



Research Funding Scheme

Wales Office of Research & Development for Health and Social Care

IF YOU INTEND TO SUBMIT A FULL APPLICATION UNDER THE RESEARCH FUNDING SCHEME 05-06 PLEASE REFER TO THE GUIDANCE NOTES THAT HAVE BEEN ISSUED WITH THIS FORM
Full application form

Project title:

Increasing independence and assistive technology: quality of life, acceptability and costs

Reference number: ReF06/2/233

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1. Title of investigation *(not exceeding 120 characters)*

Increasing independence and assistive technology: quality of life, acceptability and costs

2. Lay summary *(not exceeding 300 words)*

Staffed community housing for people with learning disabilities provided in the wake of deinstitutionalisation tended to adopt a fully staffed model. Such services have average unit costs in excess of £50k p.a. Increased longevity is resulting in a growing number of adults with learning disabilities requiring support. This is putting pressure on resources. The estimated 1,500 additional places required in Wales have a revenue cost implication of over £75 million p.a.

Policy goals emphasize independence, choice, social inclusion and achieving balance between under- and over-protection by creating a culture of enablement. Research has indicated that some current provision may be overstaffed, overstaffing may inhibit independence and self-determination, and semi-independent living may be a cost-effective alternative to fully staffed homes for some people. However, these propositions have not been tested experimentally.

West Glamorgan Housing Consortium (WGHC) and Neath Port Talbot are proposing to change the way staffing is organized in their provision. Specifically, they intend to use assistive technology (telecare) and increase the deployment of peripatetic staff linked to specific support needs. Progressive implementation of this change across service networks within the territory which WGHC serves allows a natural experimental control evaluation to be undertaken of the new arrangements.

The primary focus of evaluation is on the total package costs of service input (including costs of staff, other accommodation inputs, day services and hospital and community professional input) and their quality of life outcomes (including social and community inclusion, independence, choice, health, safety, and consistency of support). A second, more limited goal is to gain the perspectives of staff and families about the acceptability of the new arrangements (for staff in relation to possible changes in job satisfaction, job stress, propensity to leave; for families in relation to changes in perceived adequacy and consistency of support).

3. Key terms and phrases

Learning disabilities, residential services, service reorganization, assistive technology, service costs, quality of life.

4. **Priority policy areas addressed by the research** (*please identify which areas this research covers*)

- Prevention and early intervention No
- Service organisation and delivery Yes
- Chronic disease* management Yes

*(management of chronic conditions is a more appropriate term because learning disabilities is not a disease).

5. **Research area** (*please identify which areas this research covers*)

- Health No
- Social care Yes
- Health and social care No

6. **Priority policy areas - discussion**

Please indicate (in no more than 500 words) how this research fits in with the priority policy area(s) that you have indicated above, and the Welsh Assembly Government policy context of the project

Designed for Life focuses on health and wellbeing (not illness) and the provision of safe and effective services which promote service user independence and get the most from resources. It is anticipated that the equivalent statement for social care (aka *Designed for Care*) will emphasize similar criteria. The current study sets out an investigation of the cost-effectiveness of an innovative approach using assistive technology and increased peripatetic staff deployment, applied to a life-long disabling condition which makes individuals significant users of health and social care (on average, local authorities planned to spend £15,220 per 'open learning disability case' in 2004/5, expenditure on users of supported accommodation services is considerably more, over £50k p.a.).

The thrust of the change in service delivery to be evaluated is in line with current Welsh policy principles. Section 7 Learning Disability Guidance on Service Principles and Service Responses (WAG, 2004) calls for a range of community services and supports to be available and for them to promote health, independence, citizenship, relationships and lifestyles. It recommends that support may need to be provided flexibly and when it is most needed rather than when provider organizations can deliver it. The innovation to be evaluated has the potential to expand the options available to adults with learning disabilities. It offers greater flexibility of support targeted towards individual needs.

