Institution: BRUNEL UNIVERSITY (H0113)

Unit of Assessment: 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Improving services for Electrically Powered Indoor/Outdoor Chair (EPIOC) users

1. Summary of the impact (indicative maximum 100 words)

Brunel's research identified the ways in which electrically powered indoor/outdoor chair (EPIOC) use improves the quality of life (QoL) of people with disabilities; key findings have been used to inform public policy, enhance professional standards and international evidenced based guidelines for professional practice and improve the health and social welfare through the empowerment of disabled person's organisations. The impacts are based on the newly gained recognition, based on the research findings, that young people need an EPIOC to provide opportunities for social inclusion, positive risk taking behaviours, successful transition into the work environment and to enable general healthy development and capacity for independent living. Older people need EPIOCs to reduce the physical and emotional stress on elderly carers. The impacts have ensured more effective policies are developed, professional practice is enhanced and more appropriate assessment and prescription services are provided for these service users.

2. Underpinning research (indicative maximum 500 words)

Professor Lorraine De Souza, the lead academic of the research group, has held the post of Professor of Rehabilitation at Brunel University throughout the REF research and impact periods. Also employed at Brunel University, in related research posts, were Davies (1998-99), Neophytou (2002-04) and Evans (2005-06). Frank, A.O. and Frank, J., were the clinical collaborators based at the Royal National Orthopedic Hospital, Stanmore. The Brunel studies were partially funded through two grants: De Souza (1998-99) Changes in Quality of Life of wheelchair users after EPIOC provision) from Hillingdon Primary Care Trust. £11,000 and De Souza. (2002-4), User satisfaction with provision of EPIOCs from North West Thames NHS SHA, £21,183.

This research programme explored the impact of the provision for very severely disabled people of an Electrically-Powered-Indoor-Outdoor-Chair (EPIOC). In 2000, the NHS Executive and Department of Health estimated that there were over 11350 EPIOC users in the UK and this number was growing steadily by over 3500 per year. The impact of the provision of EPIOCs needed to be fully understood to inform policy and practice.

In the first research phase, Davies et al (2003) demonstrated how changes in quality of life (QoL) could be objectively measured. Initially the researchers adapted and developed the EuroQoL (EQ5D) to enable people with very severe disabilities to report their quality of life before and after provision of an EPIOC. Prior to this there was no existing QoL measure available that was sufficiently sensitive to measure the level of disability of this client group. Davies et al were able to use the adapted measure to research the effect of EPIOC use on QoL. The research demonstrated for the first time that provision of an EPIOC significantly improved the QoL of the user as well as mobility, pain and discomfort.

The second research phase then moved into identifying the needs and potential benefits of EPIOCs for specific user groups (younger and older people). Evans et al (2007a) took an in-depth qualitative approach to explore the views and opinions of young people using EPIOCs. It was clear that young people with severe disabilities had the same needs and ambitions as their able-bodied peers. The study found that young EPIOC users not only relied on an EPIOC as a means of mobility i.e. to physically access school/college, but equally importantly it allowed them to be able to be socially included; this gave them the opportunity to build relationships with their peers and, with ongoing training in the use of the EPIOC, it facilitated their overall development. It also was found that the use of EPIOCs successfully enabled them to enter the world of work. Users particularly valued the independence and privacy from their parents that an EPIOC provided. Both parents and children described "risky" behaviours as a result of the greater independence gained through the use of an EPIOC. The children described these behaviours with excitement and relish, whilst the parents were much more cautious and fearful. Until these findings came to light, EPIOC provision had only been prescribed as a mobility aid; this research evidenced the equally important benefits derived from enhanced social inclusion through the development opportunities afforded.

Evans et al (2007b) undertook research into EPIOC use by older people, exploring an underlying assumption that benefits would be minimal for this ageing population. The research took a qualitative approach to explore the insiders' views of what it means to be provided with an EPIOC. The major finding was not only that the older people gained independence and increased their activity by using their EPIOC but also that their major carer (often a spouse, usually older) gained benefits by becoming more independent, as they had more time for themselves. As a result of not having to push the wheelchair, they found their physical health improved and they experienced a great relief from this physically demanding responsibility.

