance from residents

6. Valuing residents and relationships

7. Alignment of staff with organisational values

Useful diagnostic tool – for services and organisations

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Inconsistent culture across services in organisations
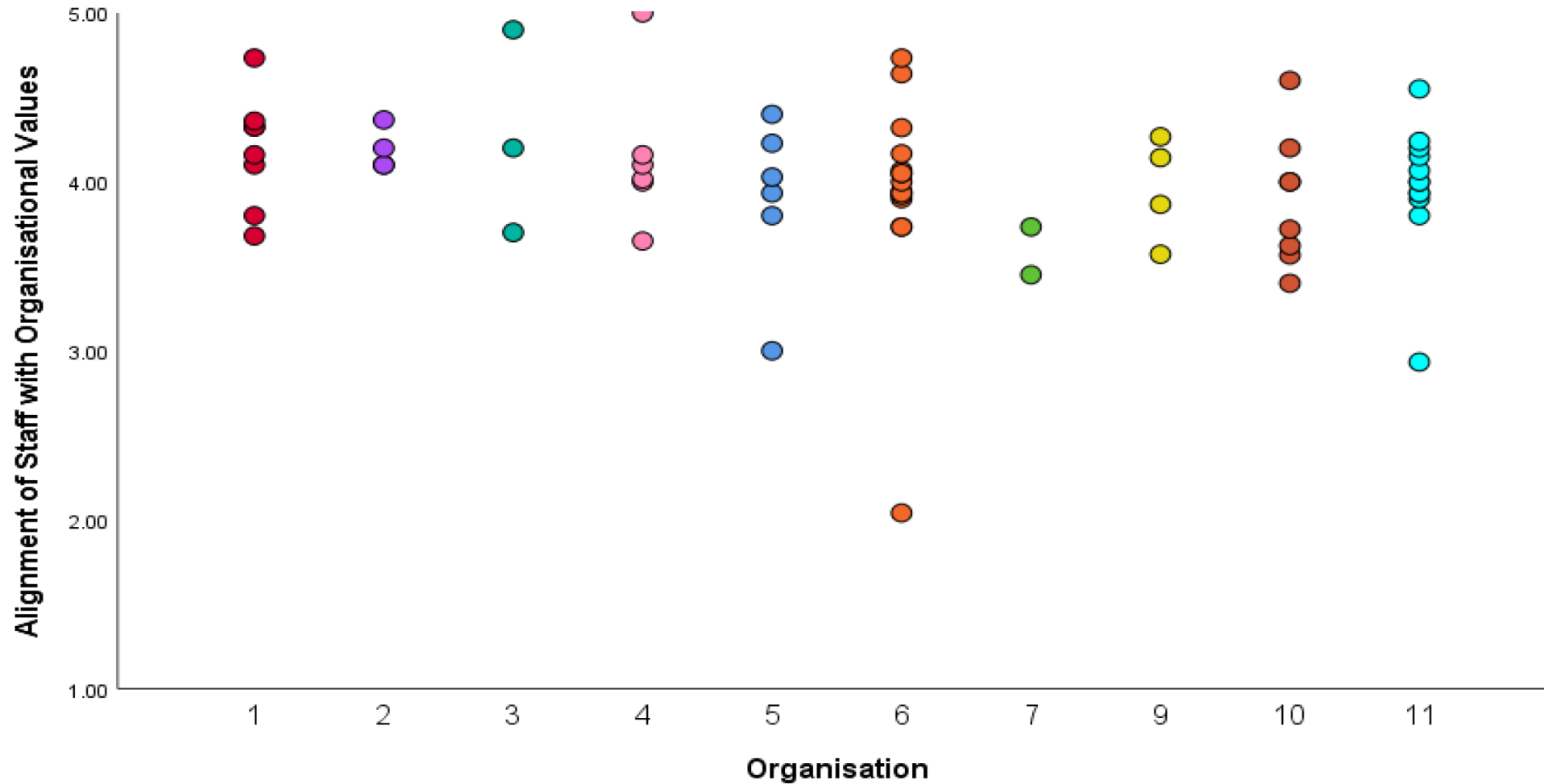
Inconsistent culture across services in organisations
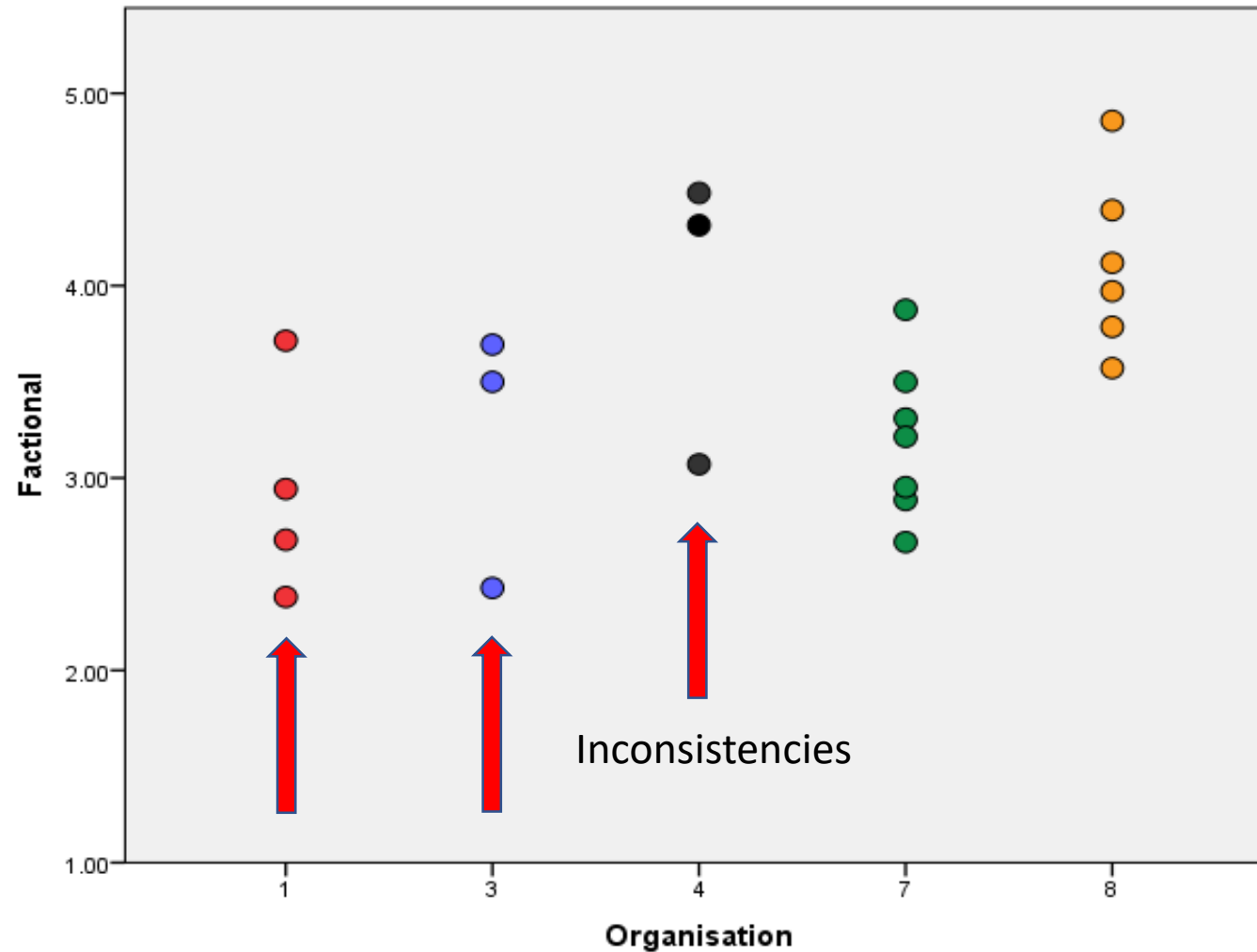
Organisational characteristics

- Staff training in Active Support

- Front line staff positive perception of management

- Senior managers' shared prioritisation of practice and support for front line practice leadership

- Organisation of practice leadership close to front line and concentrated in one position

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Shared prioritisation of practice and Active Support

'Practice is really, really important'

(9)

Saw practice as very significance to achieving aims

Understood Active Support

Demonstrated commitment

Investment of resources and mechanisms to lead Active Support

Whole of organisation approach

Language diffused through the organisation

Continuous reflection on progress and to finding strategies for improvement.

