

# Active Support

**Roger J. Stancliffe**

*Research and Training Center on Community Living,  
University of Minnesota*

*Centre for Developmental Disability Studies  
University of Sydney*





# Group Homes – the Dominant Model of Community Living

- The majority of Australians with intellectual disability living in supported accommodation live in **group homes**.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Problems with Group Homes

- Community living provides better client outcomes and higher quality living environments than institutions
- Research shows that there is wide variation in outcomes and quality in the community.
- Group home residents with more severe disability have **low levels of participation in meaningful activity.**



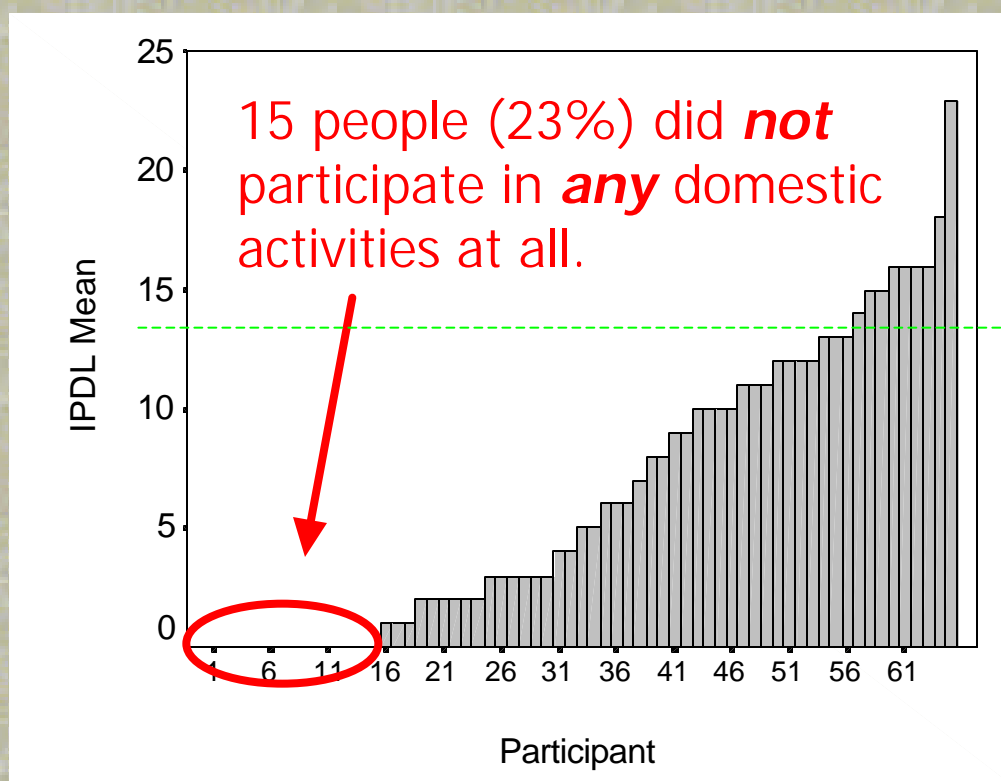
The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

