Building competent support for people with severe learning disabilities and challenging behaviour

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Focus

- On housing for adults with learning disabilities +/- severe challenging behaviour
- Research on what staff do
  - Change in extent and quality since institutional days
  - How well matched staff attention is to service user needs
- Link between staff-to-user ratios and quality of outcome
  - Training staff to provide ‘Active Support’
- Comparing outcome across service models
  - ‘Congregate’ vs. ‘non-congregate’ care for people with CB
  - Semi-independent living vs. fully staffed group homes
  - Targeted support and assistive technology
- Evidence-based design

Poor quality institutional care

- Major causes of concern:
  - low staff presence
  - low rates of staff attention to service users
  - low stimulation
  - absence of meaningful or constructive activity

  (Burg et al., 1979; Duker et al., 1989, Felce et al., 1980, 1986; Moores & Grant, 1976; Rawlings, 1985)

Poor quality institutional care

- Too little attention →
- Poor quality attention →

- Wright et al. (1974)
  - 16 children in 5 wards
  - 4 hours observation each
  - Received attention for 13 minutes (5.6% of time)
  - No attention for 227 minutes (94.4% of time)
  - 0.4% positive
  - 5.1% negative
  - 94.5% neutral

Poor quality institutional care

- Under-investment
- Difficulties in staff recruitment
  - Poor staff-to-service user ratios
- Medical/custodial models
- Low expectations/poor attitudes
  - Lack of support/stimulation
- Institutional environment

