What is necessary for good quality supported accommodation services for people with intellectual disabilities

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Outline

- Review the evidence about contributing factors to good quality of life outcomes for people with intellectual disability in group homes.

- Identifying those for which there is most evidence

- Use data from longitudinal study to illustrate how service providers have used research to improve service quality.

- Discuss challenges providers face in maintaining high quality services.

Service user outcomes - quality of life

— Social Inclusion

— Interpersonal Relations

— Self-Determination

— Rights

— Personal Development

— Emotional Well-Being

— Physical Well-Being

— Material Well-Being

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

■ Use of Engagement as a proxy for QoL

Continuing importance of group homes

- Approx. 17,000 people live in group homes - most have intellectual disability

- Shared accommodation – staffed 24 hours- 2-6 people - dispersed ordinary housing

- Despite calls for innovative models – still being built

- Will remain significant form of supported accommodation in short to medium term

- Reform emphases choice - type of support and provider

- Using research evidence to design and demonstrate quality will become increasing important for providers as consumers make judgements

Who lives in group homes ?

- Has been the only option for many years

- Wide range of people in terms of severity of disability – much wider than supported living

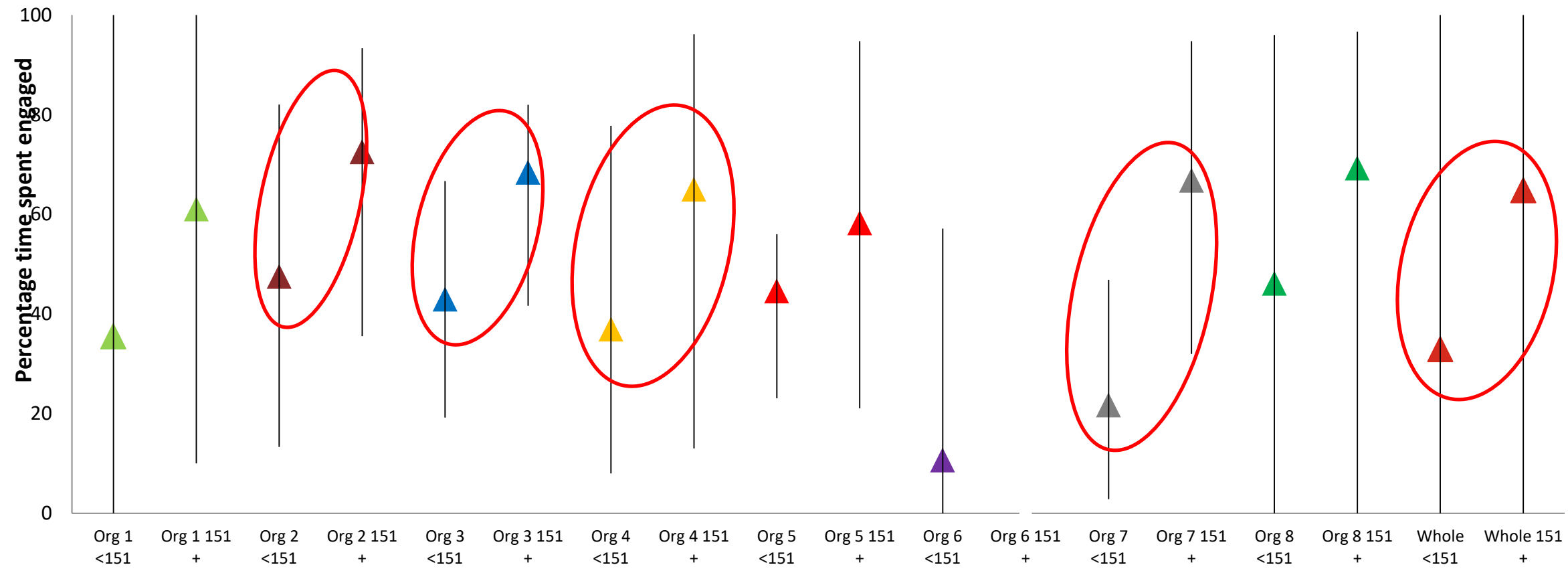- Significant overlap between the two groups between 30 - 35 %

Supported Living
239
(166 – 282)

31%
(166 – 263)

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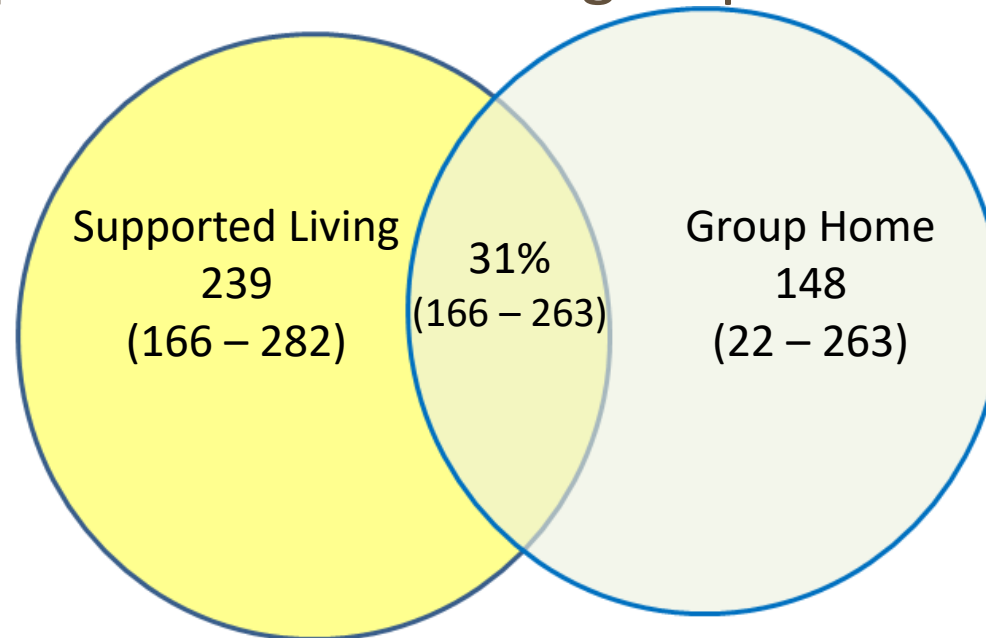
- As funding changes maybe characteristics of service users will change