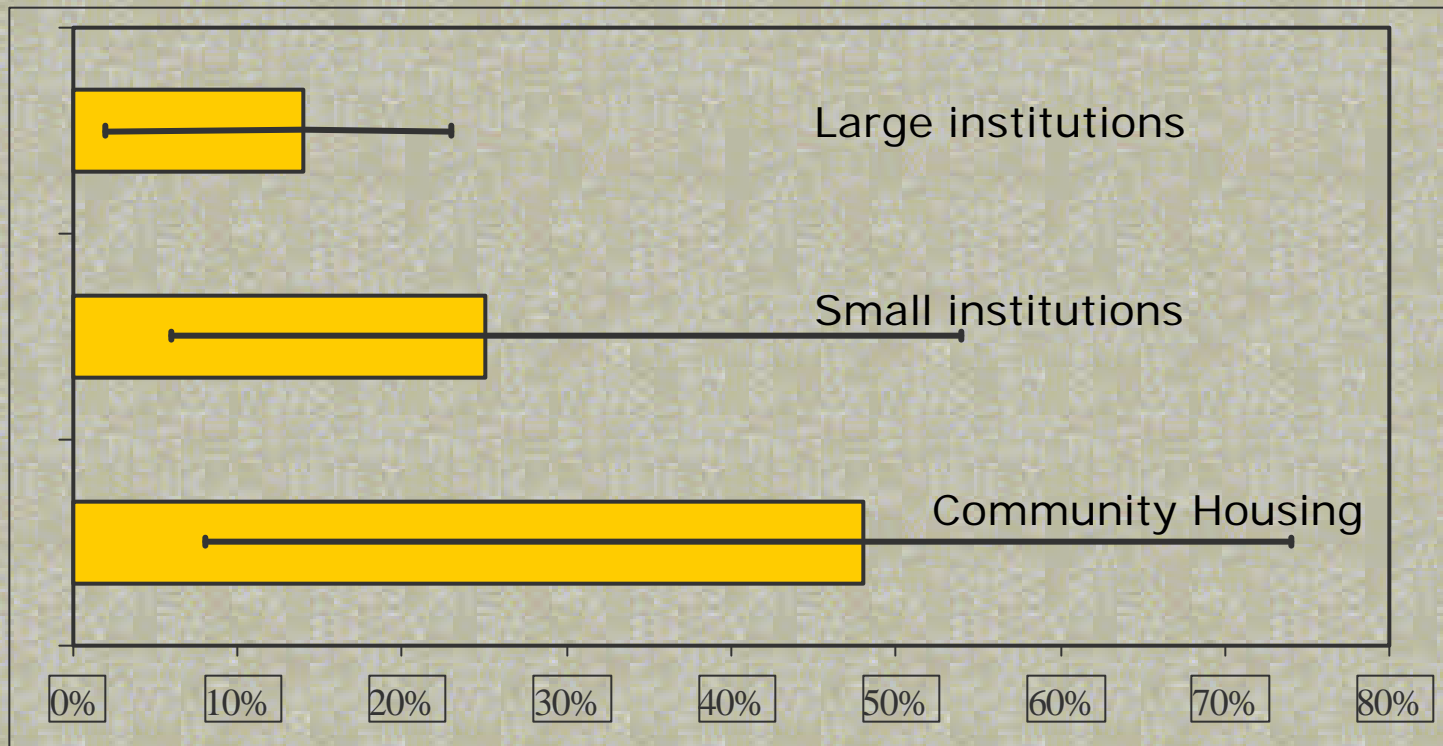


# Wide variation in Outcomes: Participation in Domestic Activities





# Overlap with institutional levels of activity: Engagement in residential settings in England and Wales.



Percent time residents engaged

From Mansell (2006), using data from Emerson & Hatton (1994)



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Problems with Underactivity

- Underactivity/passivity is associated with many serious problems:
  - Increased challenging behaviour
  - Physical health problems
  - Depression
  - Learned helplessness



The University of Sydney

**CDDS**

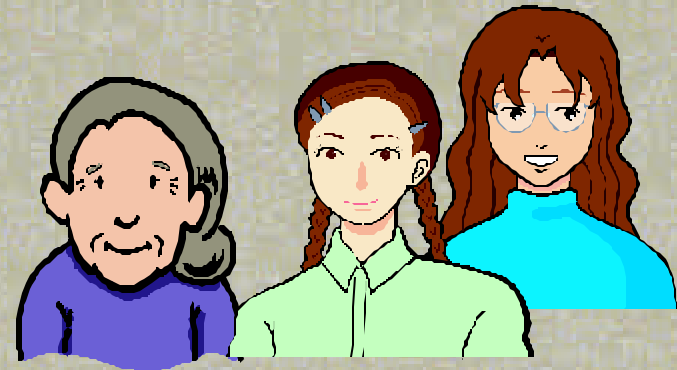
Centre for  
Developmental  
Disability  
Studies



# The “Hotel Model”



Staff



Residents

Residents are spectators in their own lives.  
 Staff feel like glorified domestics.



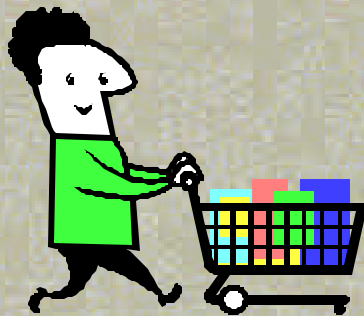
The University of Sydney

**CDDS**

Centre for  
 Developmental  
 Disability  
 Studies



# The Active Support Model



People participate in everyday activities with support



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Support and Participation

- Basic issue about *how* support is provided. Staff can do things *for* residents or can do those same activities *with* residents and support them to participate.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Support and Participation

- The primary focus is on **participation** with *whatever support is needed* (“partial participation”) so the person can take part in life *now*.
- There is no necessary expectation that the person will become more skilled or independent (a key difference from Active Treatment).



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

**RTC**



# Active Support DVD

ACTIVE SUPPORT

Video Directed by Edwin Jones

Welsh Centre for Learning Disabilities

Applied Research Unit

(Director, David Felce)



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support is not new: it was developed and tested in the UK

- Nimrod – Kathy Lowe et al.
- Andover – David Felce et al.
- Special Development Team – Eric Emerson et al.
- **Welsh Centre for Learning Disabilities – Edwin Jones et al.**
- Tizard Centre – Jim Mansell et al.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Research Findings Underpinning Active Support

- Direct observation in group homes shows that many people with severe intellectual disability spend lots of time doing *little or nothing*.
- These people need support to initiate and participate in activities.
- Staff can be trained to provide the support needed and so substantially increase residents' participation.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support: Strengths

- Well researched, evidence based, and has been shown to be effective in real group homes with real staff and residents
- Research mostly reports directly observed **outcomes** for staff and residents (benefits are directly measured and do not have to be inferred)
- Individualised
- Focuses on day-to-day reality, not one-off events or “pie in the sky”



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



## Jones, Felce, Lowe, Toogood et al., (1999)

- Jones et al.'s (1999) study, the first *experimental* evaluation of Active Support
- Examined its effects in five Welsh group homes.
- Jones et al. found increased observed levels of ***staff assistance*** to residents and increased observed ***resident engagement*** in activities.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