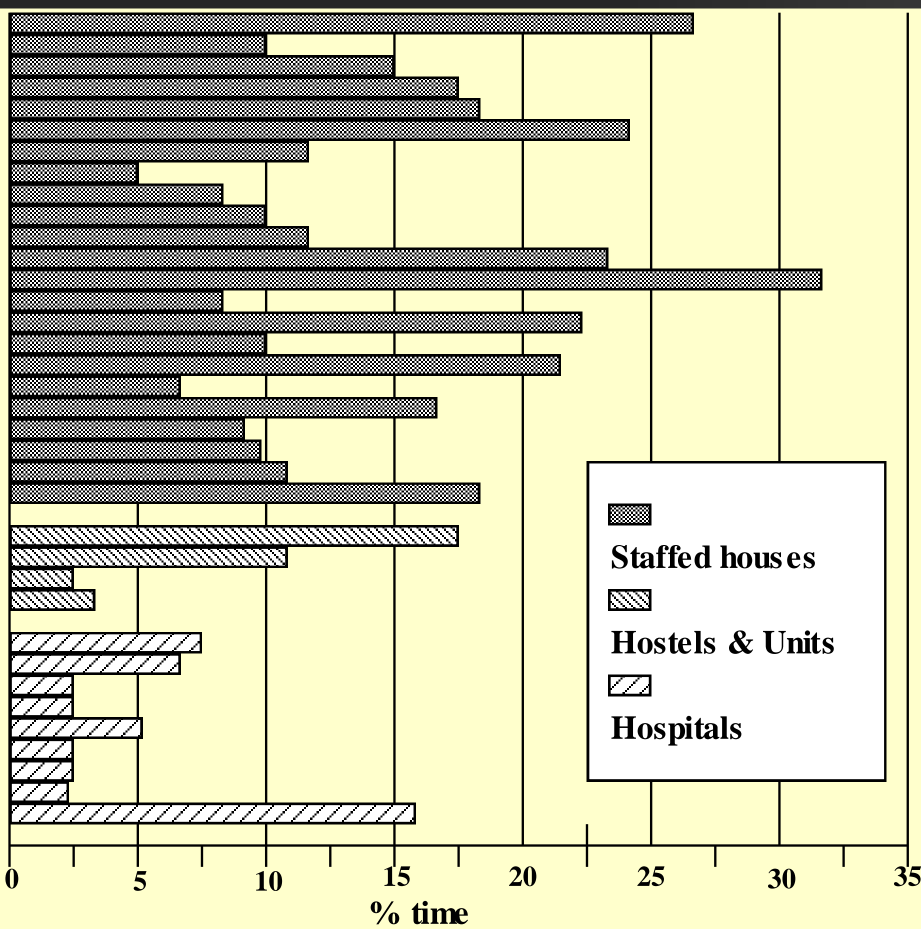
Reversal of institutional conditions

- Deinsitutionalisation in UK associated with increased resource investment…&
- Improved staff-to-service user ratios
- Social care, ‘ordinary life’ model
- Normalisation ideology … inclusion
- Community integration, normative buildings/ locations/furnishings
- Trend towards smaller, more staff intensive settings over time (Felce & Perry, 2004)

Community housing & supported living

- Given the extent of reform, has it been accompanied by improved staff performance?
  - extent of attention
  - quality of attention
  - balance of staff activities
  - more intense for people with higher needs for support

Emerson & Hatton (1996) review of level of staff attention to service users



- % of time attention received by service users:
  - 4.2% (3%-16%) in hospitals
  - 9.3% (2%-17%) in community units/ hostels
  - 14.8% (5%-31%) in houses

Extent & quality of attention (% of time per service user)

	Other Attention	Support	
		Encouraging	Assistance
Rawlings 1985	7%	6%	
Hewson/Walker 1992	19%		2%
Felce/Perry 1995	12%		3%
Felce et al. 1999	12%		4%
Felce et al. 2002	14%		6%

Extent & quality of attention (% of time per service user): Special services/samples

	Other Attention	Assistance
Andover Felce et al. 1986	6%	18%
SPT Mansell 1995	15%	9%
S/P MD Hatton et al. 1995	7% specialist 11% ordinary	20% 5%
CB Felce et al. 1998	12%	10%
S/PMD Emerson et al. 2000	15%	1%
CB Robertson et al. 2004	11% congregate 7% non-congregate	6% 4%

Staff activity (% time per staff)

	Felce et al. 1998 Hospital	House	Felce et al. 2002 House
Attending to service user	16%	21%	31% (3-61%)
Service user-related act	11%	7%	5% (0-19%)
Sub-total	37%	28%	36%
Household act	15%	23%	19% (1-40%)
Administration	7%	9%	7% (0-29%)
Staff-staff interaction	26%	17%	10% (0-24%)
'Other'	25%	23%	27% (6-70%)

Relationship between service user support needs and the extent of attention they receive

- Most studies show an absence of association

- Some show that people who are more able (i.e., have lower support needs) get more attention and assistance

(Hatton et al., 1996; Felce et al., 2002; Felce et al., 2003, Robertson et al., 2004)

Relationship to service user needs (Felce & Perry, 2004)

Houses	Group 1 (n=12)	Group 2 (n=13)	Group 3 (n=13)	Group 4 (n=13)
Mean ABS	84	154	197	239
Mean ABC	52	37	20	26
Attention received (% time)	12%	19%	16%	19%
Assistance received (% time)	2.6%	2.5%	1.7%	2.2%

Conclusion: Staff performance

- Levels of attention have gone up - but high variation between settings
- Attention is still largely “neutral”
  - people receive low levels of support (assistance, encouragement)
- About a 1/3 of staff time is directly related to supporting service users
- Staff do not give more help to people who need more support
  - people with lower skills do not receive more assistance
- Some services for ‘special’ populations show evidence of increased support

Focus

- Link between staff-to-user ratios and quality of outcome
- Link between staff performance and quality of outcome
- Increasing effective support
  - Training staff to provide ‘Active Support’

Impact of staff-to-service user ratios on how much attention people receive

- Higher staff-to-user ratios result in service users receiving more attention in some studies
  - (e.g., Felce et al., 2002, 2003, Robertson et al., 2004
- but not in others
  - (e.g., Hatton et al., 1996, Emerson et al., 2000)
- But also higher ratios result in a reduction in the extent to which each staff member attends to service users (i.e. diminishing marginal returns from adding staff)
  - (e.g., Mansell et al., 1982; Felce et al., 2002)

Impact of costs on service user outcomes

- A high proportion of costs is accounted for by staff-to-service user ratios

… and ….