# Recent Australian data – variability of outcomes over time, within and between organisations

Percentage time spent engaged
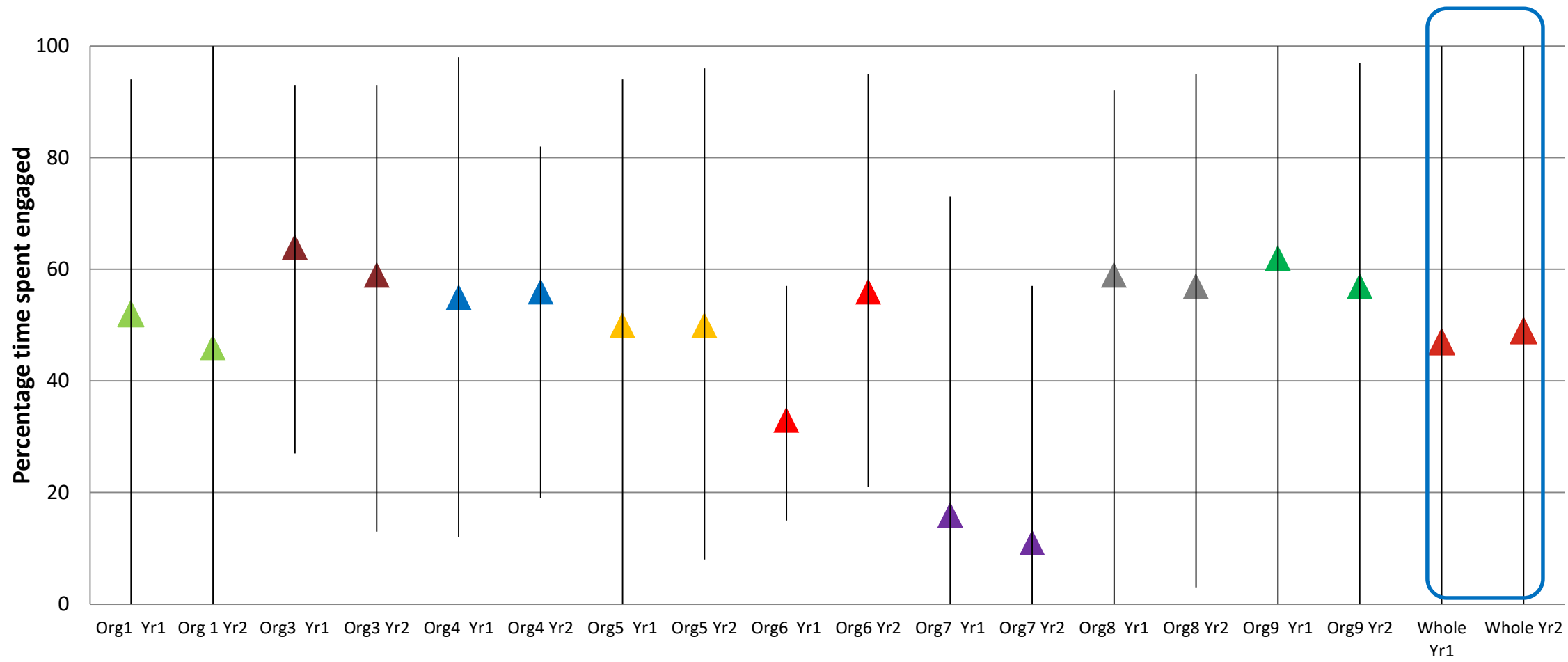
minutes per hour
Year 1 = 28
Year 2 = 29

Consistently poorer for service users with more severe disability

Percentage time spent engaged

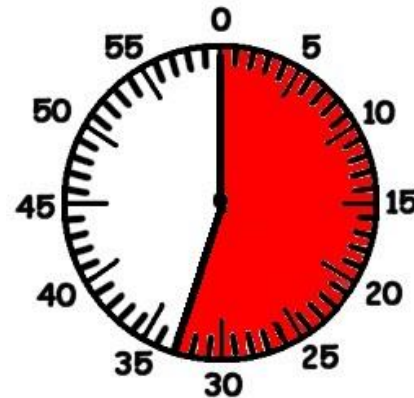|																	
Org 1 <151	Org 1 151 +	Org 2 <151	Org 2 151 +	Org 3 <151	Org 3 151 +	Org 4 <151	Org 4 151 +	Org 5 <151	Org 5 151 +	Org 6 <151	Org 6 151 +	Org 7 <151	Org 7 151 +	Org 8 <151	Org 8 151 +	Whole <151	Whole 151 +

Sig difference

Adaptive behavior – outcomes consistently poorer for people with more severe disability – spend a lot of time doing nothing
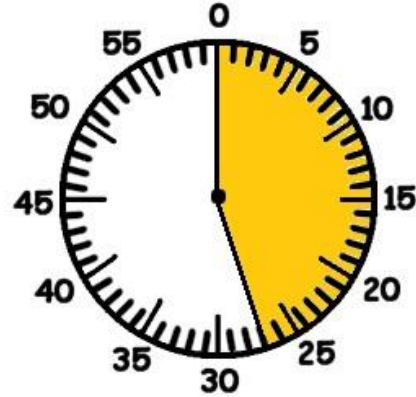
Overall
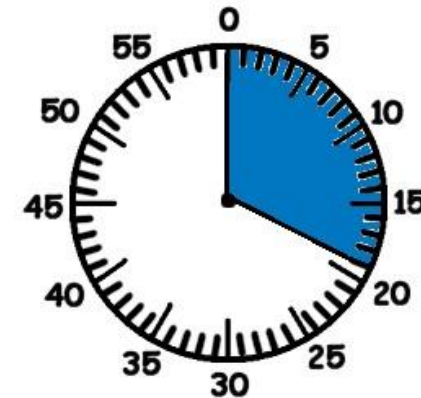**46% (27 minutes)**
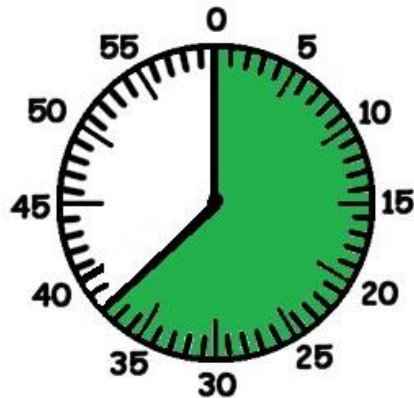
ABS <=80
63% (38 minutes)

ABS 81-150
54% (33 minutes

ABS 151+
32% (19 minutes)

Outcomes and staff practice high and lower performing organisations

Sample average and people with higher support needs – variability across and between groups

	Whole Sample	Org 1	Org 2	UK study Good active support (Ashman, Beadle-brown, 2006)
Engagement in meaningful activity and relationships	**47% (31%)**	**64% (54%)**	**25% (16%)**	**60% (54%)**
Quality of Support (Person Centred Active Support)	**49% (38%)**	**67% (64%)**	**28% (12%)**	**79% (79%)**
Time spent receiving assistance and contact from staff	**12 mins (11)**	**18 mins (15.5)**	**7.5 mins (6)**	**23 mins (25)**

What makes a difference…Good quality of life outcomes when…… Complex interactions 5 main elements (Bigby & Beadle Brown 2016)

+++Size and Design

- Adequate resources
- Size & Type

+++Staff and managerial working practices that
- Reflect active support
- Front line practice leadership
- Compensates for difference

Organisational characteristics, policies and processes
- Strong HR
- Processes assist staff to focus on practice
- Staff training in active support including hands on

+Culture that is
- Coherent
- Enabling
- Motivating
- Respectful

An external environment that is congruent and reinforces the mission and values of the organisation - Social reforms – regulatory frameworks ?

Research Evidence
Size & Design
Necessary but not sufficient for good outcomes

+++ large vs. small supported settings

"There can be no doubt, in general, that people with an intellectual disability benefited from deinstitutionalisation" (Mansell & Ericsson, 1996).

(Emerson & Hatton, 1996 & Kozma, Mansell & Beadle Brown, 2009)

- 1-6 stepped rather than gradual (Tossebro, 1995)

++ clustered housing vs. dispersed group homes

'Dispersed housing is superior to cluster housing on the majority of quality indicators'
(Mansell & Beadle Brown, 2009)

+ supported living vs. group homes

- Few differences other than choice and control
- Both groups mediocre Quality of Life (Stancliffe & Keene, 2000, Bigby et al., 20017)

Adequate Resources – Does skilled support 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

Staff and managerial working practices that

+++ Reflect active support

+ Front line practice leadership

++ Compensates for difference

Active Support - Early Adoption of a Person Centred Approach

Origins 1960s (from Mansell & Beadle-Brown 2012)

- Isolation and inactivity – defined as major problem (Kushlick, 1966)

Fundamental importance of Engagement - If people are doing nothing cannot exercise control

Engagement in meaningful activity changes - competence – independence – attitudes of staff

Mansell et al., 1982 demonstrated that manipulating the environment, staff and materials to increase engagement by can be done with relative ease - behavioral approach

Challenged – division of life – waiting for and engagement in constructed activities

Major rethink - goal of services

' instead of doing all the housework as effectively as possible, and then attempting to occupy clients for long periods of each day with toys, staff could perhaps be organized to spend most of the day doing housework with clients, arranging each activity to maximize the opportunities for clients with different levels of activity to participate' (Mansell, Felce, & de Kock, 1982).