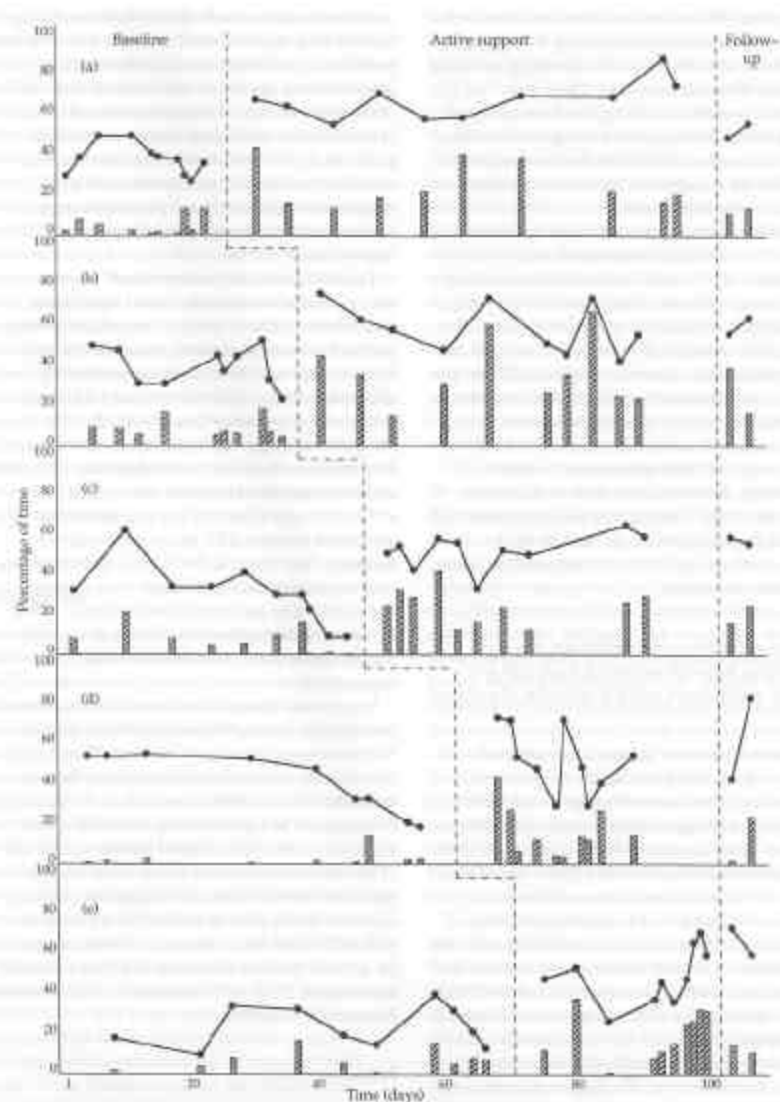


Figure 1. Percentage of time for which residents at houses (a) 1, (b) 2, (c) 3, (d) 4 and (e) 5 were engaged in activity (●) and received mail (cross-hatched bars) before and after the introduction of active support and at follow-up.

Jones et al., 1999: Results



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Jones et al., (1999)

- Large positive changes were evident for 18 of the 19 participating residents
- Changes were maintained in most houses at follow-up observations 8 to 12 months after the introduction of Active Support.
- The intervention not only positively affected staff behaviour, but also resulted in improved outcomes for residents. Such significant effects of staff training are not commonly observed.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support Procedures

- Detailed *staff training*:
  - 16 hours classroom training for the *entire staff* of the group home including the first-line manager
  - Individualized 1:1 on-site training for each staff member in supporting resident(s) to participate in activity.
  
- Straightforward paper planning tools to produce:
  - **Daily Activity and Support Plan**
  - Opportunity plans (for practising new skills)
  - Protocols



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Activity and Support Plan

Staff: Anne (A) and Colin (C)

Time	HELEN	S W	PAUL	S W	DIANE	S W	Household	Options
8:00	Eat breakfast	A	Eat breakfast	C	Eat breakfast	C	Put rubbish out Set table	
8:30	Clear dishes (on own)	A	Load dishwasher	A	Start laundry	C	Clear dishes Wash up/load dishwasher	
9:00	<b>Shopping</b>	C	Clean bedroom	A	<b>Shopping &amp; PO – pay phone bill</b>	C	Start laundry Unload dishwasher	Go for a walk
10:00	Unpack groceries	C	Start laundry <u>Have coffee with mother</u>	A Mrs F	Finish laundry	A	Hang out clothes	Water plants  Gardening



The University of Edinburgh

**CD**

Centre for

Developmental

Disability

Studies



# Activity and Support Plan

Staff: Anne (A) and Colin (C)

Time	HELEN	S W	PAUL	S W	DIANE	S W	Household	Options
8:00	Eat breakfast	A	Eat breakfast	C	Eat breakfast	C	Put rubbish out Set table	
8:30	Clear dishes (on own)	A	Load dishwasher	A	Start laundry	C	Clear dishes Wash up/load dishwasher	
9:00	<b>Shopping</b>	C	Clean bedroom	A	<b>Shopping &amp; PO – pay phone bill</b>	C	Start laundry Unload dishwasher	Go for a walk
10:00	Unpack groceries	C	Start laundry <u>Have coffee with mother</u>	A	Finish laundry	A	Hang out clothes	Water plants Gardening



# Active Support

- Active Support focuses on **what staff do** to support resident participation in individually meaningful activity.
- Staff plan and monitor daily activity with residents and interact with them in a way that encourages and supports their participation.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Doing *with*, not doing *for*

- Staff members' main job should be to **work directly with residents**. Active Support helps us refocus on this.
- Active Support is designed to provide a bridge to participation in everyday activities for people who lack the skills to participate independently.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

# *Active Support*

- Felce, D., Jones, E., & Lowe, K. (2002). Active support: Planning daily activities and support for people with severe mental retardation.
- In S. Holburn, & P. M. Vietze (Eds.), *Person-centered planning: Research, practice and future directions* (pp. 247-269). Baltimore: Paul H. Brookes Publishing Co.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

RTC



# CDDS Active Support Project

Implementing and Evaluating  
Active Support in Australia



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# CDDS Active Support Project