Active Support is our whole approach, not just an add on... you come here any day and you will see that... active support is something that you can ask anyone in organisation, "Do we do this?" They'll say, "Yes." Of course, we don't always all the time, but people do know what it is" [Org 7].

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Strongly supporting practice leadership

"Practice leadership isn't just what we'd like you to do, this is a must"

(7)

Not only recognised importance of practice leadership but ongoing search for ways to promote and strengthen

Multiple strategies adopted to complement any structural changes that may be been instigated

Giving greater emphasis to practice leadership tasks and reducing competing demand

Providing support to front line managers with practice leadership responsibilities

Increasing oversight by middle level managers

I was able to redirect those financial resources to increasing the mentoring and observations times of practice leaders… specifically, on roster for mentoring rather than being an active worker" [Org 3].

"It [practice leadership] needs to be at the top of their thoughts…making sure that's how they are supervising their staff" [Org 8].

Organisation of practice leadership

Close to every day service delivery (10)

Concentration of practice leadership tasks (10)

we've had team leaders who have worked across three houses, even been four … we definitely realise that the optimum number is two houses, which gives that team leader the opportunity in theory to be able to get out to their locations and be more present in the houses and that sort of thing [Org 8]

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Organisational Leadership

~~Coherence of paperwork – policies- procedures -size- scope location time implementing Active Support, annual turnover~~

Senior Managers share prioritisation of practice

Strong support for practice leadership

Organisation practice leadership close to front line and concentrated

Group Home Design

~~Staff to resident ratio~~

6 or less people – dispersed in the community

mix of people living together not too heterogeneous

Staff

~~Qualifications – experience - role clarity perceptions of practice leadership- attitudes~~

Strong Front line practice leadership

Staff trained in Active Support

Staff with positive perception of management

Culture

Enabling

coherent

Motivating

Respectful

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Good Practice and Good Outcomes are Fragile

Organisation	2009-2010	2011-2012	2013	2014	2015	2016	2017	2018
1	0%	0%	20%	60%	80%	60%	100%	40%
2	100%	75%	71%	71%	43%	38%	71%	57%
3	25%	0%	40%	40%	60%	80%	100%	80%
4	13%	0%	50%	63%	75%	44%	33%	29%
5			25%	75%	63%	38%	71%	50%
6			57%	57%	20%	0%	86%	75%
7				14%	13%	50%	13%	
8				50%	33%	29%	57%	
9					29%	57%	33%	
10					0%	83%	43%	
11					25%	50%	50%	

Active Support Score

67% - 100%

50% - 66%

Less than 50%

Using research knowledge about housing and support

People with intellectual disabilities and families

- What to see and look for - in specific service and broader organisation managers, boards
- Enables claims to be checked

Blueprints for good service design

- Design
- Practice model
- Staffing and training
- Organisational structures
- Senior staff appointments

Funders

- What to include in funding provisions
- Benchmarks of performance

Regulators

- What constitutes quality – what to look for and ask about in audits

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Guide to visiting: some suggestions

Office of the Public Advocate

Personal development

What to look for:

- Are staff supporting residents to engage in activities in the home and garden?
- Are staff using appropriate communication, such as speech, handling materials and gestures, to clearly present the task so residents understand what they are being invited to do?
- Are staff doing things for residents rather than with residents? Are you seeing many missed opportunities?
- Are most opportunities to involve residents (e.g. in simple parts of tasks) taken?
- What are residents doing for most of the time you are observing? Are they engaged in meaningful activities, social interaction, or in passive listening, watching or sitting?
- Is the TV on? Is anyone engaged in watching it?