If the Problem is lack of engagement – the Goal is facilitating engagement in everyday activities and relationships.

Person-Centred Active Support is...

- a 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.

- One of a family of person centred approaches But research evidence for the impact of the other approaches on quality of life is currently very weak –even for PBS

Evidence - Active Support

- If staff use active support consistently people with intellectual disability show increases in engagement, growth in skills, more choice and control and less challenging behavior (Mansell & Beadle-Brown 2012)
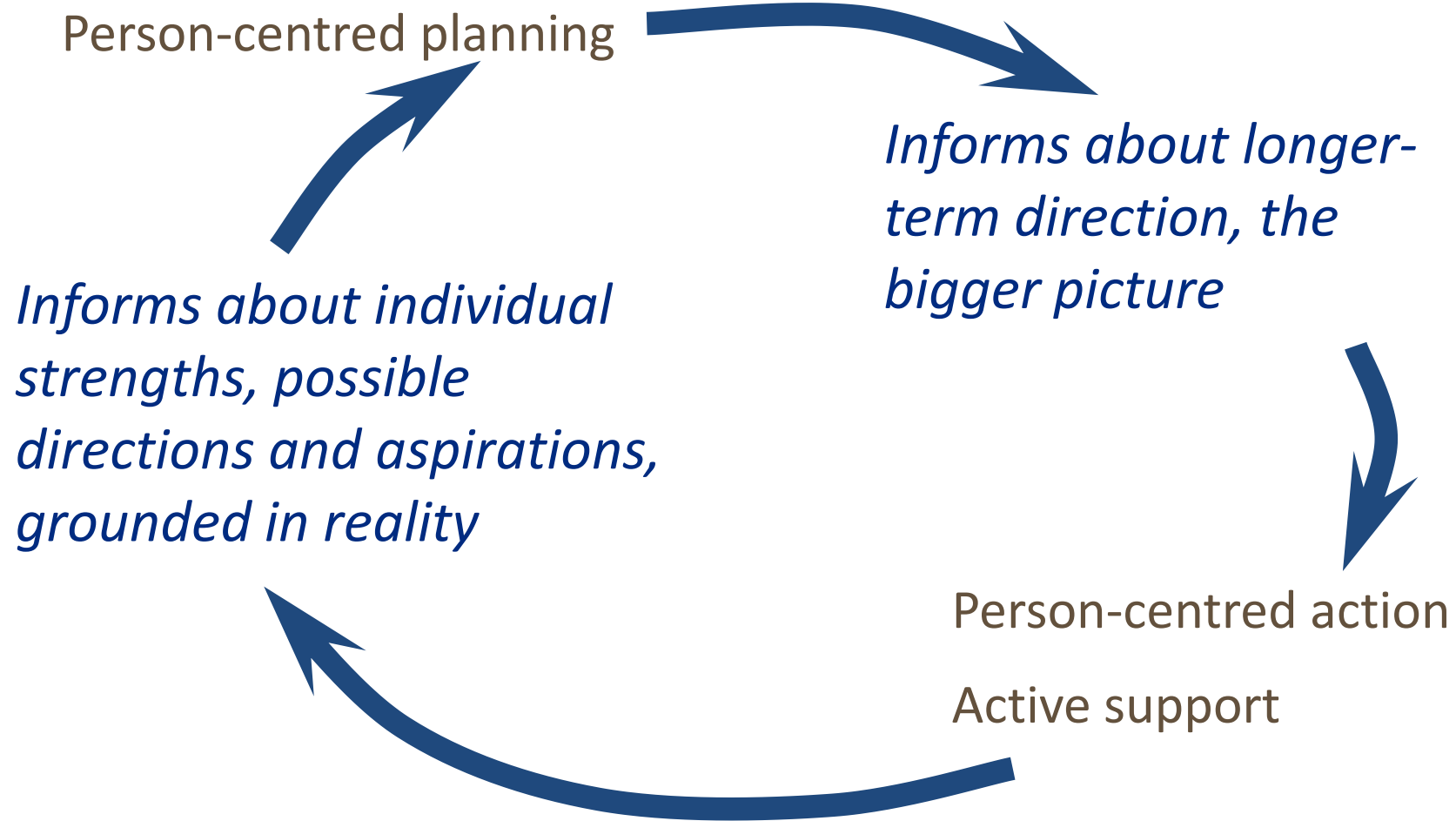
Findings also suggest

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

- People who receive consistent good active support have better outcomes in other QoL domains – personal development, interpersonal relations, social inclusion, self-determination and rights

- Does not require more staff or cost significantly more – available resources are used much more efficiently in services where the support was skilled (Beadle-Brown et al, 2016)

Measuring Active Support

- The score on the Active Support Measure is based on the observer's overall judgement of 15 items relating to quality of support, with each item scored from 0 (lowest score) to 3 (maximum score):

1. Age appropriateness
2. Real activities
3. Choice
4. Demands presented carefully
5. Tasks analysed appropriately
6. Sufficient staff contact – not too much
7. Graded assistance
8. Speech matches developmental level

9. Interpersonal warmth
10. Differential reinforcement
11. Staff notice and respond to client communication
12. Staff [do not only] respond to challenging behaviour
13. Staff work as a team
14. Incidental teaching
15. Written programmes in routine use

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
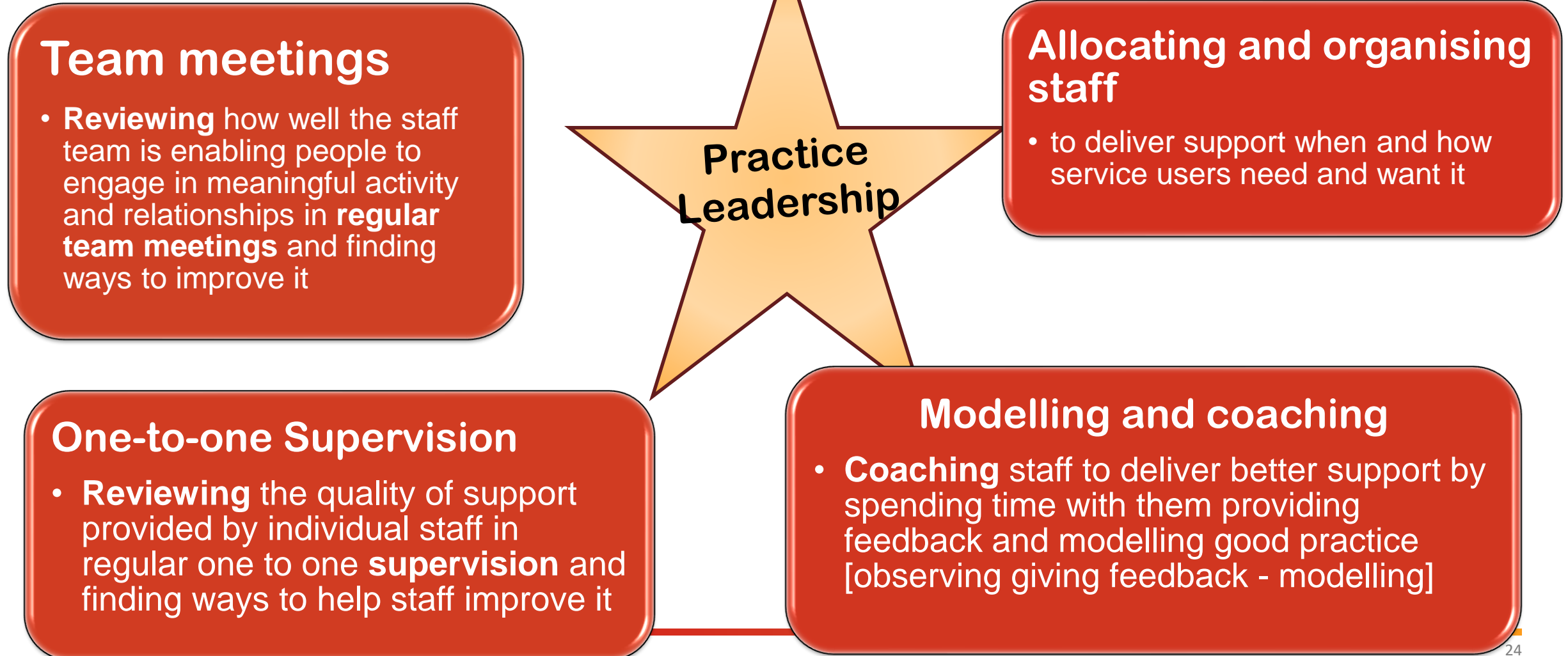
Person-centred action