7. Timetable and milestones

Please give an indicative timetable for the project including key milestones and outputs (*please add more rows if necessary*)

Date ¹	Action and/or outputs
2006	
April	Seek ethical approval for initial phase of study. Collate measures. Train WGHC data collectors. Achieved ¹
May/June	Pre measures in Networks 1&2 (n=40) [WGHC data collectors] Achieved ¹
July	Implementation of intervention in Network 1 Currently in progress ¹
Oct/Nov	Post measures Network 1 Pre measures Networks 2&3 (n=60) [WGHC data collectors] [R&A 1A]
2007	
March	Implementation of intervention in Network 2 Construct SPSS database – ongoing data entry.
July	Post measures Network 2 Pre measures Networks 3&4 (n=60) [R&A 1A]
Oct	Implementation of intervention in Network 3
2008	
Jan/Feb	Post measures Network 3 'Pre' measures Network 4 (n=40) [R&A 2]
Feb-April	Analysis, write-up, feedback and dissemination [R&A 2]

¹ The first stages of the evaluation (until 1/11/06) will be funded by the West Glamorgan Housing Consortium. Dates relating to this period are included here to provide context for the current proposal. Figure 1 (question 8) should clarify this.

8. Please give a detailed project proposal (no more than 2500 words) to include the following sections:

Aims, objectives and purpose

Background Replacing institutional care with community provision for adults with learning disabilities has involved increased staffing and costs (Felce & Emerson, 2005). Unit costs average £50-60k p.a. (Curtis & Netten, 2005). Service expansion is required to prevent even greater reliance on family care arising from increased prevalence due to increased longevity (Felce, 2004). The Learning Disability Advisory Group (2001) estimated that 1,500 additional places were required in Wales with a revenue cost implication of over £75 million p.a. Current policy suggests that services should be person-centred, responsive to need and promote health, choice, independence, citizenship, relationships and lifestyles (WAG, 2004). As staff costs constitute 60-80% of accommodation costs (Curtis & Netten, 2005), it is important for staffing input to relate to resident support needs and to quality of outcome.

Wales is similar to other countries in the UK in having growing numbers of adults with learning disabilities and a static supply of out-of-family support. Families have prolonged caring responsibilities which have been increasing. However, the capacity of families is clearly limited by ageing. Affordable alternative support arrangements are required which deliver high quality outcomes in line with policy.

Unit costs and staff-to-service user ratios vary considerably across residential services and only a minority of this variation is associated with service user characteristics (Felce et al., 2003). Association between resource input and the outcomes espoused by policy has rarely been found (Felce & Emerson, 2005). In fact, higher staff-to-service user ratios have been associated with individuals exercising less choice, participating less in household activities, and using community amenities less independently (Felce et al., 2000; Robertson et al., 2001; Stancliffe, 1997).

Evaluation of semi-independent living (i.e., partial staff support) compared to fully staffed group homes has found improved outcomes (more varied social networks and greater independent community use, choice and participation in household routines) at lower cost (Perry et al., 2006; Stancliffe & Keane, 2000).

Experimental Innovation Although existing research provides evidence that moving from traditional staff patterns towards more flexible semi-independence would be feasible and cost effective, such a move has not been experimentally evaluated. An opportunity to do this arises from proposed developments within West Glamorgan Housing Consortium (WGHC), a provider of supported accommodation in Neath Port Talbot (NPT) and the City and County of Swansea. WGHC and NPT are piloting the application of assistive technology (telecare) to help people to live safely but more

independently. Having trialled this with 12 service users, they are now reorganising service delivery within the two service networks which span NPT. Each network serves about 20 adults with learning disabilities. This may be followed by extension to Swansea. Change in service delivery entails introduction of assistive technology coupled with restructuring of staff support. At the centre of the assistive technology is a technologically sophisticated yet user friendly hub which manages a system of alarms and sensors such as bed/chair occupancy sensors, epilepsy and enuresis monitors, inactivity sensors and temperature sensors. The hub is also an intruder/smoke/carbon dioxide and flood alarm, a medication reminder and it allows two-way communication between residents and a peripatetic team who will monitor hubs remotely and provide episodic support to individuals when it is needed. While some existing staff will remain allocated to certain residential homes, the majority will be reassigned to new peripatetic teams.