- there were "no links between costs and outcomes" (Cambridge et al., 1994)
- no association between service costs and any indicator of quality (Hatton et al., 1996)
- association between costs and outcome weak (Emerson et al., 2004)

Impact of staff-to-service user ratios on service user outcomes

- Engagement in activity was associated with the extent of attention or assistance received, but not directly related to staff-to-service user ratios (Felce et al., 2002; 2003; Perry & Felce, 2005)
- Choice and involvement in household management found to be related to lower staff-to-service user ratios (Felce et al., 2000; 2002, Stancliffe & Keane, 2000)

… or unrelated to them (Perry & Felce, 2005)

Impact of staff-to-user ratios on service user outcomes

- Some evidence that more frequent community activity is related to higher staff-to-service user ratios (Emerson et al., 2004, Felce et al., 2002)

… but …

- Stancliffe & Keane (2000) found the opposite

(Note: May differ depending on ability of service users)

Conclusion: Impact of resource or staff input

- Clearly, having sufficient staff is important
- But limited evidence that there is a straightforward relationship between more resource intensive services and quality of outcome
- Certainly, resource input should not be viewed as a proxy for outcome
- Better to view it as getting the balance right between too few and too many staff

But staff are important: Impact of staff performance on outcome

- Increased staff attention or assistance linked to service user:
  - engagement in activity (Emerson et al., 2000, Felce et al., 1999, 2002, 2003, Hatton et al., 1996, Perry & Felce, 2005)
  - community activities (Perry & Felce, 2005)
  - choice and autonomy (Perry & Felce, 2005)
- Staff orientation and working methods are important
  - Implication for staff training

The problem in support

- staff availability does not necessarily translate to people receiving more support
- people with lower adaptive behaviour do not receive differentially more support from staff
- staff attention is typically conversation
- too little from the perspective of someone with severe intellectual disabilities is assistance to do activities (particularly non-verbal assistance) …