Active support

Staff and managerial working practices that

- Reflect active support
- **Front line practice leadership**
- Compensates for difference

Practice Leadership

Front line managers

Quality of life outcomes
- Focusing on **all aspects of work** as the front-line manger on quality of life of services users and how staff support this

Team meetings
- **Reviewing** how well the staff team is enabling people to engage in meaningful activity and relationships in **regular team meetings** and finding ways to improve it

Practice Leadership

Allocating and organising staff
- to deliver support when and how service users need and want it

One-to-one Supervision
- **Reviewing** the quality of support provided by individual staff in regular one to one **supervision** and finding ways to help staff improve it

Modelling and coaching
- **Coaching** staff to deliver better support by spending time with them providing feedback and modelling good practice [observing giving feedback - modelling]

"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*

Practice Leadership Associated with Better Quality of Staff Support

First evidence of relationship between Practice leadership and Active support
(Beadle- Brown, Bigby, Bould, 2015)

- Active support was significantly better in services where practice leadership overall was better

- At service and service user levels

- Strongest correlation active support and coaching domain

- Scores on practice leadership too low for very strong relationships

- Different models of practice leadership – as yet no evidence re these

Quality of staff support- people observed with PL absent vs. people observed with PL present
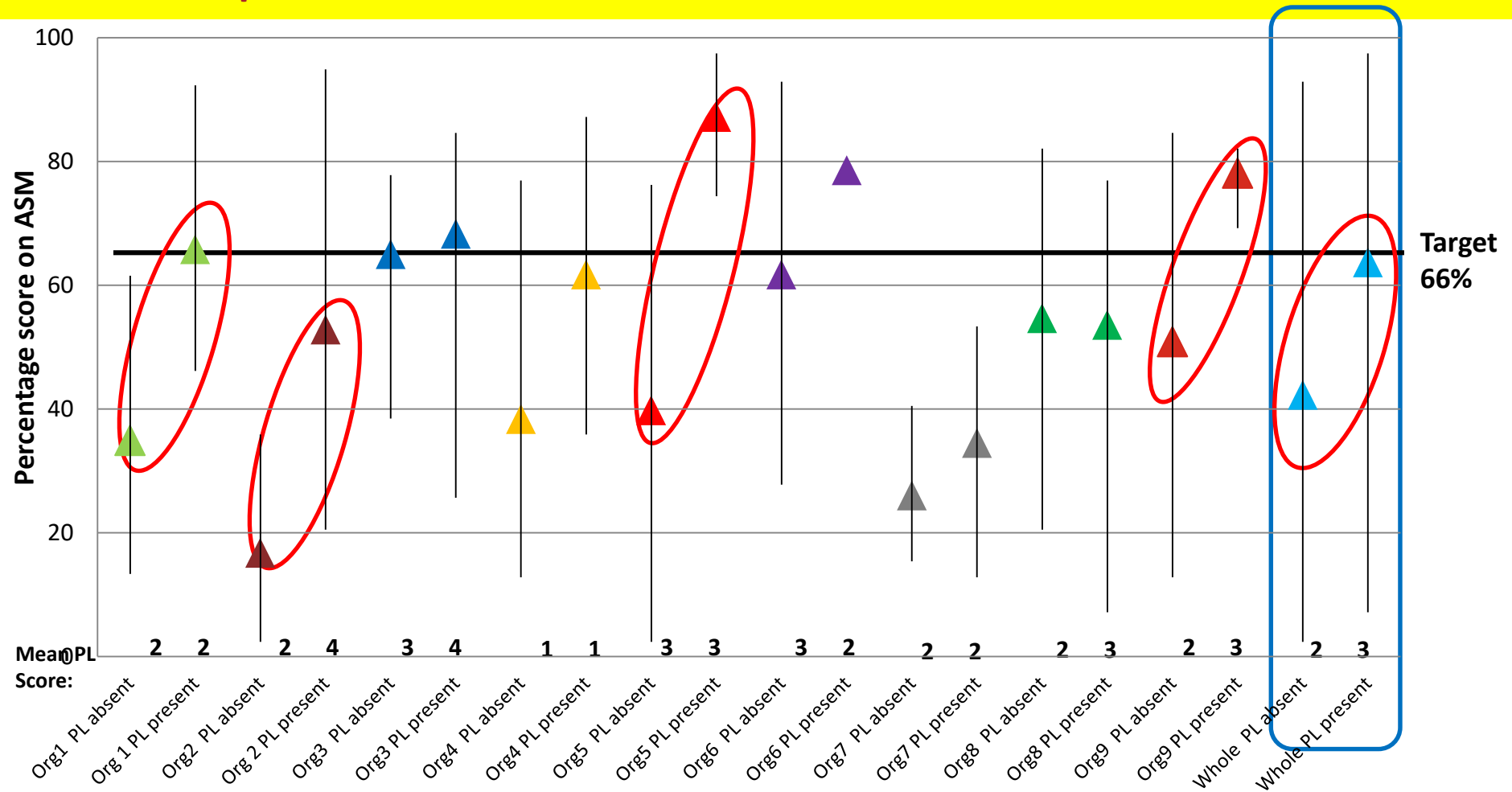
- Staff support better when the PL present in the house during the observation (Bould et al., 2016)

Staff and Managerial Working Practice that Compensates for Difference

Adapting support and the environment to the unique needs of 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

Culture that is

- Coherent

- Enabling

- Motivating

- Respectful

Culture

Likely to be found in underperforming homes	Dimensions of Culture	Likely to be found in better homes
	Overarching characteristics →	**Cohesive, Respectful , Enabling Motivating**
Misalignment power holder and staff values with organisations espoused values - staff cliques.	**Alignment of power-holders values**	Alignment of power holder and staff values organisation values - strong leadership, shared team responsibility
Seen as other –fundamentally different – too disabled- no skills	**Regard for residents**	Positive regard -part of the same diverse humanity –attending to difference.
Doing for not with – looking after people – getting people out.	**Perceived purpose**	Making the life each person wanted it to be – recognising and respecting preferences – including and engaging – care, dignity and comfort.
Staff- centred – staff needs prioritised- group treatment.	**Working practices**	Person-centred – attentive, relational, flexible, momentary fun interactions.
Resistance – to external influences and ideas	**Orientation to change and new ideas**	Openness to ideas and outsiders

Generative factors of cohesive culture

Frontline staff and managerial working practices

Bringing together knowledge - about communication, attachment, intensive interactions, processes to support relationships, supporting inclusion in community places and active support.