Considering the 20 people supported in the first network to undergo change, currently a quarter live in homes with the constant presence of two staff, half live in homes with the constant presence of one staff and a quarter live with partial staff support. After change is implemented, all will live with assistive technology: a quarter in homes with the constant presence of one staff with episodic additional peripatetic input and the remainder semi-independently. It is envisaged that staff support would reduce by 10-20% overall.

Research Aims The primary aim is to evaluate the costs and quality of life consequences of living with assistive technology but less intensive staff support. A secondary more limited aim is to gain the views of staff and families about the acceptability of the new arrangements. Hypotheses: the null hypothesis states that there will be no differences between the new and pre-existing arrangements. One-tailed alternative hypotheses state that costs in the new arrangements will be less and outcomes related to choice and independence increased. Two-tailed alternative hypotheses are stated in relation to other outcomes and staff and family views

Design and methodology

Figure 1 Proposed experimental design

	T1		T2		T3		T4
Group*	Apr 06	July 06	Oct 06	Mar 07	July 07	Oct 07	Jan 08
Network 1	Pre	X	Post				
Network 2	Pre		Pre	X	Post		
Network 3			Pre		Pre	X	Post
Network 4					Pre		Pre

* n=20 in each group

X=introduction of service delivery change

Research sample and experimental design The sample would be 20 service users in each of four WGHC networks. The design combines a multiple time series and an experimental control group comparison, with staggered introduction of the intervention – see Figure 1. The design allows 2 comparisons: replicated within-subject change for groups of n=20, and an experimental (n=40) control (n=40) between groups comparison. A recently completed study of semi-independent living and fully-staffed groups (both n=35) (Perry et al., 2006), using similar measures with a similar client group, suggests that the proposed sample size would have power to find significant differences.

Measurement The proposal replicates the methodology of a study on the costs and quality of life outcomes of semi-independent living and fully-staffed group homes (Perry et al., 2006). Quality of life is a multi-dimensional construct (Schalock et al., 2002). Moreover, it has been argued that service evaluation is best conducted through the use of a range of objective measures (Felce, 1997) rather than a single lifestyle satisfaction scale. Therefore, the proposed methodology employs a multiple measurement approach. While this may appear to be unwieldy, experience of using this measurement approach over several projects has shown it to be feasible. The following measures will be used:

(i) Setting Descriptors: The modified version of the Residential Services Setting Questionnaire used by Perry et al. (2006) will be administered. This was based on that used by Emerson et al. (2000). The questionnaire covers: the size and location of the setting, age, gender and general ability of the people served, homelikeness of the setting, the number and qualifications of staff, professional input, and the stability of residence and of living companions in the preceding 3 years.

(ii) Participant Descriptors: Information on individual characteristics (age, gender, etc.) plus skills using the Adaptive Behavior Scale – Residential and Community 2nd edition (Nihira et al., 1993); challenging behaviour, using the Aberrant Behavior Checklist (Aman & Singh, 1986) and mental health status, using the PASS-ADD checklist (Moss et al., 1998) will be collected.

(iii) Independence: Two measures reflect independence of household and economic management:

(a) *Domestic Management*: The degree and independence of individual participation in domestic management will be assessed using the Index of Participation in Domestic Life (Raynes et al., 1994).

(b) *Economic Management*: This will be assessed using the Money Management Scale (Stancliffe and Keane, 2000).

(iv) Choice: This will be assessed by using the staff informant version of the Choice Scale (Stancliffe, 1997). This version has been shown to correlate highly with self reports (Perry et al., 2000).

