

Information Exchange

The P Pod



This is an option for alternative seating for people with PMLD who use moulded seating in their wheelchairs. Bean Bags have been used for years as a relaxed form of seating but most children and adults with complex needs need more postural support. The 'P' Pod addresses this problem by adding a customised moulded seat on to the bean bag. Being very lightweight and available in a range of materials, the 'P' Pod offers an aesthetic, easy to move around the home, simple approach to providing a versatile seat support system.

For more information visit:

www.specialisedorthoticservices.co.uk

or tel: 01283 520 400.

Housing Improvement Grants

A new system of financial assistance has been introduced in Scotland for people living in privately owned housing. This includes, for the first time, mandatory grants to cover the costs of adapting a property to meet the needs of a disabled person or other family members living with you. Under the new rules, councils have to offer help with a wide range of structural adaptations e.g replacing the bath with a walk in shower.

Firstly you have to be assessed by your local authority to see whether your need is a priority (you are entitled to appeal against the result of this assessment). If you are successful in your assessment the local authority must cover 80% of the actual cost of the work or 100% if you are receiving certain benefits. There is no longer any fixed upper limit on the amount of a mandatory grant.

A booklet - Help with adaptations to your home: a guide for disabled people in private housing is available free to download at www.scotland.gov.uk/Resource/Doc/266465/0079748.pdf

SCLD Training Courses

New dates for Learning Disability open training courses from the Scottish Consortium for Learning Disability see their Course Calendar at www.sclld.org.uk



PAMIS Contact Information Area Offices

Fife	Tel: 01382 385 154	email: j.e.roberts@dundee.ac.uk
Grampian	Tel: 01224 784 456	email: jenny.pamis@btconnect.com
Greater Glasgow	Tel: 0141 572 0782	email: liz.pamis@btconnect.com
Tayside	Tel: 01382 385 154	email: pamis@dundee.ac.uk
S. Lanarkshire	Tel: 01698 452 836	email: michelle.pamis@btconnect.com



The PAMIS library has now joined the Scottish Health Libraries Catalogue www.shelcat.org

PAMIS library members can now not only borrow resources from the PAMIS library but also request to borrow resources from all the other members of Shelcat. There are over 40 member libraries including many of the NHS Scotland libraries. The online catalogue is easy to search and books can be requested and renewed online once you are a library member. Contact j.t.taylor@dundee.ac.uk for more information.

Join the Campaign to find the Missing Millions!

for Scotland's Disabled Children (fSDC) has just launched a national campaign to turn some of the missing £34million into services and support for disabled children and young people, and now they are looking for supporters' help to take the campaign local.

This year every Scottish council will receive a share of £11million that's supposed to be spent for transforming disabled children's services. In the next few weeks local authorities will be meeting to decide their budget priorities, so we need you to contact your local councillors and MSPs to make sure this money is used to make a real difference to disabled children and young people's lives.

For more information visit:

www.fsdc.org.uk

or tel: 0131 659 2939

Local Area Coordination Service under Threat!

It is very disturbing to hear of Argyll and Bute Council's decision to withdraw all funding from Local Authority Coordination (LAC) across the region. LAC provides a valued and essential part of learning disability provision, promoting meaningful inclusion for people and their families and ensuring that they play equal, active roles in their local communities.

Although this situation is unique to Argyll and Bute area at present, the implications of their proposal to cut the Local Area Coordination service has wider reaching implications throughout Scotland.

For more information visit www.ldascotland.org

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Transition Pathways: Taking it Forward

PAMIS was delighted to hear that they had been successful in their application to the Self Management Fund, managed by the Long Term Conditions Alliance Scotland (LTCAS), on behalf of the Scottish Government. PAMIS was awarded a grant of almost £250,000 which will then enable us to address an issue that is of great concern to people with PMLD and their parents.



This Transition Pathways project gives free support to young people with profound and multiple learning disabilities (PMLD) and their families to manage the complexity of the transition into adult life and services. It has long been recognised that the transition from children to adult services is a particularly stressful and difficult time for young adults and their families. This grant will allow us to support families offering both practical help and advice before and after leaving school. This project is modelled on the successful existing PAMIS Futures project, which has run for some years in the City of Glasgow.