- With the support of **Dr Sandy Toogood** from the UK, CDDS conducted an Australian implementation and evaluation of Active Support in 2004.
- Active Support was introduced to five Australian group homes *one home at a time* by training the staff in each group home.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

RTC



# Project Report

- Available from CDDS website:  
[www.cdds.med.usyd.edu.au](http://www.cdds.med.usyd.edu.au)

[http://www.cdds.med.usyd.edu.au/html/ActiveSupport/Active\\_Support\\_Publicity.html](http://www.cdds.med.usyd.edu.au/html/ActiveSupport/Active_Support_Publicity.html)

and click on

[Active Support Report & Appendix](#)



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Journal Article

Stancliffe, R. J., Harman, A. D., Toogood, S., & McVilly, K. R. (in press).  
Australian implementation and  
evaluation of active support. *Journal of  
Applied Research in Intellectual  
Disabilities.*



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# CDDS Active Support Project

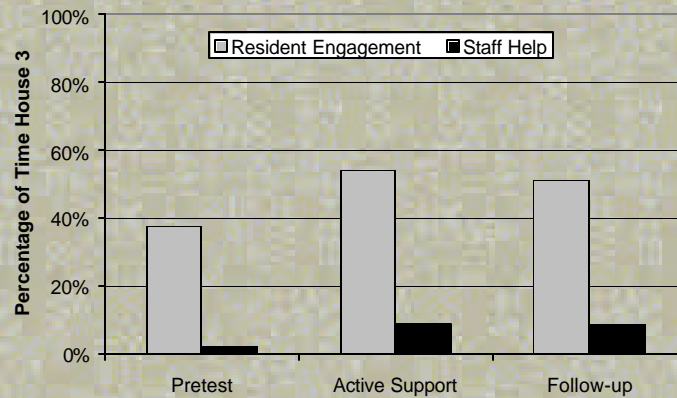
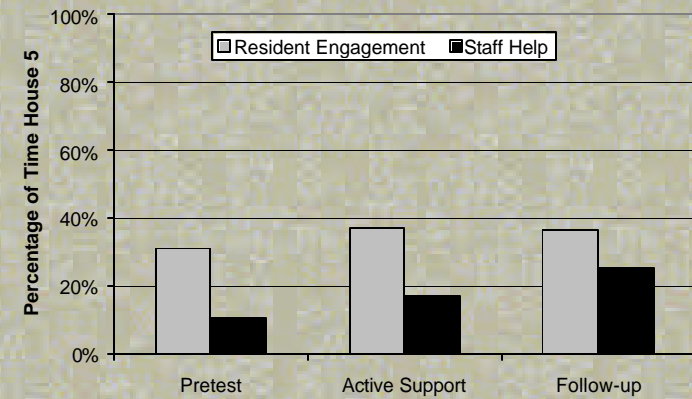
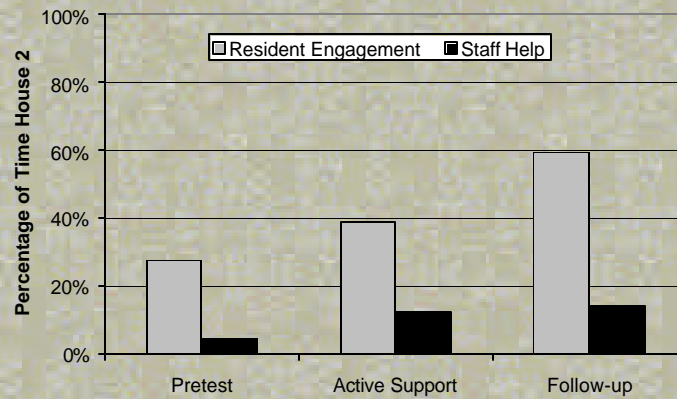
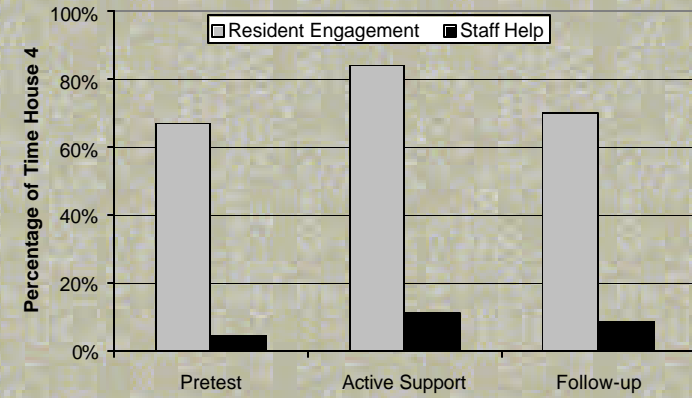
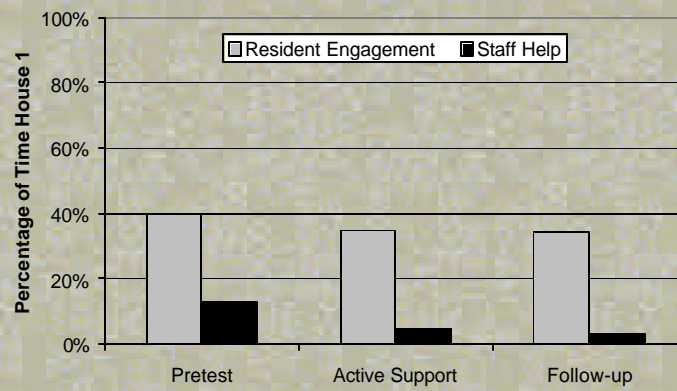
- Effectiveness was assessed using:
  - **direct observation** of
    - *resident engagement in activities*
    - *staff help for resident participation*
  - **written assessments** of other key resident outcomes (based on information from staff)
  