What to ask staff:

- How do staff know what residents like and dislike?
- Have any new activities been tried recently?
- How do staff support residents to be engaged when they are out shopping or using community facilities?
- Who does the housework, the laundry, cooking, shopping and gardening?

Interpersonal relations

What to look for:

- How do staff talk about residents? Do they talk about the residents as people who can think, feel, communicate and understand?
- Are staff interactions with residents warm and respectful?
- Do staff seem to know about residents' family members and the degree of involvement they have in their relatives' lives?
- Do staff communicate appropriately with residents? Do they use any aids or alternative means of communication other than speaking if required?
- Is there separate crockery for staff and visitors?

What to ask staff:

- How do staff communicate with residents?
- Do residents have any communication aids and, if so, do all staff use them?
- How do staff support residents to be involved with their family members?
- When did a resident last see a family member and what did they do together?

Self-determination

What to look for:

- Are residents doing things that reflect their individual choices and preferences, or are they all doing something similar?
- How do residents know what their day will look like?
- How do staff offer choices to residents? Do they use communication aids?
- Do staff respect the choices made by residents?

What to ask staff:

- Do all the residents go to bed and get up at the same time, or do residents have their own individual routines?
- How do staff offer residents choice in meals, eating times and activities?
- How often do residents all go out together?
- What limits individual choice for residents? How do staff weigh up decisions about respecting residents' choices?

Social inclusion

What to look for:

- Does the house stand out from others in the street as being a group home?
- Is there evidence of residents' activities in the community or neighbourhood, such as photos or invitations?
- Is there evidence that staff are familiar with the local area such as local newspapers, council guides or event fliers?

What to ask staff:

- If a resident returns home, do staff ask where they have been, what they have been doing and who they have been with?
- Do people in the neighbourhood recognise residents and say hello to them?
- Do residents have any friends or acquaintances in the neighbourhood who know them by name?
- Do any residents belong to clubs or societies?
- Do any residents take part in regular community activities with people who do not have disabilities?

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2 Guide to visiting: some suggestions

Office of the Public Advocate

Emotional wellbeing	Material wellbeing
What to look for: • What is the demeanor of residents? Do they seem content? Do you see people smiling or laughing? • Do staff respond to cues from residents and interpret their needs? • Do residents seem resentful or resistant to staff support? • Are residents engaged in self-stimulation, self-harm, repetitive behaviour, pacing or other forms of challenging behaviour? **What to ask staff:** • How do staff know what a residents wants or if they are not happy? • What cues do residents give staff which indicate their needs? • Are any residents resentful or resistant to staff support? • Are there particular things that trigger challenging behaviour and how have staff addressed these?	**What to look for:** • Do residents have easy access to private space as well as shared spaces? • Is the house adapted for residents' needs, such as benches at an appropriate height, use of communication aids, easy access to the garden? • Do residents have their own possessions around the house? **What to ask staff:** • How are decisions about household expenses made? • How are residents' preferences taken into account when staff manage their finances? • Are there problems with house or vehicle maintenance that are causing difficulties?

Physical wellbeing	Rights
What to look for: • Are residents eating healthy, fresh food rather than processed, packaged or fast food? • Are residents a healthy weight? • Are the bathrooms and appliances clean? **What to ask staff:** • Are residents eating healthy, fresh food rather than processed, packaged or fast food? • Are residents a healthy weight?	**What to look for:** • Do staff behave and talk in a way that suggests residents have rights and that it is the residents' home? • Do staff knock on bedroom, bathroom and toilet doors before they enter? • Who opens the front door? • Do residents have access to the office and all other parts of their home? **What to ask staff:** • Do residents have anyone who acts as their advocate? • Have staff members ever questioned a decision made by another staff member, their organisation or a family member about something that affects a resident? What would happen if they did?

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RESEARCH TO ACTION

>> Bridging the gap between what we know and what we do

GUIDE TO GOOD GROUP HOMES

What to look for and things to ask

- Available from https://www.cadr.org.au/about-cadr/research-to-action-guides/research-to-action-sheets/good-group-homes

- Review of evidence and consumer guides

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Thank You

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