(v) Social and Community Inclusion: Two measures will be used to reflect different aspects of inclusion:

(a) *Range and Frequency of Social and Community Activities*: A scale of community participation will be used which combines the Index of Community Involvement (Raynes et al., 1994 as modified by Felce et al., 1998) and a scale of community participation used by Stancliffe and Keane (2000). The former gauges the frequency of participation in 5 social and 10 community events in the previous month. The latter gauges the frequency of participation in 18 community events in the previous 3 months and the number of community places used without staff support.

(b) *Social Networks*: These will be assessed by the modified version of the Social Network Map (Emerson et al., 2000) and the Social Network assessment used by Stancliffe and Keane (2000).

(vi) Health and Safety:

(a) *Health*: This will be reflected in selected items from the Health Survey for England as used by Emerson et al. (2000) and the Health Care Scale used by Stancliffe and Keane (2000).

(b) *Safety*: This will be reflected in the Risks Scale developed by Emerson et al. (2000).

(vii) Resource Input: Cost data will be collected under two main categories: accommodation and non-accommodation related services (those services provided independently of the accommodation setting such as daytime services, hospital and community based services). Non-accommodation services will be assessed using the Client Service Receipt Inventory (CSRI) (Knapp et al. 1992). This gauges benefits, income, and professional and day services used in the preceding 3 months. Alongside collection of service use data, accommodation data will be collected from agencies providing housing related care and support to participants. Health economics support in this proposal will be obtained through Professor David Cohen - see co-applicants.

(viii) Staff and family views: Brief questionnaires based on existing measures will be developed to explore staff views (changes in job satisfaction, job stress, propensity to leave) and family views (changes in perceived adequacy and consistency of support).

Analysis Conventional parametric or non-parametric tests of significance will be used for independent or related samples. Costs and quality of life outcomes have been found to be related to participant characteristics, particularly adaptive behaviour. Where groups are compared and where data meet parametric criteria, differences will be controlled statistically (e.g., by ANCOVA). Such analyses will be reinforced by analysis of within group change and of matched between group subsamples. Such analytic approaches have been used before (Perry et al., 2006). The methodology for the cost comparison will follow that used before, in this instance supported by Professor Cohen. Accommodation will be costed using information from

agency accounts for the financial year 2005/2006. Four categories of accommodation information will be provided for each participant: direct staffing in the setting, non-staffing costs within the setting (such as heating, light and food), on-site administration and central agency overheads. Non-accommodation costs will also be based on 2005/2006 estimates and from a national compendium of publicly available unit costs (Curtis & Netten, 2005). This costing methodology follows well-established approaches employed in research in intellectual disabilities (Emerson et al., 2000, 2001b; Felce et al., 1998; Hallam et al., 2002). Due to the non-normality of the cost data, bootstrapping will be used to test for differences between the groups.

Resources

The principal applicant, Jon Perry, will undertake and manage the project on a two-day-per-week basis. Data collection takes two half days per participant at each round. 200 data collection days are required: 60 in the initial phase undertaken through WGHC resources, 100 by an R&A 1A (Andrea Meek, 40%) for 15 months and the remainder by the principal applicant. Dr Perry has worked in partnership with Professor Felce on the measurement of quality of life and evaluation of residential services for people with learning disabilities for 15 years. Andrea Meek has been a member of the research team for 7 years and has considerable experience in administering the measures which would be used in this study. The Welsh Centre for Learning Disabilities is an internationally known research centre, which is now part of the Centre for Health Sciences Research, an arrangement which enhances its own internal multi-disciplinary strengths. Support for travel is the main consumable.