The project is being rolled out in five regions across Scotland; Fife, Tayside, South Lanarkshire, Grampian and Greater Glasgow. Five Development Workers are now in place: Rachel Houston – Fife; Sarah Murphy – Tayside; Gemma O'Hagan – South Lanarkshire; Tracey Bell – Grampian; and Alana McDicken – Greater Glasgow; with Marion Anderson as project secretary; based in Dundee.

If you are interested in more information on this project please contact the PAMIS Head Office.



Campaigning in the Parliament for Changing Places Toilets



Shona Robison & Guests at the Scottish Parliament

PAMIS has been busy campaigning in the Scottish Parliament for more Changing Places toilets throughout Scotland. We started in early September with a celebration of the inclusion of Changing Places standards in the new British Standard BS8300:2009. Shona Robison, Minister for Public Health & Sport and Jackie Baillie, MSP joined us in our celebrations along with other MSPs, invited guests and families that have given their support over the years.

Linda Burke and Rhona Lamond, two PAMIS parents, spoke eloquently about how the provision of adequate toilet facilities made such a difference to their family lives, and that without these specialised toilets a family day out was not possible.

A few days later Linda Burke was back in Parliament to address the Petitions Committee. Linda handed over the petition 'Calling on the Scottish Parliament to urge the Scottish Government to ensure that local authorities use British Standard 8300:2009 to ensure that at least one public toilet built to the Changing Places standard is provided within the centre of each town with a population greater than 15,000 and within each new larger publicly accessible building and complex'. There were over 3000 signatures on this petition and thanks to all of you for supporting us.

continued overleaf

www.dundee.ac.uk/pamis

February 2010

Newsletter

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Changing Places - Changing Lives



But what about us?
What we need is a Changing Places toilet.



www.changing-places.org

The Petition Committee responded very favourably to the petition and fully supported our request. Over the last few months the committee has written to a number of local authorities, the Scottish Government, CoSLA, Historic Scotland, and the Scottish Retail Consortium to clarify what action these bodies were taking to make sure Changing Places toilets were incorporated into their plans. PAMIS supported by the Learning Disability Alliance Scotland (LDAS) will continue to lobby the Scottish Government and other public bodies and follow up the committee's suggestions and recommendations.

Other members of the Changing Places Consortium are at the same time putting pressure on Westminster and the Northern Ireland Assembly. Craig Kelly from Strictly Come Dancing and Coronation Street delivered a giant toilet roll to the Department of Communities and Local Government in December.

There are now over 40 Changing Places toilets across Scotland which are now all shown with contact details on the LDAS website at www.ldas.org.uk. We are also producing a leaflet with all the Changing Places toilets in Scotland.

PAMIS have also recently had talks with IKEA in Edinburgh who are planning an expansion of their store which will include a Changing Places toilet.



Carers, users and staff celebrating the opening of a new Changing Places toilet at the Bells Centre, Perth.

Invasive Procedures Project - Breaking barriers and achieving control for people with profound & complex disabilities

The conference held by PAMIS at Dundee University last year was a great success with over 140 delegates attending. The recommendations from the conference consensus workshops are available in the conference report which can be obtained from b.garrard@dundee.ac.uk along with a DVD of all the presentations. Brenda Garrard is presently analysing the results from the questionnaires which have recently been sent out to families and professionals. These results, together with the conference recommendations, will be taken forward to produce guidelines, including examples of good practice. It is hoped these guidelines will be implemented uniformly across Scotland and so eliminate the differences of practise across different professions and different areas of Scotland.

New Carers Strategy for Scotland.

The Scottish Government, in partnership with the Convention of Scottish Local Authorities (CoSLA) is currently developing a new Carers Strategy for Scotland. This will build on progress since the publication of the Care 21 Report and The Future of Unpaid Care in Scotland. More information on the development of the Carers Strategy can be found at www.scotland.gov.uk/Topics/Health/care/Strategy/Carer
For anyone who would like to contribute to the development of this strategy, the Scottish Government, in conjunction with the Coalition of Carers in Scotland and local carer organisations, is hosting four events in February and March 2010 in Dundee, Melrose, Inverness and Glasgow. Please email: coalition@carersnet.org for further information.