Both of the Evans et al papers in 2007 raised the need to explore carers' views of EPIOC provision for their cared for relative and also to explore whether or not the needs of carers should form part of the formal assessment for EPIOC provision (which it did not at that time). Frank et al (2010) undertook the third phase of research to address these issues: Frank et al (2010) paper. This research was the first time that carers' perspectives had been systematically researched. The study found that the greatest benefit to carers was the reduction of the physical burden of care, not just the burden of pushing a manual chair, but also transferring the cared for person in and out of the chair several times a day. The study recommended that the needs of carers should be taken into account when assessing users for EPIOC provision.

3. References to the research (indicative maximum of six references)

1 Davies, A., De Souza, L., Frank, A.O., Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs, Disability and Rehabilitation: Assistive Technology, 2003: 25(6): 286 – 290. doi: http://dx.doi.org/10.1080/0963828021000043734

2 Evans, S., Neophytou, C., De Souza, L., Frank, A.O., Young People's experiences using electric powered indoor-outdoor wheelchairs (EPIOCs): Potential for enhancing users' development? Disability and Rehabilitation, 2007(a); 29(16): 1281-1294. doi: http://dx.doi.org/10.1080/09638280600964406

3 Evans, S., Frank, AO., Neophytou, C., De Souza, L. Older adults' use of, and satisfaction with, electric powered indoor/outdoor wheelchairs, Age and Ageing 2007(b): 36: 431-435 doi: http://dx.doi.org/10.1093/ageing/afm034

4 Frank, A., Neophytou, C., Frank, J., De Souza, L. Electric-powered indoor/outdoor wheelchairs (EPIOCs): users' views of influence on family, friends and carers, Disability and Rehabilitation: Assistive Technology, 2010; 5(5): 327-338 doi: http://dx.doi.org/10.3109/17483101003746352.

4. Details of the impact (indicative maximum 750 words)

Impact 1. Impacts on public policy in the UK: government health policy decisions have been informed through evidence presented to national government committees and national government consultation with regard to the value of EPIOCs in enabling employment and supporting young people's development.

Evidence source[1]: The response of the British Society of Rehabilitation Medicine to the consultation on Improving Specialist Disability Employment Services cited the Evans et al 2007a paper, stressed the importance of the independence allowed with EPIOC provision, without which many teenagers are unable to enter the world of work. The proposals outlined in the consultation formed part of the December 2008 White Paper.

Evidence source[2]: In January 2010 the College of Occupational Therapists (COT) gave oral evidence, followed by written evidence to the Health, Wellbeing and Local Government Committee Inquiry: Wheelchair Services in Wales. The consultation sought views on proposed changes to the current legislation. The COT evidence drew on Evans et al's 2007a paper on children which found that on-going training in EPIOC use was important to support young peoples' development to adulthood. COT's evidence to the Inquiry recommended that training in the use of EPIOCs should be routinely made available to all child EPIOC users and their carers.

Impact 2. Impacts on practitioners and services internationally: professional standards, guidelines and evidence-based sources have been shaped by the research. The evidence has broadened assessment to include provision based on social development needs of the user, not just their mobility needs, as well as the needs of the carer. Understanding has been shifted to recognise the importance of EPIOC use in terms of overall development and successful transition to independence in adulthood, both socially and occupationally. Internationally, practitioners have been enabled to enhance the quality of their professional practice and service provision.

Evidence source[3]: The 2010 NHS Scotland Wheelchair and Seating Services Modernization Project- Clinical Healthcare Quality Standards for Wheelchair and Seating Services, Standard 1.5 - Assessment of mobility and mobility needs – states that “Disabled people may have carers who have different needs, capabilities and level of involvement. Assessments should cover the needs of carers with regular or substantial caring responsibility.” This recommendation was based upon the Frank paper 2010.

Evidence source[4]: In North America, the Evidence for Practice Series: “Power mobility for school-aged children and adolescents” (Health Centre for Children, Canada, 2011) cites Evans’s 2007a; this provides best practice evidence for clinicians concerning enhancement of participation. It draws on the findings, stating that power mobility facilitates increased independence and participation by children in outdoor and social activity as well as the importance of training in EPIOC use for outdoor and more complex environments to facilitate the development of the child through proficient use and also for safety.