… therefore …

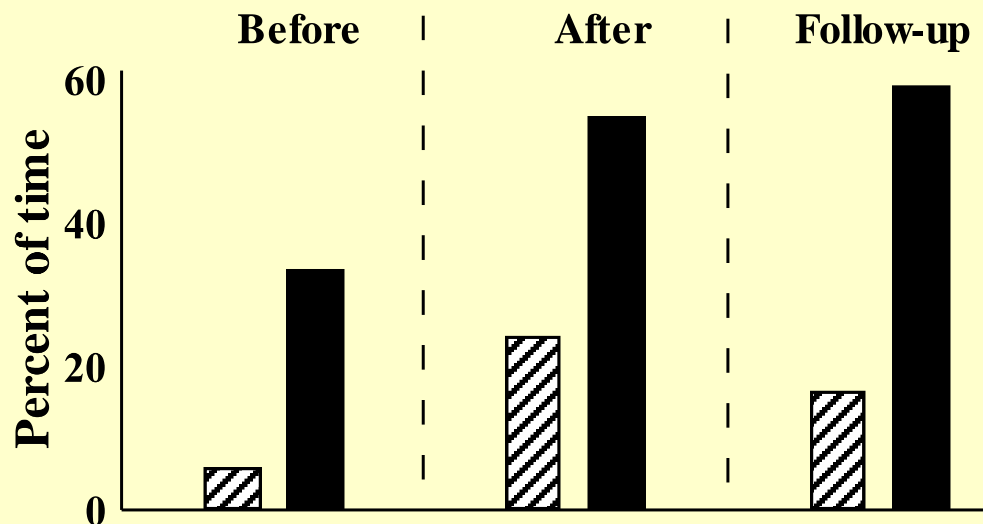
The problem of under-occupation

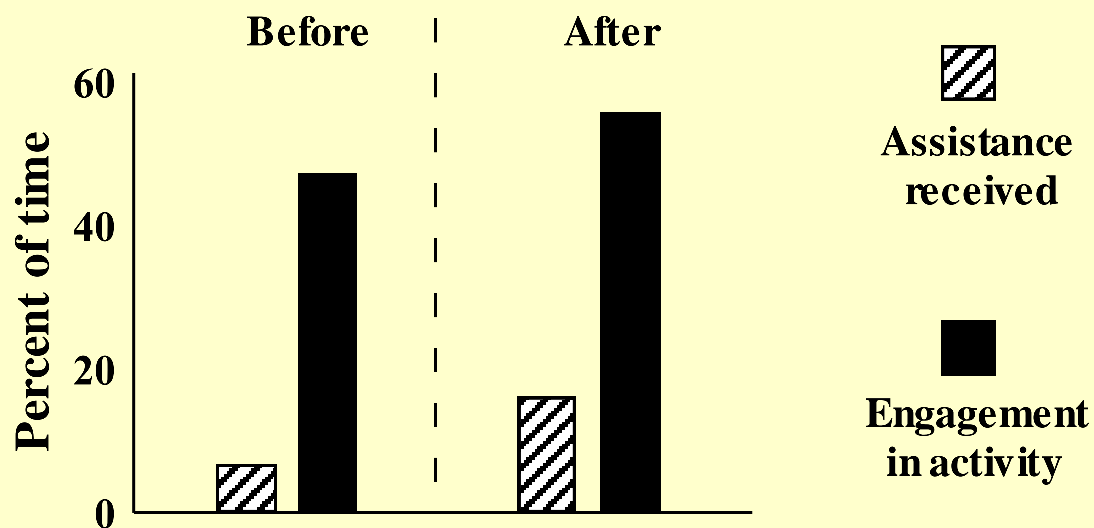
- people with lower adaptive behaviour have consistently been found to
  - have fewer activity opportunities (in the home and the community)

  … and to ….

  - spend substantial periods of the day unoccupied

Training staff to provide 'Active Support'





Conclusions: Training staff to provide ‘Active Support’

- the 2 WCLD studies had consistent results:
  - service users received more assistance
  - people with greater disabilities received more assistance
  - service users were more constructively engaged
  - increases in engagement were related to increases in assistance
  - people with lower adaptive behaviour scores derived most benefit

Conclusions: Training staff to provide ‘Active Support’

- Research on Active Support has been replicated in studies by other researchers in UK (e.g., Mansell, Toogood) and Australia (e.g., Stancliffe) & elsewhere

(e.g., see special issue of the *Journal of Intellectual & Developmental Disabilities*)

Conclusions: Staffing and staff performance

- No longer a resource input problem
- Users are getting more attention (but variable)
- However, still questions about quality of support and matching support to need
- In the UK, ‘ordinary life’ model did not stress need for staff to learn how to give effective support
- Nor do subsequent refinements (e.g., supported living, self-directed support etc.)

Conclusions: Staffing and staff performance

- ‘Active Support’ illustrates potential for improvement (i.e., to provide more effective support without increasing resource input)
  - so do other approaches to training carers
- Staff training may be the ‘missing link’ between resource input and quality of outcome

Focus

- Comparing outcome across service models
  - ‘Congregate’ vs. ‘non-congregate’ care for people with CB
  - Semi-independent living vs. fully staffed group homes
  - Targeted support and assistive technology

Evaluating the costs & outcomes of housing for adults with severe CB: Congregate vs Non-congregate housing (Robertson et al., 2004)

- Adults with severe intellectual disability
  - 25 living in congregate houses (majority display challenging behaviour)
  - 25 living in non-congregate houses (minority display challenging behaviour)
- Matched on ability and severity of challenging behaviour
  - Also similar % with mental illness and autism
- All living in ‘ordinary’ houses supporting 2 - 6 adults

Results

- Cost of non-congregate provision was 83% that of congregate provision
- Non-congregate provision was associated with
  - Lower staffing ratios & less contact from staff

… but also with

  - Less use of medication and physical restraint
  - More hours per week of scheduled activity
  - Less injury to co-tenants