Front-line practice leadership - modelling, coaching, monitoring, supervision and communication among team,

Team work

Maps onto some elements found in Active Support and Practice Leadership - working practices relational as well as behavioural

Generative factors of cohesive culture

Organisational characteristics, policies and processes

HR policies regulating **entry and exit to organisation**

Recruitment – staff values, job descriptions reflect expectations

Close scrutiny of casual and prospective staff

Performance management and support to front line leaders

Organisation of work

Regulating entry to specific group homes - groups of service users - buddy shifts

Induction separated from orientation - practice same weight as procedures

**Coherent messages**

Explicit translation of organisational values – into grounded expectations - no doubt what's expected

Development of Group Home Culture Scale (Humphreys et al work in progress)

Factors

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

- Potential measure of factors associated with better outcomes

Inconsistent culture across services in an organisation - Factional
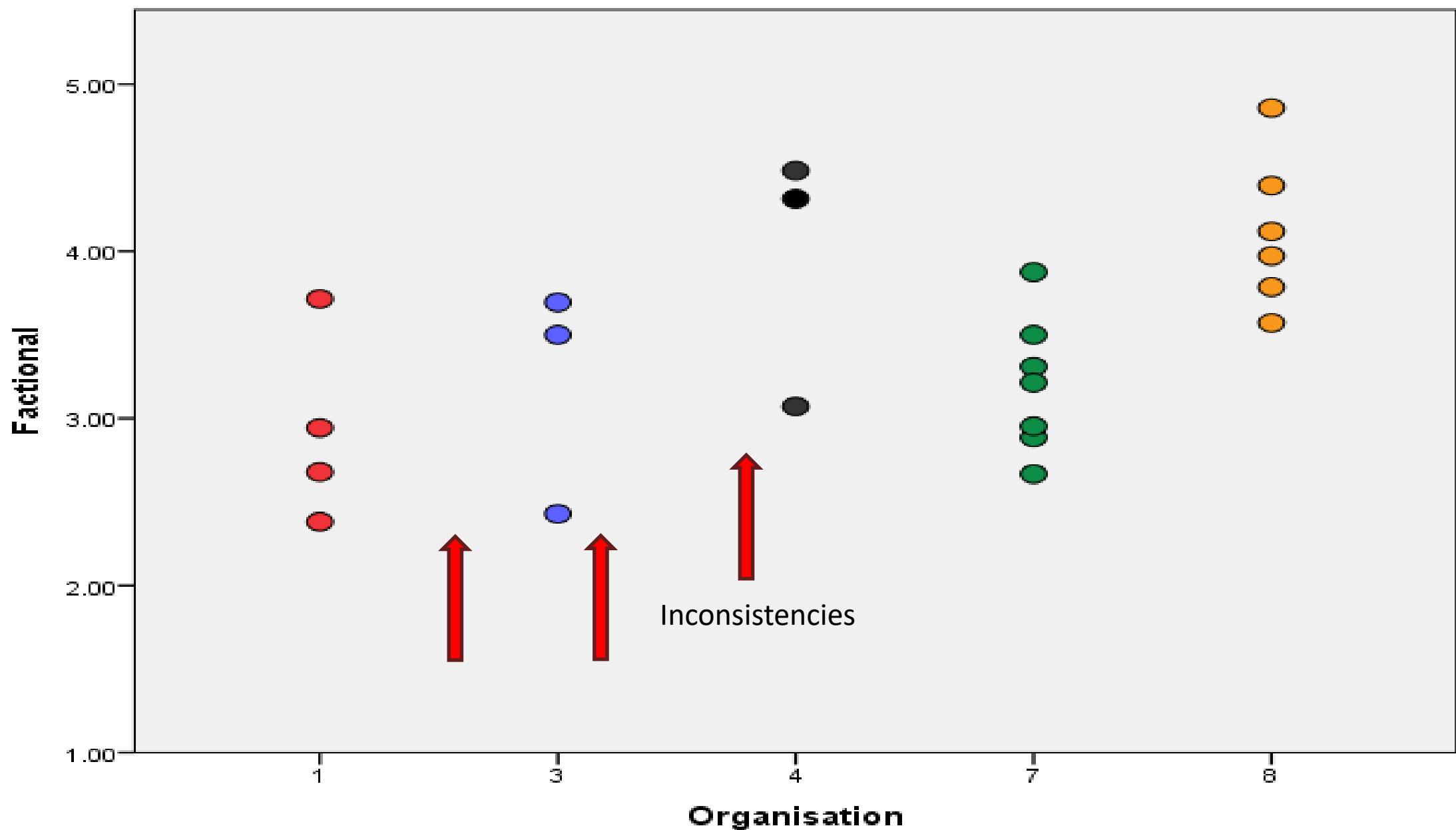
Inconsistencies

Organisational characteristics, policies and processes

- Strong HR
- Processes assist staff to focus on practice
- *Staff training in active support including hands on

- Less evidence than other elements – indicative of less research not necessarily that the practice wisdom is flawed.

An external environment that is congruent and reinforces the mission and values of the organisation

- Social reforms – regulatory frameworks ?

- Almost no evidence
- Other than perspectives of regulators rarely reflect those of researchers re quality
- Reliance on paperwork and process to measure quality inherently flawed

Using Research Evidence to Improve Quality of Support and Service User Outcomes

- Organisations in our study have used this body of evidence & organisational specific data from an annual report on service users Engagement and Quality of staff support to change the way they do things.

- For example

  - Restructured to create better model of practice leadership

  - Redistributed admin work to free up time for coaching

  - Drawn up new job descriptions

  - Rolled out Active Support training across the organisation

  - Process of culture change – confidence to take risks, stories, reflective practice

  - Changed recruitment practices

  - Changed the messages and narratives to families and board members about their services

- Things have changed but not always in the direction expected.

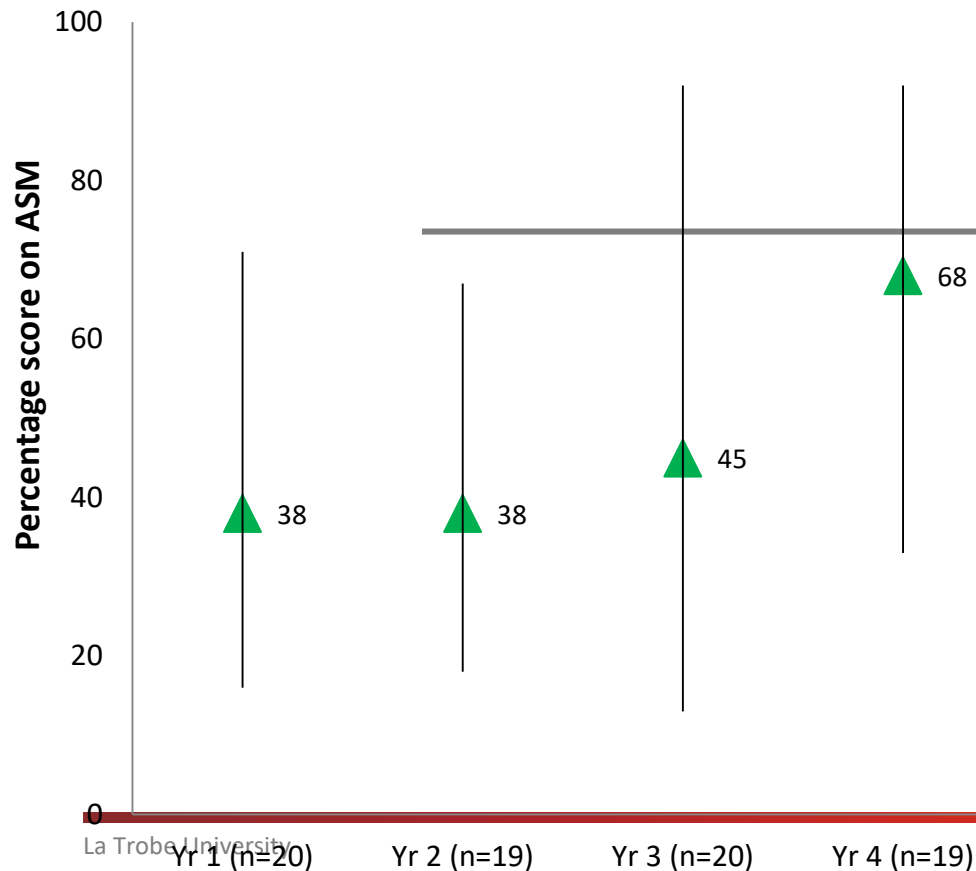# Quality of Active Support Improves over Time with Attention