Evidence source[5]: The 2007 Annual Report to the Director of Public Health about the health of the people within the Lanarkshire NHS Board Area, where there are between 600 and 800 children dependent on a wheelchair, uses the 2007 Evans et al paper in Section 12.4 - CHILDREN’S WHEELCHAIRS. The section underlines the importance of the provision of an appropriate wheelchair to enable children to gain independence and develop real social independence, thus improving their quality of life as outlined in the 2003 Davies et al paper. The Lanarkshire report highlighted that some children who would benefit from EPIOC were being excluded in the present process and recommended that ways of making EPIOCs more widely available should be explored and that users’ views should be represented in service developments. The Evans et al 2007 paper on older adult EPIOC users drew attention to the need to provide extra support to older users so that they gain the most benefit from EPIOCs and was critical of lengthy wait times for chair modifications to address changing needs. Standard 4.11 of the Lanarkshire Clinical Healthcare Quality Standards incorporated this finding stating: “the provision and updating of instructions and if necessary training ..is crucial to safe and efficient use..”. The same paper informed Standard 5.2 : “Quality Management and Service Provision” incorporating the Evans et al research process for “Satisfaction with the Chair” and “Satisfaction with the Service”, which calls for an independent survey on these matters once every two years.

Impact 3: Impacts on health and welfare: groups of service users and their carers have been empowered by the research evidence to lobby for improvements in services.

Evidence source[6]: In June 2010, the Muscular Dystrophy Campaign produced a report ‘Get Moving – the case for effective Wheelchair Services’, calling on the UK Government to act on the recommendations within it. The report, endorsed by the All Party Parliamentary Group for Muscular Dystrophy referred to the findings in the Davies et al paper on the improved quality of life afforded by the appropriate use of EPIOCs, “Evidence shows that access to the correct powered wheelchair not only significantly improves mobility but also prevents deformity and reduces pain and discomfort. There is also a substantial body of research illustrating the benefits of good equipment on quality of life.” The report also referenced the Evans et al 2007b paper when stressing the benefits of EPIOC provision for young people – “By reducing social isolation in this way, wheelchairs can decrease the likelihood of depression.”

Evidence source[3] : In responses to the consultation, on the 2010 ‘NHS Scotland Wheelchair and Seating Services Modernization Project- Clinical Healthcare Quality Standards for Wheelchair and Seating Services’, disability groups welcomed the recognition given the needs of primary carers resulting from the findings of Evans (2007b). They called for an explicit recognition of carers’ legal right to a carer's assessment from their local authority. A typical comment was: *"We welcome the criteria that assessments should consider the needs of primary carers as well as the individual with support needs."* - Disability organisation (anon).

5. Sources to corroborate the impact (indicative maximum of 10 references)

Sources to corroborate Impact 1:

1. Response of the British Society of Rehabilitation Medicine to the consultation on Improving Specialist Disability Employment Services (page 4, and reference 8) re EPIOCs needed to enter the world of work. http://www.bsrm.co.uk/Consultation/Consultations.htm
2. Ellis Peters, Peggy Frost and Ruth Crowder, College of Occupational Therapists Paper to support oral evidence to Health, Wellbeing and Local Government Committee Inquiry: Wheelchair Services in Wales. HWLG(3)-02-10-p.2: 21 January 2010. (Section 7 and responses to Q19. http://www.cynulliadcymru.org/bus-home/bus-committees/bus-committees-scrutiny-committees/bus-committees-third-hwlg-home/bus-committees-third-hwlg-agendas.htm?act=dis&id=161687&ds=1/2010

Sources to corroborate Impact 2:

3. Scottish Wheelchair and Seating Services Modernization Project- Clinical Healthcare Quality Standards for Wheelchair and Seating Services – Page 6 and Reference 17(p.23)

   http://www.scotland.gov.uk/Publications/2010/12/06095313/25
4. Health Centre for Children, Canada, 2011.

   http://www.childdevelopment.ca/best/EvidencePracticeandplanning.aspx
5. Dept of Public Health and Lanarkshire NHS Board (2007) pages 94-96 section 12.4 http://www.nhslanarkshire.co.uk/publications/Documents/Annual%20Report%20of%20the%20Director%20of%20Public%20Health%202007.pdf

Sources to corroborate Impact 3

Source 3 above (Scottish Wheelchair and Seating Services Modernization Project)

6. Muscular Dystrophy Campaign (2010) Get Moving – the case for effective Wheelchair Services. Evidence page 5 and references 5 & 8 http://www.muscular-dystrophy.org/assets/0001/7217/Get_Moving_-_the_case_for_effective_Wheelchair_Services.pdf

Contacts to corroborate Impact 3

1. Chair of the ScotRET Wheelchair Service Group
2. Lead Occupational Therapist, Barnet Wheelchair service