

Moving on: facilitating the transition from child to adult services for young people with profound and multiple learning disabilities

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Introduction

Transitions in our lives are a time of change with which we all cope differently. For individuals with profound and multiple learning disabilities (PMLD) and their parents/carers one of the most significant transitions is from child to adult services. This is a time filled with huge anxiety and uncertainty. For most parents of a child with PMLD their experience of the education system and paediatric health services has been a positive one. A specialised resource has been accessed, their child's educational needs have been met using an adapted curriculum supported by an array of specialised equipment to promote and enable progress and skill development. Where necessary, those individuals with complex health care needs have had access to appropriate medical professionals in their school. Therefore the educational setting provides a co-ordinated approach to the individual's support which involves professionals from education, health and social work.

There is clear evidence that there is a need for good transition planning well in advance of the young person with PMLD leaving school. The *Raising Our Sights* report (Mansell, 2010) on services for adults with PMLD recommended that the government needs to continue to encourage the development of more effective transition arrangements so that there is proper planning and timely provision of appropriate services as people move into adulthood. The Department of Health (2011) response to Mansell urges a joined up approach to transition that includes individuals, communities, statutory organisations, the voluntary and private sector. A number of recent publications also highlight the importance of early transition planning, Scotland's Additional Support for Learning Act's Code of Practice (2005) stresses that

appropriate measures should be implemented a minimum of 12 months prior to transition and most regional strategies echo this with local policy such as Perth and Kinross Council (2007) Education's '*Preparing for Adulthood Post School Transitions*' document. Yet despite all this, young people with PMLD and their families continue to find the transition from school to adult service an extremely stressful and protracted process, often resulting in less than adequate day opportunities being provided. *Getting it Right for Every Child* (Scottish Government, 2011) is a model of practice that promotes a shared approach towards building solutions with and around young people and families, enabling them to get the multi-agency support they require when they need it.

Research has shown that there is a catalogue of shortcomings in the way transitions are planned (Heslop, 2002). Among these are failings in:

- **Communication:** A lack of effective communication between health, education and social services resulting from current detailed information regarding the individual not being forwarded to the appropriate professionals in a timely fashion to enable effective planning.
- **Co-ordination:** A lack of joint assessment procedures between health, education and social work (social services) to facilitate effective interagency collaboration and cohesive strategic approaches to day service and health care provision.
- **Continuity:** There is usually not a designated person to support fully the young person and their family through the transition process, particularly in post education planning. Therefore the transition can be disjointed causing great anxiety and stress to those involved.

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- **Choice:** Young people and their families are not always fully involved in the process and don't have access to all the options that are available post school to enable them to make informed and effective choices and decisions.
- **Comprehensiveness:** A widespread strategy is not in place to ensure all young people with PMLD have an effective transition plan that encompasses health, education and social work.

In addition to the above the constraints on local authorities' budgets need to be taken into account. Regardless of the level of support needs required, service provision can only be purchased in line with the allocated budget, and in the light of the current financial climate, most providers are having to make cuts to service delivery. With re-occurring negative themes around transition, a growing awareness has developed regarding the inadequacies in effective transition planning. Parents are fully aware of this state of affairs and requested *PAMIS* to undertake work in this area. In response, the *Futures Project* was set up with the aim of addressing the inadequacies noted above. The project operates in Glasgow, initially funded by Glasgow City Council and later also by the Big Lottery Fund.

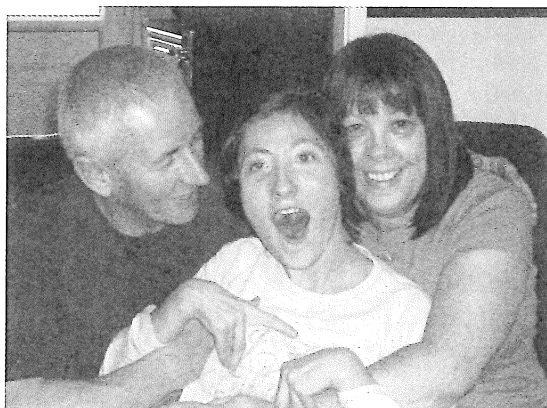
The overall aim of *PAMIS' Futures Project* was to provide an independent, unbiased service on all aspects of transition planning to families caring for a child with PMLD. The project's specific aims were to:

