

# PMMLD LINK

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## **PAMIS Healthy Lifestyles Project: Supporting Healthy Lifestyles for people with profound and multiple learning disabilities and their carers**

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This 3 year project run by *PAMIS* brings together good practice and research on improving the health of people with profound and multiple learning disabilities (PMLD) and their carers in order to enhance the quality of health in this disadvantaged group. The project is funded by a grant from the Big Lottery Fund, with complementary funding from six statutory agencies across Scotland. The project is being delivered to families with input from health, local authorities and *PAMIS*. A team of Project Development Workers were appointed to set up and deliver the programme of work in the six areas of Scotland where the project operates.

Over the three years (now into year two) the project is running a series of training workshops for carers on a wide range of health related topics. These are complemented by a parallel programme of community based leisure activities that have obvious health benefits. The workshops and leisure based activities respond to the recommendations highlighted in the NHS Scotland Health Needs Assessment Report of people with learning disabilities (NHS Health Scotland 2004). By promoting activities that allow access to the outdoors and increased physical movement and exercise, the poor physical, psychological and emotional well-being of people with learning disability can be addressed (Hogg 1992) and by improving access to good health care delivery, particularly primary health services, and training for family and front line staff can have a significant impact on the health of the person with PMLD (Hogg, 2001). The project is being conducted in Aberdeen city, Aberdeenshire, Angus, City of Dundee, Fife, Greater Glasgow, Perth & Kinross and South Lanarkshire.

### **Training Workshop Programme**

Individuals with PMLD have very complex health problems. As a result of their long-term caring roles, the health of their prime carers is also affected. "*Current policies and increasing longevity are leading to a lifetime of care giving, limiting aspirations for self-realisation with apparently damaging consequences for the health of carers*" (Lancioni and O'Reilly 1998). The training workshop programme covers the principal health difficulties of both the individual and their parent/carer. These are noted in Figure 1 on page 16.

All the workshops from year one have been completed successfully and we are now working on year two. For example, physical management awareness workshops involving two or three days

of informative awareness training have already had a very positive impact on families. The physical demands of positioning, transferring and lifting a person are usually extreme. However, through dissemination of knowledge and practical skills carers are now more able to perform lifting in as safe an environment as possible.

### **Evaluation**

Information has been collected on the health of the person with PMLD using the *Rochester Health Survey* (Janicki and Davidson 1999) and that of their parents/carers using the *General Health Questionnaire – 12* (Goldberg 1978). Results from these questionnaires will be used to monitor changes in health throughout the lifetime of the project the impact of the individual workshops and the leisure activities will be evaluated using structured questionnaires.

### **Leisure Activities Programme**

The intervention programme of leisure activities that is anticipated to be beneficial to both the individual's health and that of the carer is being run alongside the workshop programme on health topics. As previously noted, gaining access to physical activity can help the overall well-being of the person with profound and multiple learning disabilities and their family members/carers. Being outdoors also allows exposure to sunlight which increases the body's absorption of vitamin D. Many people with learning disabilities have been identified as deficient in vitamin D due to limited outdoor access and also due to the lack of adequate vitamin D content of the various diets used (Tohill and Lavery 2001). The topic of healthy eating is being addressed in the health care workshops being delivered as part of the overall project.

Examples of the types of leisure activities on offer include:

- Adapted Bike Rides
- Alexander Technique
- Equine Activities
- Hydrotherapy and Water Sports
- Music & Movement
- Wheel-chair based Exercise
- Tai Chi
- You & Me Yoga
- Wheelchair Ice-skating and wheelchair roller-blading
- SOMA – Sporting Opportunities for Motor Activities

Adapted bikes are already available to families in different regional parks in Scotland as a result of campaigning by PAMIS. Wheelchair ice-skating has also been enjoyed with families attending sessions held at Dundee and Kirkcaldy Ice-rinks and these have now been extended to Glasgow, Aberdeen city and Aberdeenshire.

Music workshops, fun/sensory walks and wheelchair dancing, have also been offered in different regions where the project operates. Sporting Opportunities for Motor Activities (SOMA) has been highly successful in Tayside with new groups starting in Aberdeenshire and Fife involved in planning future SOMA activities. Taster days on SOMA are also being held in the other areas with a view to them becoming integrated into local leisure activities programmes.

Overall the Healthy Lifestyles Project is running successfully and will continue to do so as PAMIS, in collaboration with the many professionals involved in delivering care to this vulnerable group endeavour to improve the lifestyles, health and wellbeing of people with learning disabilities and their carers. During the first year of the project, 264 family carers and 177 people with PMLD attended the health care training workshops. Additionally, 127 paid carers and 27 other professionals participated in them and 474 people with PMLD took part in the leisure activities programme.

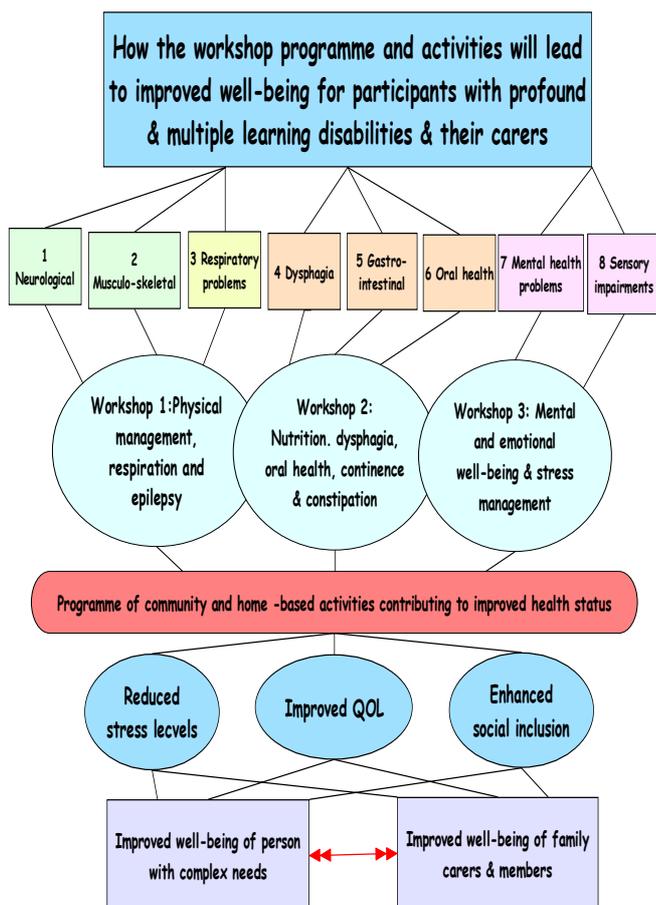


Figure 1 Health areas targeted in the Health Lifestyles Project and anticipated benefits.

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