- Over time for 6 organisations
- Upward trajectory
- Continuing variability

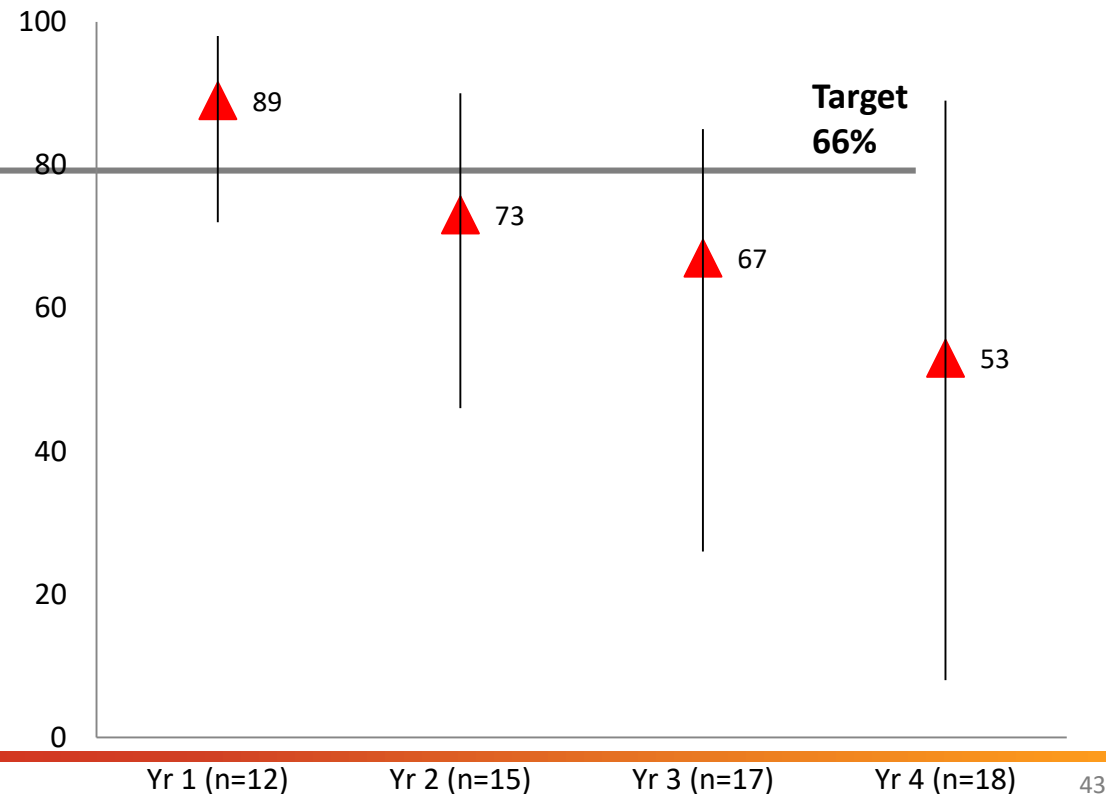|	Yr 1	Yr 2	Yr 3	Yr 4
Org 1	38 (16-71)	38 (18-67)	45 (13-92)	68 (33-92)
Org2	89 (72-98)	73 (46-90)	67 (26-85)	53 (8-89)
Org3	52 (8-93)	38 (18-59)	51 (13-87)	55 (38-75)
Org4	33 (12-74)	37 (5-69)	-	62 (23-85)
Org5	-	-	28 (13-53)	42 (20-77)
Org6	-	-	54 (7-82)	64 (17-87)
Overall	47 (8-98)	45 (5-90)	48 (7-92)	58 (8-92)

Not a Straightforward Journey Multiple Factors at Play, Obstacles and Distractions.

- Org. 1 - significant increase from Year 2 to Year 4 (Friedman X2 =13.38, p=0.004, n = 13); and between Year 3 and 4 (Wilcoxon z=3.127, p=0.002, n=16).

- Org. 2 - significance decrease over time (Friedman X2 =11.449, p=0.01).

Organisation 1

Organisation 2
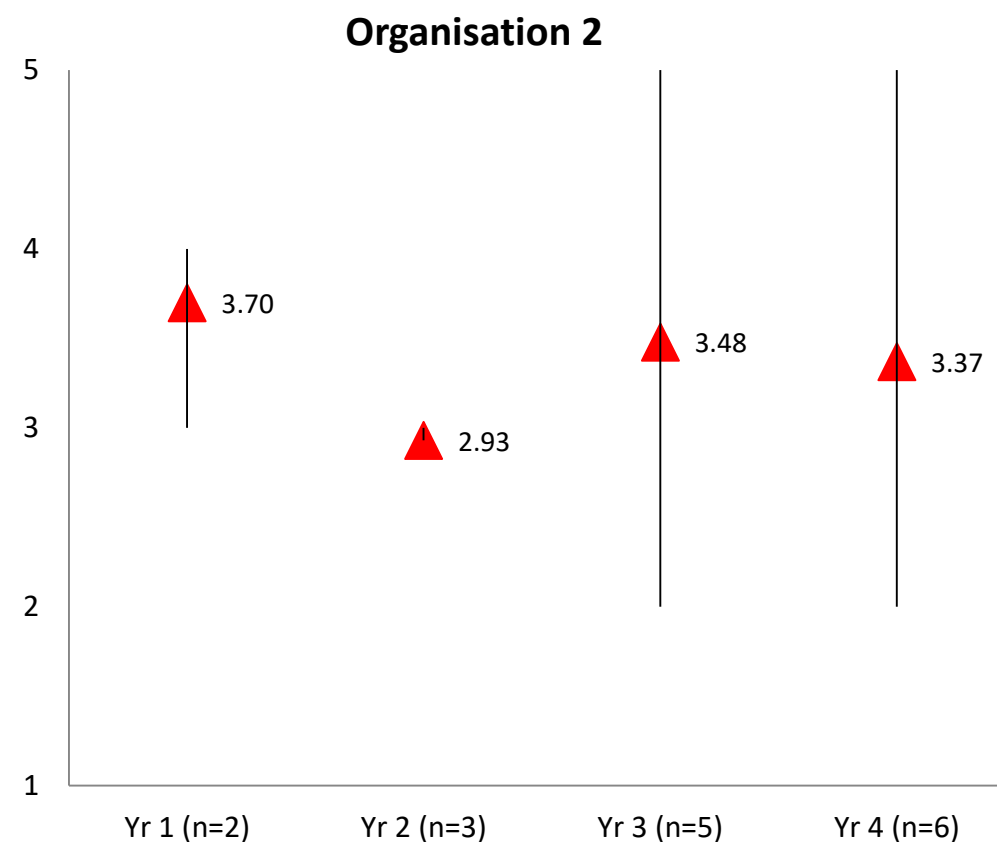
Target 66%

Percentage score on ASM

38 38 45 68

89 73 67 53

Yr 1 (n=20) Yr 2 (n=19) Yr 3 (n=20) Yr 4 (n=19)