- Active Support was effective in increasing **staff help** and **resident engagement** in 4 of 5 group homes.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



The University of Sydney

## CDDS

Centre for  
Developmental  
Disability  
Studies

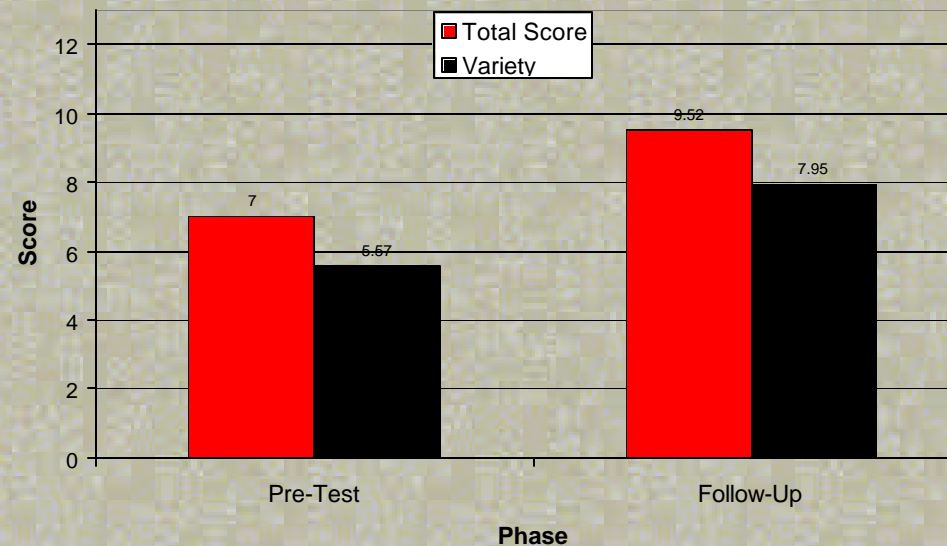


# Domestic Activities

(Staff Report)

- There was significantly greater participation in a wider variety of domestic activities:
  - Total score ( $p < .001$ )
  - Variety ( $p < .001$ )

Domestic Participation (Staff Report)



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

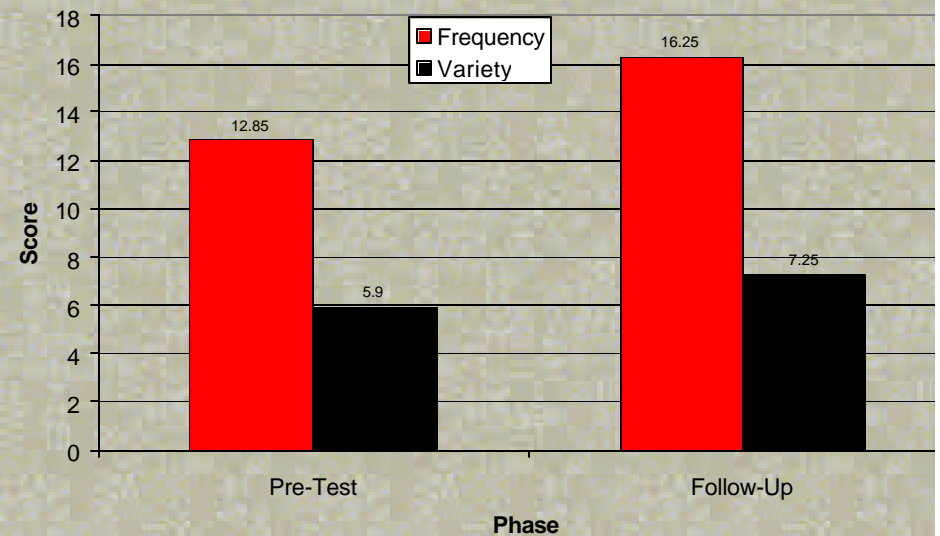


# Community Participation

## (Staff Report)

- There was more:
  - frequent ( $p < .01$ ) &
  - varied ( $p < .01$ )community participation

Community Participation (Staff Report)



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# CDDS Active Support Project: Additional Findings

- There was no significant change in **choice**, **challenging behaviour**, or amount of **contact with family or friends**.
- In one way, the choice finding is reassuring, in that Active Support could potentially be *misused* by using daily scheduling of activities *rigidly* as a method of staff control over residents' lives, so reducing resident choice.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# CDDS Active Support Project: Additional Findings

- Nonsignificant trends toward:
    - **reduced depression** ( $p = .064$ , two-tailed)
    - **increased adaptive behaviour** ( $p = .079$ , two-tailed)
- appear to warrant further investigation.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Factors Associated with Increased Client Engagement

- We examined:
  - The association between *Change in Engagement and Adaptive Behaviour*
  - The association between *Change in Engagement and Change in Staff Help*