Results

- The greater the % of people who challenge that live together, the
  - greater cost
  - less choice
  - more institutional routines
  - greater drug use for control of CB
  - more injuries
  - smaller social networks

Results: Treatment and management of challenging behaviour

- Very few (10%) had a written programme other than for reactive management strategies (i.e., only 5/50 had a written plan to reduce challenging behaviour)
  - No difference between setting types
- Congregate settings linked to increased use of physical restraint
- Greater use of restraint associated with greater PRN sedation and use of seclusion
- Use of physical restraint associated with the proportion of staff who had been trained in physical restraint (not with level of challenging behaviour)

Conclusions & Implications

- It is cost-ineffective to congregate together people who challenge
- Congregation ≠ specialism
- English policy (Mansell Report) recommends avoiding congregating together people who challenge
- In practice, UK has seen ….
  - Provision of 'specialised' CB houses
  - Growth of private institutions & out-of-area placements

Semi-independent living vs. fully staffed group homes (Felce et al. 2008)

- 35 ‘matched’ pairs in FS & SI
- FS = staff cover when users present
- SI = no staff cover for 28+ hours/week when users present
- Measurement of quality of life outcomes & costs

Results

- Advantages of FS
  - More people lived in a home with a garden
  - Greater emphasis on healthy lifestyle
  - Fewer money problems
- Advantages of SI
  - Staff did more teaching & arranged more activities
  - More choice
  - Greater independence in community activities
  - Lower costs
    - Total weekly costs of care = £379 vs. £1,076

Results

- No difference between FS and SI
  - % underweight, overweight or obese
  - % inactive
  - % receiving various health checks
  - risk of accidents, injuries, exploitation or abuse
  - perceived safety
  - frequency of community activities
  - size of social network
  - frequency of visits to and from family or friends
  - perceived loneliness
  - lifestyle satisfaction

Conclusions and implications

- SI advantageous to independence
  - People who can do a lot to look after themselves need fewer staff and can exercise more control and be more independent
- FS advantageous to protection
- If support could be targeted within SI to provide equal protection, then SI would be cost:effective
- … and then …current expenditure in some FS homes could be reallocated to help fund service expansion or more intensively staffed services

Targeted support & assisted technology

- Targeted support employs assistive technology with a hub for 2-way communication and staff re-allocation to target staff input when needed
  - some core + peripatetic; some peripatetic only
- 63 people living in 25 settings
  - Age range 21-84 years
  - ABS range 27-306
  - ABC range 0-73

Results

- 23% reduction in staff hours
- Higher Health Scale scores (healthier lifestyle)
- Otherwise no change in
  - % underweight, overweight or obese
  - % active/inactive
  - % receiving various health checks
  - perceived safety/risk
  - social and community activities
  - Independence in household activities
  - choice

Evidence-based design: providing effective services

- To achieve a typical quality of life, need to offer typical conditions of life
  - individual or small group living
  - Typical housing, furnishing, equipment & access to rooms
  - community location & access to amenities
  - close to social ties and connections
- Congregation does not make a 'specialist' service and may inhibit achieving desired outcomes
- High staffing does not make a 'quality' service and may inhibit achieving desired outcomes

Evidence-based design: providing effective services

- Need sufficient carers
- Need to target support according to need
  - More flexible models (e.g., peripatetic)
  - Capable of being there when needed but not when not
  - Assistive technology may help manage risk
- Also need competent carers

Evidence-based design: providing effective services

- Competent carers can provide
  - individualisation of approach
  - routine opportunity + assistance to engage in constructive activity (e.g., Active Support)
  - understanding of aetiology of challenging behaviour & implications for carer interaction
  - ability to teach (i.e., to accelerate skill acquisition in key areas like autonomy and communication)
  - ability to implement behaviour development plans
  - ++

Evidence-based design: providing effective services

- Effective evidence-based professional input & treatment
  - health checks, healthy living and health promotion
  - medication (but only if therapeutic)
  - psychological therapies (e.g., functional analysis, positive behaviour support, CBT)
  - augmentative and alternative communication
  - ++