- provide a holistic person centred approach to individuals with PMLD, their families and those working with them through the transition from child to adult services
- offer a wide range of intensive, independent support to families, parents and carers during a significant period of challenging change
- provide families, parents and carers with the necessary information to enable them actively to participate in transition planning and make informed and sustainable choices
- provide information, advice and where necessary, training/workshops on current issues surrounding transition
- advocate for the young person and their parent/carer if necessary
- attend and support parents at planning pre- and post-meetings regarding all aspects of transition

- liaise and work in partnership with all external agencies and professionals involved
- visit day and respite services with families to enable them to make informed choices around future provision
- create a *Personal Communication Passport* and a *Transition Planner* for each participant by linking with families and significant others across health, education, social work and social care who are involved in the transition process to enable new health and social care professionals to get to know the individual
- disseminate this information to adult service providers to assist them in devising an appropriate support and activity plan.

The participants

The *Futures Project* was first established within Glasgow City in 2002 and worked with a small number of families – initially two, building up to seven – who were going through the transition from child to adult services. The project identified potential young people and families by developing effective, multi-agency relationships with health, social services and education. A free independent service was



Elizabeth and Sarah and Danielle and her parents – young people who were part of the transitions project

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Table 1: Summary of *Futures Project* work with 28 families (April 2011–February 2012)

| Type of support | Number achieved |
|--|-----------------------------------|
| Day service visits | 13 |
| Respite service visits | 8 |
| Residential service visit | 5 |
| School visits | 14 |
| Review meetings | 27 |
| Home visits | 57 |
| Transition Planners: New | 6 |
| Transition Planners: Updated | 10 |
| Passports: New | 8 |
| Passports: Updated | 9 |
| Family enquiries | 104 |
| Professional enquiries | 82 |
| Workshop/information sessions | 1 workshop: 1 information session |
| Presentation/training given to professionals | 2 |

provided to all young people and their families within the Glasgow City geographical area who had profound and multiple learning disabilities and who were between the ages of 14–19 years. Over the last nine years the *Futures Project* has continued to grow and develop and was able to increase the support offered to parents/carers and individuals with PMLD by securing additional funding to recruit two staff members to the existing team. Having the increased staff not only enabled more families to be supported but allowed intensive one-to-one support and the development of a detailed transition tool.

PAMIS' Transition Planner (PAMIS, 2010) was developed by the *Futures Project* to be used as a tool for gathering, recording and sharing information specific to the individual with PMLD. The intention of the Transition Planner was to address the shortcomings in transition planning by clearly documenting individual support needs, wants and wishes; enabling effective planning and communication; promoting partnership working and the sharing of information. In conjunction with the Transition Planner, PAMIS developed a *Personal Communication Passport*; a small, personalised, easily accessible document which provides a positive overview of the individual with PMLD. It aims to share vital information with new people, encouraging positive relationships. The success of the *Futures Project* enabled PAMIS to secure funding for a further project on transition, the *Transition Pathways Project*. This 18-month project was based on the principles and values

of *Futures* and worked across the five geographical areas where PAMIS operates.

The types of support involved in the transition work and the number undertaken are summarised in *Table 1*. As may be seen, enquiries from families and home visits to them are the main activities, followed by professional enquires and review meetings. These are complemented by visits to various services and creating or updating both transition planners and communication passports. Workshops and information sessions played an important part in communicating the aims of the project and these were to be realised.

Providing support in these areas facilitates communication between multi agencies and the family, which in turn, promotes effective partnership working and enables adult services to become involved at an early stage in the transition planning.

Challenges faced

One of the major challenges that impacts on our ability to support families in the forward planning of service provision and through a seamless transition is the absence of a designated adult social worker who is central to communication, co-ordination, continuity, choice and comprehensiveness in adult services. In such cases, the *Futures Project* aims to bridge these gaps. However, as the local authority holds the budget for provision of services, transitions are hindered without the input from this important link professional.

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Futures Project has successfully built positive working relationships with colleagues from child and adult social work teams though in the past there has been some initial resistance from social workers in relation to our intensive involvement with families during transition. This has been overcome by informal discussions and an information session detailing the work of *PAMIS* and our role in the *Futures Project* and the transition process.

Poor communication and sharing of inaccurate information causes anxiety, stress and leaves families unable to make informed and effective decisions. As a project we strive to ensure that the information we provide to families and professionals is current, relevant and accurate. Parental/carer expectation often poses a challenge during the transition period as they can present with unrealistically high or low expectations of professionals, service provision and budgets.