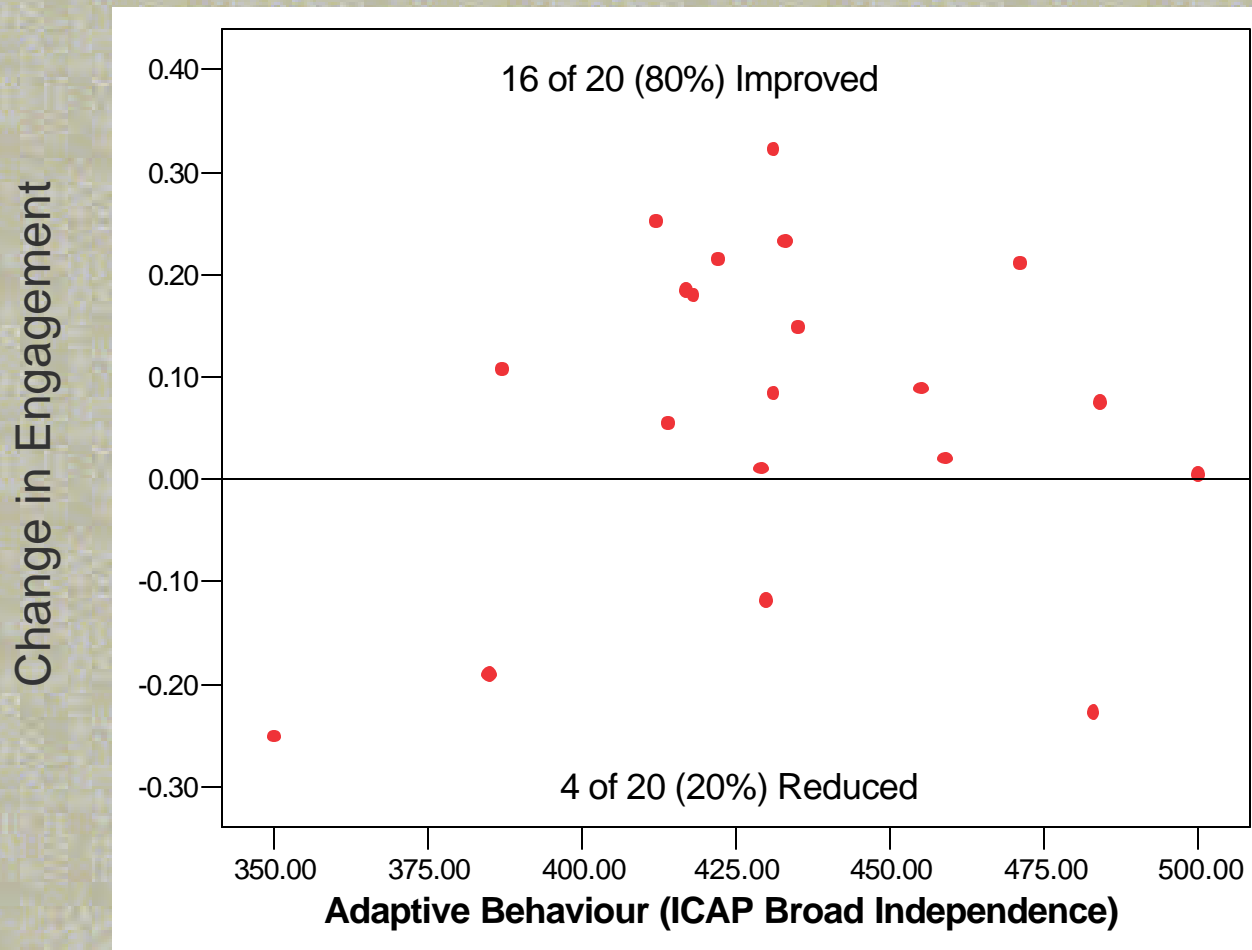
The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Change in Engagement and Adaptive Behaviour: Pre-Test to Post-Test



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Correlation: Adaptive Behaviour & Change in Engagement

- pre-test to post-test  $r = .13$ ,  $p = .58$
- pre-test to follow-up  $r = -.18$ ,  $p = .45$
- Suggests that **the effectiveness of Active Support is independent of the person's level of adaptive behaviour.**