Yr 1 (n=12) Yr 2 (n=15) Yr 3 (n=17) Yr 4 (n=18)
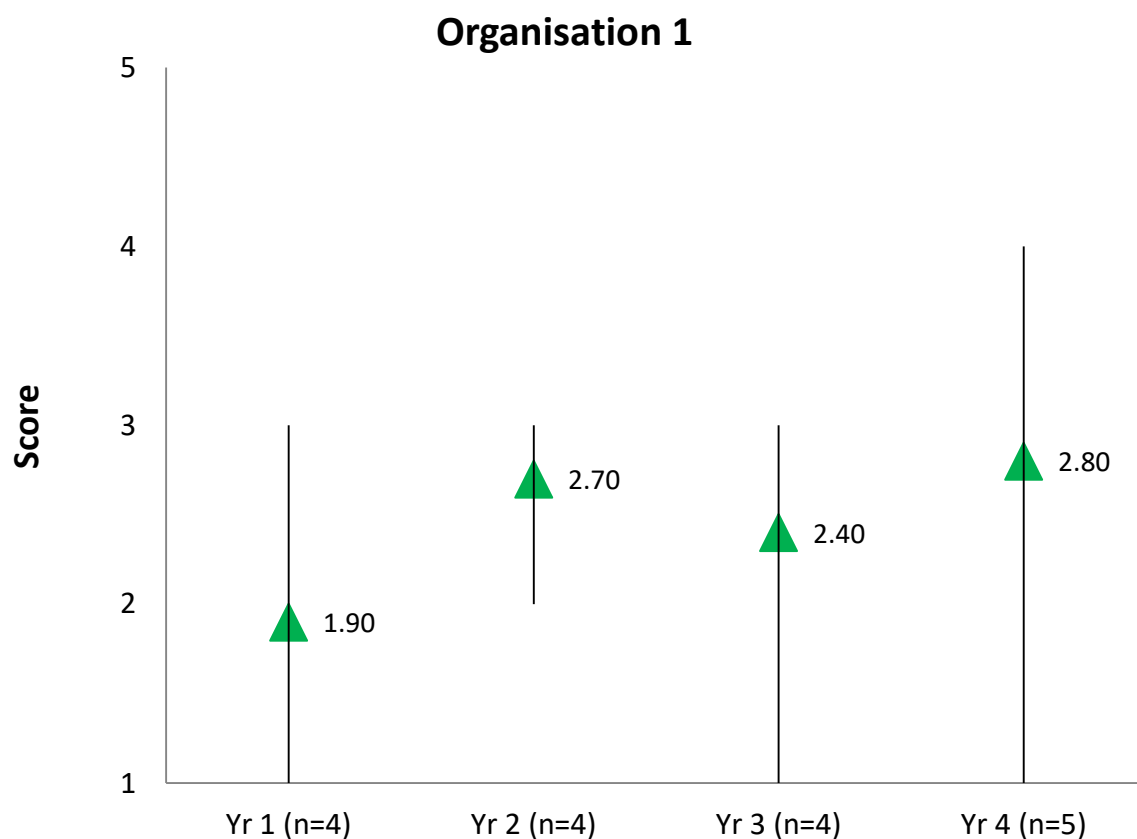
Practice Leadership

- Org. 1 - significant increase in practice leadership between Years 1 and 4 (Wilcoxon signed rank test z= 2.455, p=0.014, n=16).

- Org. 2 - slight but non-significant decline over time from Year 1 to Year 4.

Staff without training in Active Support Training

- Decrease for Org. 1: Year 1, 63% vs. 8% in Year 4.

- Increase for Org. 2: Year 1, 7% vs. 29% in Year 4.

Organisation 1

Organisation 2
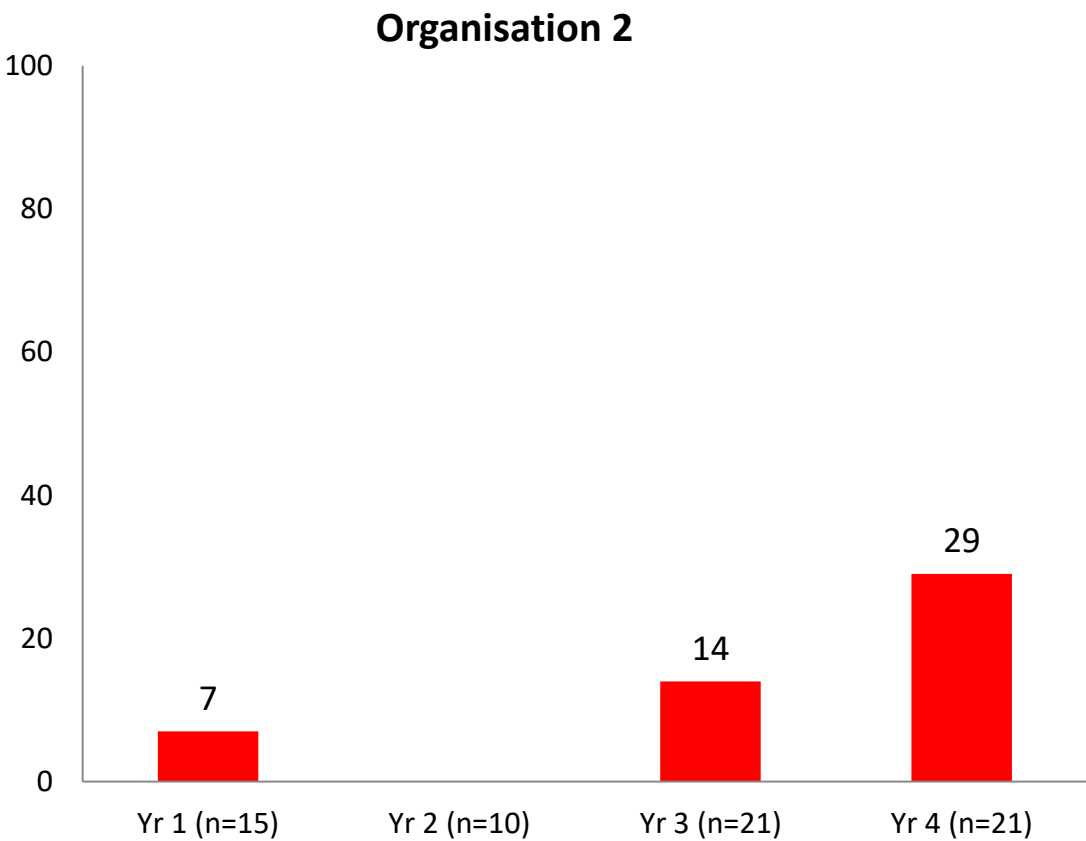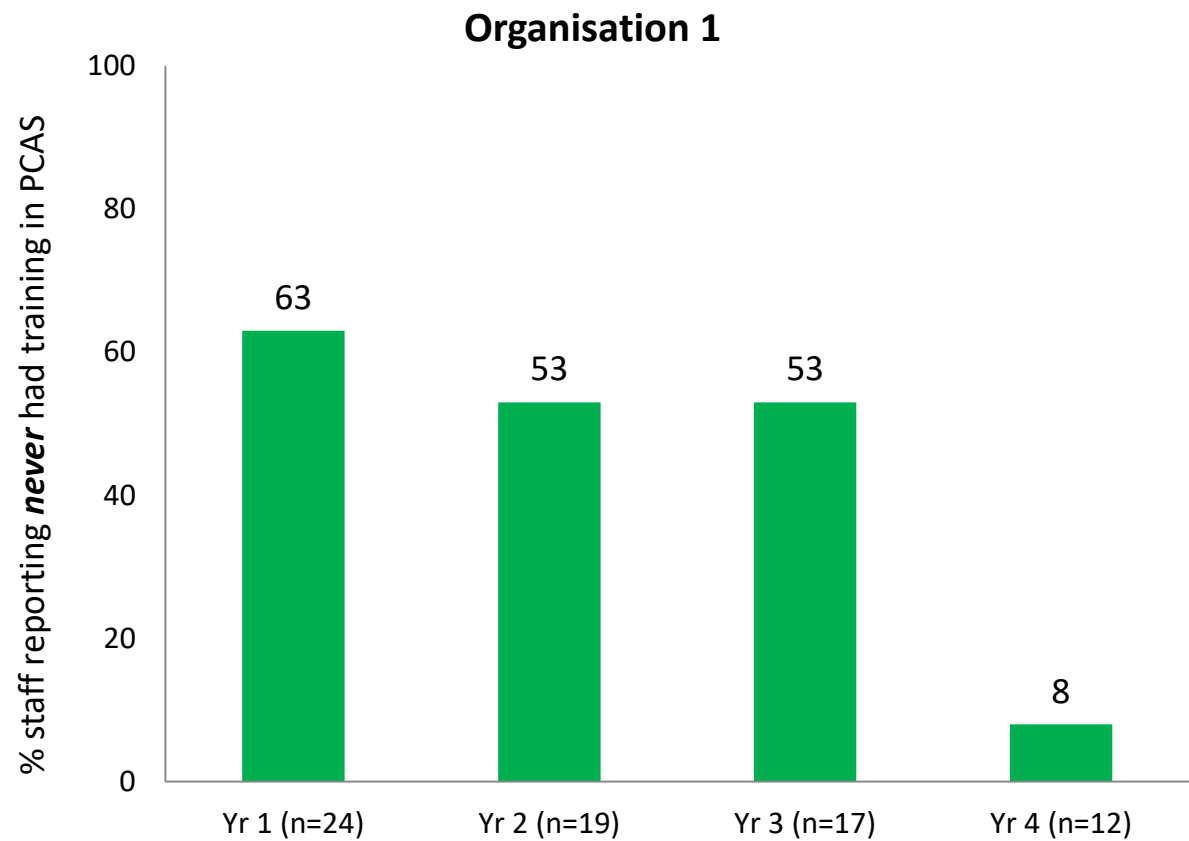
Not just a Project – Good Practice is Fragile and Requires Continuous Attention