Over the last nine years the *Futures Project* has collated a vast amount of knowledge and information which enables staff to discuss realistic expectations with parents/carers. Limitations on budgets, service provision, specialised resources and placement availability for individuals with PMLD are some of the ongoing challenges faced by the project. These challenges have been further impacted by the closure of the *Independent Living Fund* in May 2010 and the recent implementation of the personalisation policy and the introduction of Self-Directed Support (SDS). The latter enables parents and carers to plan and purchase a suitable package of support for their son/daughter. However, feedback from some parents indicates that although this form of funding provides them with greater choice, autonomy and flexibility over service provision, many feel overwhelmed at the enormity of the decisions that they are faced with and often feel unsupported at a very stressful time. The *Futures Project* supports parents and carers to identify the most appropriate financial system for them. The project provides direct independent support to parent and carers to explore both traditional and non traditional service provision and can assist if necessary in discussions around service level agreements and finances with service providers. In the current climate of austerity cuts it is vital that parents and carers are supported to explore all possible opportunities available for their son/daughter with PMLD to enable them to secure the best possible package of support for them.

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Case Study

Angus, a 17 year old man with PMLD, was scheduled to leave school in May 2011. Transition planning began approximately 12 months prior to this with the *Futures Project* providing direct support to his parents. An adult social worker was allocated in December 2011 to take forward transition planning and the SDS strategy. The *Self Evaluation Questionnaire* (SEQ) – Glasgow City Council's initial assessment tool – was completed, submitted and an indicative budget of £30,000 was allocated. Service provision was identified and details regarding service level agreements were confirmed. Angus' *Outcome Based Support Plan* was completed and submitted to the finance department. However, due to a discrepancy over the cost of the service the funds were not released until August 2011. This impacted heavily on Angus and his family as there was a period of three months with no adult service provision in place. There was a lack of continuity and structure for Angus which had a negative effect on his behaviour. As there was no service level agreement in place the adult service provider was unable to engage with the school prior to Angus leaving school. There was therefore no formal introduction to the service or the staff team, resulting in the disintegration of cohesive planning.

Evaluation

Annually we request parents/carers and professionals to complete an evaluation of the project. Participants are asked to rate various aspects of the support they have received using a five point spectrum from strongly agree to strongly disagree. Qualitative data is also obtained which allows participants to detail the benefits of receiving this support during the transition period. By collating this information from participants we are able to evaluate the service and identify areas for development. The following quotes from a parent and a professional clearly illustrate the benefits of participation in a project such as *Futures*.

'Without the help of Elizabeth (Futures Officer) and PAMIS, with help I mean loads of hard work and support, many hours spent writing reports, sourcing information, supporting us as a family my daughter would have been left with little choice. However with the help and support we have been given she has choices and her future doesn't look so bleak for a young adult going through transition. Everyone should be given the help of an Elizabeth and PAMIS to get them through the minefield that is transition. She has helped to keep us

sane.' (Mother of 18 year old young woman)

'I have found the support from PAMIS Futures Project to be invaluable in several transition cases of young people with complex needs that I have been involved with. The level of detail in the work produced by PAMIS undoubtedly supports the future planning of all multidisciplinary professionals involved with the young person and ensures all information is communicated. The support they give to families is immeasurable.' (Social Worker)

Discussion

Young people with PMLD will continue to make transitions from child to adult services every year and parents and carers will continue to need intensive support during this period. Early intervention and planning, effective communication and co-ordination, accurate recording and sharing of information are imperative to a successful transition. Unfortunately, disjointed and ineffective transition planning still exists. Unless a 'key' individual from the statutory sector adult services to take the lead role in planning is identified at an early stage, the process will continue to lack co-ordination.

PAMIS believes that there is a real need for projects such as *Futures*, a service that is independent of the statutory sector, to support the whole family at this crucial time in their lives. To sustain such a project at this time of financial cuts is difficult and PAMIS is now working on ways and means of disseminating our experiences and sharing information and our resources with others working on transition matters. We would welcome hearing the views of readers of *The SLD Experience* on the challenges they have faced or are about to

face in supporting people with PMLD in their transition to adult services.

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Alana McDicken joined PAMIS in November 2009 as a Development Worker within the PAMIS Transition Pathways Project. This funding came to an end in summer 2011. Alana remains with PAMIS and is now developing the Accessible Leisure Project in Glasgow.

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