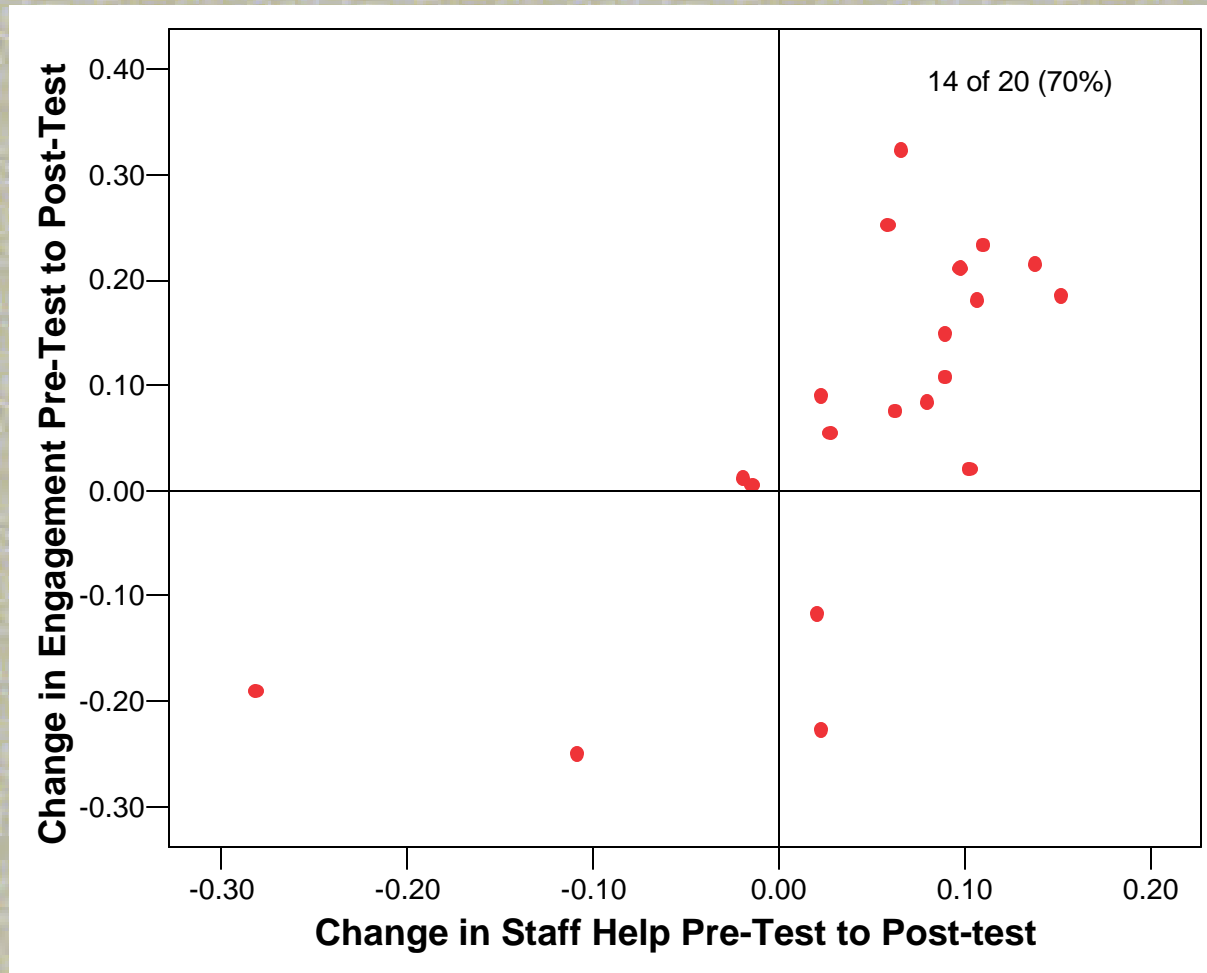
The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Change in Engagement and Change in Staff Help



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Correlation: Change in Engagement and Change in Staff Help

- Pre-test to post-test:

- $r_s = .73, p = .000$

- Pre-test to follow-up:

- $r_s = .53, p = .01$

- These correlations show that **increases in the amount of staff help were significantly associated with increases in resident engagement** (and *decreases* in staff help with *decreases* in engagement).



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support in Australasia

- Projects under way or **planned** in:
  - Australian Capital Territory
  - New South Wales
  - Victoria
  - Tasmania
  - **South Australia**
  - **Queensland**
  - **New Zealand**



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Scale of Australasian implementation

- Widespread interest but limited implementation.
- Mostly in small non-government organizations.
- One major train-the-trainer project in Victoria with planned **statewide roll out**, and a similar project being planned in Queensland.



The University of Sydney

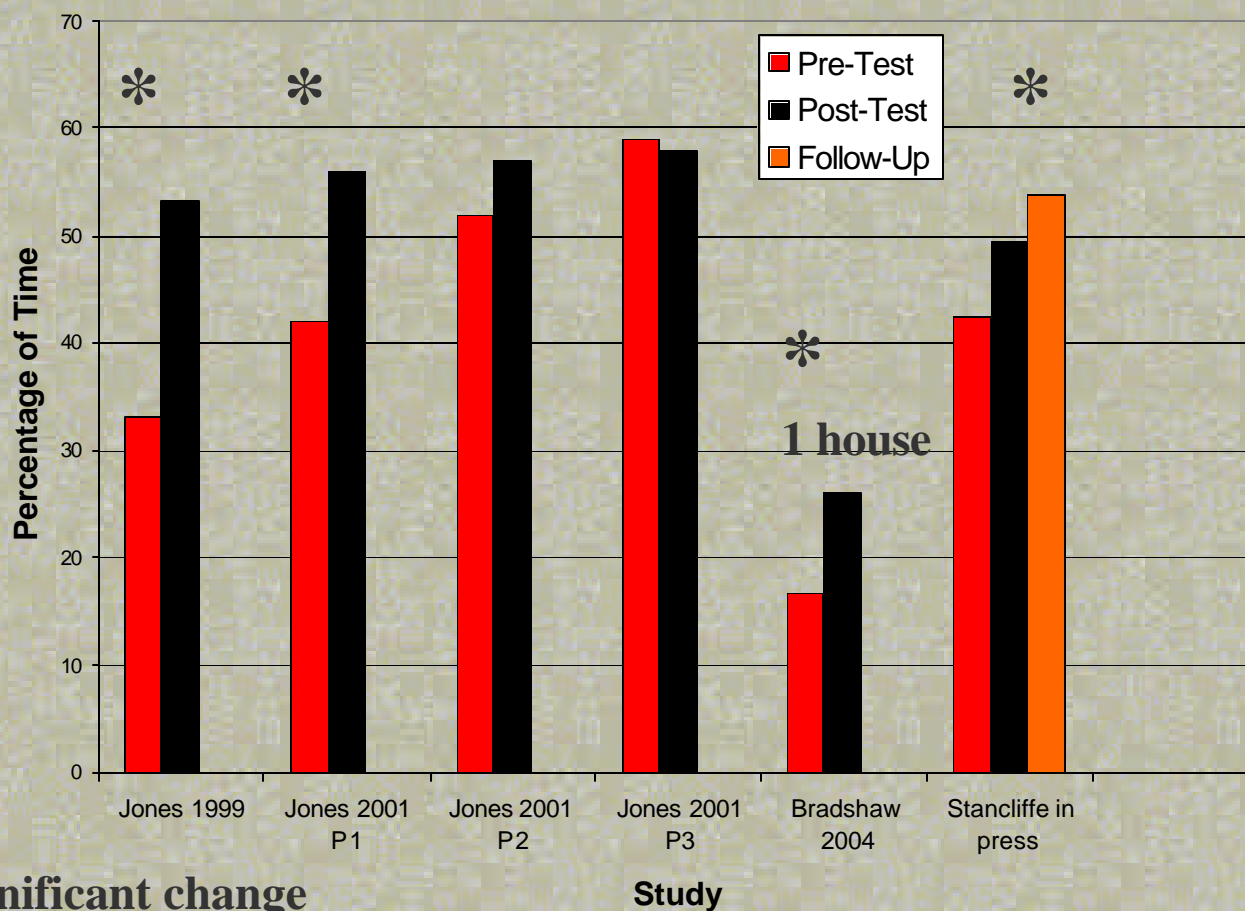
**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Making Active Support More Effective