- Ongoing internal or external training capacity in Active Support
- Low and fluctuating levels of classroom and hands-on training.
- Disruptions by front-line staff and practice leadership turnover and crisis.

"One team has just imploded...we put a lot of energy into this team...active support now seems secondary as staff are thrown back onto survival mechanisms. We are trying to move them forward and coach them through, making sure the staff group feel heard (but) we are almost back to the beginning of starting a new team" (minutes, June 2013)

"Our staff were prepared to be engaged in the project, they didn't mind the researchers coming, they were now interested. I would put a lot of that to the process of focusing on the cultural change of telling stories, having conversations, talking about it, moving away from the blame, that seemed to produce a shift right across the organisation over two to three years" (CEO interview, 2013)

Creating and Supporting Conditions Necessary for Good Outcomes and Practice – the Value of Research Evidence

- Good practice is not achieved by an individual worker in isolation – not just training

- Lots of propositions – about what makes a difference

- Most evidence

  - Active Support

  - Practice leadership

  - Culture – for which we now have values and measure

  - Organisational processes that support cohesive culture and good practice

- Research knowledge can help to focus actions for change

- Independent measures provide annual evidence for managers to reflect on

- Senior managers are often distracted and leave core business to front line staff – research can help refocus

References

Many of those authored by LaTrobe authors are available on open access in the LaTrobe Research Repository
http://www.latrobe.edu.au/library/research-and-grant-support/research-online

Bigby, C., Bould, E., & Beadle-Brown, J. (2017) Implementation of active support over time in Australia. *Journal of Intellectual and Developmental Disability* http://www.tandfonline.com/doi/full/10.3109/13668250.2017.1353681

Bould, E., Beadle-Brown, J., Bigby, C., Iacono, T (2016) The role of practice leadership in active support: impact of practice leaders' presence in services. *International Journal of Developmental Disabilities.* *http://www.tandfonline.com/doi/abs/10.1080/20473869.2016.1229524?journalCode=yjdd20*

Bigby, C., Bould., E., Beadle-Brown, J., (in press). Comparing costs and outcomes of supported living with group home in Australia *Journal of Intellectual and Developmental Disabilities*

Bigby, C., & Beadle-Brown, J. (2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference? *Journal of Applied Research in Intellectual Disabilities.* http://onlinelibrary.wiley.com/doi/10.1111/jar.12291/full

Bould, E., Beadle-Brown, J.,Bigby, C. (2016). Measuring practice leadership in supported accommodation services for people with intellectual disability: Comparing staff–rated and observational measures. *Journal of Intellectual and Developmental Disability* . http://www.tandfonline.com/doi/full/10.3109/13668250.2016.1259466?scroll=top&needAccess=true&

Bigby, C., & Beadle-Brown, J., (2016) Culture in better group homes for people with severe and profound intellectual disability. *Intellectual and Developmental Disabilities, 54, 316 331*

Bigby, C., Bould., E., Beadle-Brown, J., (in press, accepted May 2016) . Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual and Developmental Disability*

Bigby, C., Knox, M., Beadle-Brown, J., & Clement. T., (2015). 'We just call them people': Positive regard for people with severe intellectual disability who live in of group homes. Journal of Applied Research in Intellectual Disability. 28, 283–295

Beadle-Brown, J., Bigby, C., Bould, E. (2015). Development of an observational measure of practice leadership. *Journal of Intellectual Disability Research*.

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L, & Bradshaw, J (2015) Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*. 10.1111/jar.12200

Beadle-Brown, J. *et al.* (2012). *Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs*. NIHR.

Mansell., J., Beadle-Brown, J., & Bigby, C. (2013). Implementation of active support in Victoria, Australia: An exploratory study. *Journal of Intellectual and Developmental Disabilities,* 38(1), 48–58

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Schein, E. H. (1992). *Organizational culture and leadership* (2nd ed.). San Francisco: Jossey- Bass Inc.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 193-222.

McEwan, J., Bigby, C., & Douglas, J. (2014). What are Victorian Disability Standards really measuring, Research and Practice in Intellectual and Developmental Disability, 2, 283-295. 10.1080/23297018.2014.956385

Bigby, C., Knox, M., Beadle Brown, J., & Bould, E. (2014). Identifying good group homes for people with severe intellectual disability: Qualitative indicators using a quality of life framework. Intellectual and Developmental Disability, 52(5), 348-366. doi: 10.1352/1934-9556-.5.348

Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., Mansell., J (2012). Uncovering dimensions of informal culture in underperforming group homes for people with severe intellectual disabilities. *Intellectual and Developmental Disabilities*   50, 6, 452–467

Clement, T., & Bigby, C. (2010). *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation*. London: Jessica Kingsley Publishers.

Bigby C. & Bould. E. (2014) Guide to good group homes.
http://webstat.latrobe.edu.au/url/hdl.handle.net/1959.9/308955

Bigby et al, Making life good reports see
http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository?start=1&query=bigby

Beadle-Brown, J, Mansell, J., Ashman, B., Ockenden, J., Iles, R., & Whelton, B. (2014). Practice leadership and active support in residential services for people with intellectual disabilities: an exploratory study. *Journal of Intellectual Disability Research,* 58(9), 838 -850.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 193-222.

United Response – What does good look like
https://www.kent.ac.uk/tizard/resources/What_does_good_look_like.pdf

On line training resources

Every Moment Has Potential – An introduction to Active Support

Supporting Inclusion for Disability Support Workers

Thank you

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Living with Disability
RESEARCH CENTRE

Supporting inclusion of people
with cognitive disability