Tackling Indifference



NHS Boards in Scotland need to get better at understanding the needs of people with learning disabilities to make sure that they get the healthcare they need. This is the key finding from 'Tackling Indifference', a report by NHS Quality Improvement Scotland (NHS QIS) that was launched in December 2009.

PAMIS carers were on the review teams that visited each Health Board to look at services in hospitals for people with learning disabilities. The report along with the individual reports from each NHS Health Board, are available to download from www.nhshealthquality.org/nhsqis/5988.html

New Staff

Hannah Young joined PAMIS in May 2009 as a Research Assistant. Hannah is working on two projects, multi-sensory sensitive stories and bereavement and loss.

Multi-sensory Sensitive Stories – Hannah is analysing and reporting on the data that Maggi Fenwick collected and recorded. The findings from the analysis will then be published in relevant journals. Hannah is also producing copies of the original sensitive stories so that schools, families and day services can make use of this fantastic resource. The Multi-sensory Sensitive Stories are listed below and can all be borrowed from the PAMIS library. Contact: j.t.taylor@dundee.ac.uk tel: 01382 384 953

Craig has Seizures (epilepsy)
Jamie's Bathtime Story (sharing)
Lee's visit to the Dentist
Ashleigh has her Period
Grant's Respite Visit

Toilet-time!
Lewis' 'Wee Turn' (epilepsy)
Daniel is Growing Up
Beth is Growing Up
Becoming a Big Girl

Bereavement & Loss Research Project – this is a pilot research project to establish whether there is a need for support for individuals with PMLD and their carers surrounding bereavement and loss issues and how best this can be achieved. Meetings with carers have involved exploration and discussion surrounding these issues. The outcomes of those discussions are currently being explored. h.young@dundee.ac.uk or by tel: 01382 384 942.

Lesley Gray and **Jean Kerr** are two other new faces at PAMIS. Lesley is personal assistant to Loretto Lambe and Professor James Hogg and Jean is finance assistant; both are working part-time.

Two New Leisure Projects at PAMIS

PAMIS has been funded by the Scottish Government to develop the FreeStyles Project which will run for 2 years with the aim of producing a guidance pack on inclusive community leisure activities and facilities for adults and children with PMLD. Lesley McLaren who was the Healthy Lifestyles Project worker in South Lanarkshire is working on this project.

The pack will include a short DVD, which we have just finished filming with the help of PAMIS families, showing people with PMLD enjoying a range of leisure activities. The overall pack will be completed early 2010 and will then be presented to local authorities, leisure providers and voluntary organisations to give them ideas, advice and information on how to organise and, where relevant, adapt all the activities featured on film. We are also hoping to support and train others to include people with PMLD in leisure opportunities over the longer term.

PAMIS also has been successful in securing funding, from NHS Greater Glasgow & Clyde, for a year to run a programme of leisure taster events organised by Alan Smart, for PAMIS Glasgow families. These taster sessions have also been open to leisure professionals, adult day care staff and other relevant professionals with the aim of promoting more relevant accessible community leisure activities for those with PMLD. It looks like there will also be regular leisure activities in Glasgow, e.g. wheelchair ice-skating and yoga, that will become established once the projects funding comes to an end in March 2010.

Sensing the Stories



On the 5th January 2010 PAMIS contributed to a training and development day at the Scottish Storytelling Centre in Edinburgh.

The theme of the day was; 'can narrative be an area of exploration and expression for those with disabilities and additional support needs?' The hugely successful day was led by a creative team from the Storytelling Centre who demonstrated many ways of engaging people in sensory storytelling. The inclusion of the PAMIS multi-sensory stories in the Sensing the Stories Day generated a lot of interest and highlighted the need for increased development of multi-sensory storytelling. The multi-sensory stories can be borrowed from the PAMIS Library, please contact: j.t.taylor@dundee.ac.uk or tel: 01382 385 154



Allan Guy & Ski Instructor Edward Brown



Colin & Dee Carriage Driving