Engagement Before and After Active Support



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Making Active Support More Effective

There is a need to identify:

- the features of training and implementation
- the characteristics of staff, settings and trainers

that relate to more successful outcomes.

For example, some agencies have been working on:

- integrating Active Support more fully with individual planning
- harmonising Active Support record keeping so paperwork is reduced and the same information is only recorded once



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



## Other Areas for Further Development

- Applying Active Support techniques more fully to community participation, social interaction etc. so there is not an overemphasis on domestic activities
- Focusing on identifying and supporting individually preferred activities rather than just activities
- Increasing resident control over which activities they participate in and when (e.g., pictorial schedules with choice)
- Finding a balance between enough paperwork for planning, consistent implementation and monitoring and too much paperwork
- Ensuring consistent long-term implementation, with agencies having the capacity to train new staff as required.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Areas for Further Development

- Future research should focus on:
  - applicability of Active Support to people with milder disabilities
  - individuals with intellectual disability living in the family home
  - non-residential services (e.g., day programs)
  - services for people with brain injury, dementia, and physical disability could also be explored
  - the role of both teamwork and management appear to be crucial but are not well understood.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support Resources

Series of six training booklets by Edwin Jones et al.

- 1 Overview
- 2 Activity & Support Plans
- 3 Opportunity Plans
- 4 Teaching Plans
- 5 Individual Plans
- 6 Maintaining Quality



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support Resources

- 25 minute Active Support video/DVD directed by Edwin Jones.



The University of Sydney

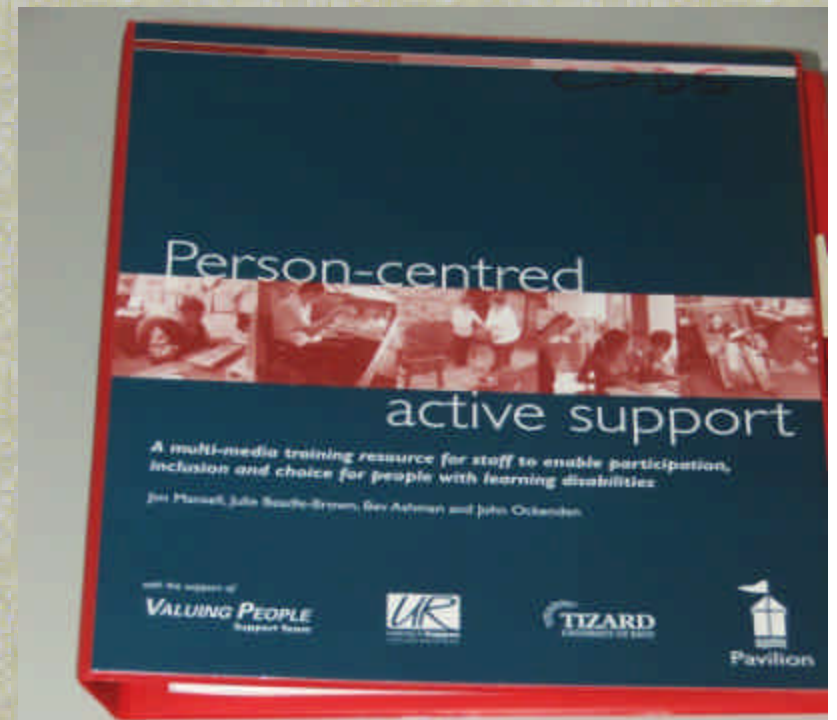
**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support Resources

- *Person Centred Active Support* by Mansell et al. (2005)
  - Includes video CD
  - OHP/Powerpoint slides
  - 6 modules
  - Handouts, worksheets
  - Photocopying waiver for person or organization purchasing
- Available from Pavilion Publishing, UK.



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies



# Active Support in the US

- No US implementation to date
- University of Minnesota's *Research and Training Center on Community Living* is developing a consortium with local providers to implement and evaluate Active Support in Minnesota



The University of Sydney

**CDDS**

Centre for  
Developmental  
Disability  
Studies

RTC



# Contact Details

Roger J. Stancliffe PhD

Clinical Associate Professor

Centre for Developmental Disability Studies

PO Box 6, Ryde NSW 1680

Tel & voicemail: +61-2-8878 0518

Fax: +61-2-9807 7053

Email: [rogerst@med.usyd.edu.au](mailto:rogerst@med.usyd.edu.au)

Web site: <http://www.cdds.med.usyd.edu.au/>



The University of Sydney

**CDDS**

Centre for

Developmental

Disability

Studies