Outcomes, Dissemination & Impact

The primary product will be a Final Report which, following consultation with the funding body and collaborating service partners, and consideration of any comments from referees appointed by the funding body, will be the basis of several scientific articles submitted to well-regarded peer-reviewed journals. In addition, the applicants have a tradition of multiple form dissemination. Therefore, as well as scientific papers, we will prepare articles for professional journals and single page research abstracts which can be directly mailed to a wide audience. We will also speak to the work at national and local conferences and seminars. The WCLD has a well maintained website through which electronic dissemination will be possible. We will arrange feedback on the results of the research to collaborating service colleagues. We will produce a user-friendly plain English version of the report in order to facilitate this. We will also produce an accessible feedback statement for the service users involved and for dissemination to people with learning disabilities more generally. In addition, we would seek ways to provide guidance to commissioners/providers on the organisation of cost-effective residential supports for adults with learning disabilities. We would expect this to be facilitated by the developing stakeholder partnership being created through the auspices of the Learning Disability and Autism Research Network in Wales.



Wales is similar to other countries in the UK in having growing numbers of adults with learning disabilities and a static supply of out-of-family support. Families have prolonged caring responsibilities which have been increasing. However, the capacity of families is clearly limited by ageing. Affordable alternative support arrangements are required which deliver high quality outcomes in line with policy. The proposed study will provide empirical evidence on the cost effectiveness of a highly innovative and potentially replicable scheme. If the results are similar to those of the Perry et al. (2006) comparative study, a double benefit may be found: (a) individuals may be supported in a way which encourages greater self-determination and independence at lower cost, and (b) current expenditure may be re-invested to provide for other people currently in need of support.

9. Please give details of ethical considerations and ethical approval that will be required before the project can be undertaken in order for you to undertake this project (no more than 250 words)

Although the proposal concerns an experimental evaluation of the reorganisation of service delivery, the service provider, not the research, is setting the occasion for the change. Therefore, the proposal to evaluate the innovation will not fundamentally alter the treatment and experience of service users. Rather, it will measure and document service user experience. One could argue that ethical considerations would favour evaluation rather than the absence of evaluation. The main impact on service users will be through the staff time consumed to complete measures (because of the spectrum of disabilities to be included it is proposed that staff-informant measures will be administered). Otherwise, the research has the potential to provide guidance to commissioners and providers on service effectiveness. The research is being conducted on the organisation of social care; NHS services and employees are not involved. Medical records will not be consulted. It is our experience that NHS research ethics committees will not consider this proposal. Because the first phase of the study is in progress we have already sought the approval of the Cardiff University Research Ethics Committee. The first phase of the study was approved by the committee. Approval of the full study, if it were funded, would be an extension of this initial permission.

Declarations

Declaration by applicants

Lead Applicant

I declare that I have completed the full application form in accordance with the guidance notes for full applications.

FULL NAME

SIGNATURE

Co-applicant 1

I declare that I will participate in the project described in this document should the application be successful.

FULL NAME

INSTITUTION

SIGNATURE

Date

Co-applicant 2

I declare that I will participate in the project described in this document should the application be successful.

FULL NAME
INSTITUTION
SIGNATURE

Date

Co-applicant 3

I declare that I will participate in the project described in this document should the application be successful.

FULL NAME
INSTITUTION
SIGNATURE

Date

Co-applicant 4

I declare that I will participate in the project described in this document should the application be successful.

FULL NAME
INSTITUTION
SIGNATURE

Date

Co-applicant 5

I declare that I will participate in the project described in this document should the application be successful.

FULL NAME
INSTITUTION
SIGNATURE

Date



Declaration by Institution

This application should be submitted through the Lead Applicant's head of department and the officer who will be responsible for grant administration within the Lead Applicant's institution. Each should sign the following declaration

I confirm that I have read this application and that, if this application is successful, the work will be accommodated and administered within this body and in accordance with the terms and conditions that will form the contractual obligations. Staff grading, salary and overheads are correct and in accordance with the normal practice of this institution.

	Head of Department	Administrative Authority
Name and Initials		
Title		
Institution		
Address		
Contact numbers		
Signed		
Date		

Appendix: References

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