

## **Executive Summary**

Consultation on services provided for children and young people with profound and multiple learning difficulties in Wirral

### **Aims and objectives**

The Faculty of Education and Children's Services of the University of Chester was commissioned by Wirral Borough Council to carry out research in order to explore with parents and carers who have a child or young person with profound and multiple learning difficulties (PMLD), their views in relation to current provision and what changes might be made to that provision in the future. In addition, the views of key practitioners who are involved in providing support across a range of services were collected. The following report presents a summary of the findings of that research.

The overall aims of the project were to explore the views of both service users (parents and carers of children with profound and multiple learning difficulties - PMLD) and service providers (educational and associated practitioners), in relation to current provision and possible future provision for) through special schools in Wirral.

Specifically, the objectives were:

- To undertake a literature review, related to the project, in order to provide an academic and policy context for the research
- To examine existing census data and other available datasets in order to provide a clear context in which special provision is located.
- To conduct a survey of all parents and carers currently accessing special school services seeking their views on key identified aspects of provision for children and young people with PMLD.
- To identify a number of key informants, (parents and practitioners) to further explore the key issues that arise from the initial survey.
- To provide an objective report on the findings from the study.

### **Background**

In April 2009 Wirral Borough Council undertook a review of proposals for the development of Wirral's special schools for children and young people who experience complex learning difficulties and a report was published (Mount, 2009). A feasibility study was undertaken into the creation of a 2 - 19 special school for children and young people with PMLD. A number of issues arose during the course of the feasibility study, which required further exploration. Specifically these related to the provision that the Council currently offers for children and young people with profound and multiple learning difficulties, particularly at secondary level, and the arrangements in place for the management of successful transition to adult services.

This is a small but important part of the school system in Wirral. It is suggested that the number of children and young people identified within the 'profound and multiple learning difficulties' category is between 60 and 80, across the full age range in special schools.

Ambiguities over definition and a lack of data on the numbers of young people in post-compulsory education settings make it difficult to be precise. Each child or young person represents a unique challenge for their family and for the agencies that support them.

## **Literature Review**

The literature review identified differences in terminology, a lack of reliable data on prevalence and different approaches to defining the population of children and young people with PMLD. Until relatively recently views about people with learning difficulties were shaped by a medicalised framework, with language, opinion and legislation all influenced by a deficit model that saw institutionalisation as the only viable way of accommodating their needs. National policy changes have begun to shift with professional and public expectations and new demands are emerging for a more coordinated and multi-professional response from different services. Educational provision tends to focus on special schools in a variety of association with other service support. The need for more staff development is a continuing challenge and the sustenance of long-term consistency and reliability of support for individual children and young people is especially important in this area of provision. For young people with PMLD, difficulties at the points of transition are magnified by the complexity and longevity of their condition. The lack of co-ordination between agencies, differing priorities between services and the minimal involvement of young people, and their carers, in planning their own future are also key issues. Caring for a child with PMLD has a profound impact on family life and is something that affects all members of the family. The pressures involved in caring for a child or adult with PMLD within the family are well documented in the literature. Many of these issues may be alleviated by the family's ability to access certain types of support such as respite or short breaks. Relationships between professionals and parents of children with PMLD are, by virtue of the prolonged and intense nature, more fluid and dynamic than those with parents of children in mainstream. Parents' concerns have been noted in relation to the extent to which different services work together. Including the views of children and young people with complex needs in decision-making and consultations on services is challenging and has historically been difficult to secure. Without accounting for the views of children and young people, or indeed their families, service planning and provision therefore has historically been shaped by professional opinion and expectation.

Provision for children with complex needs in Wirral is provided through the Wirral Special Education Support Service. This consists of a number of teams offering advice/consultation, support, training and assessment and it places particular emphasis upon effecting positive outcomes for children and young people through their direct involvement as well as engagement with key adults including parents/carers, teachers and non-teaching staff. Children with complex learning, physical disabilities or sensory impairments or acute medical and health needs are usually assessed by the Children with Disability team (currently based at the Willow Tree Resource Centre). Wirral makes extensive provision in schools for children and young people with PMLD. There are currently five schools in Wirral Borough providing a specialist service for children and young people, located at Elleray Park, Stanley and The Lyndale primary schools, and Foxfield and Meadowside secondary schools. When young people move from school into services provided for adults, there are new challenges and five new supported living units for young adults with complex needs are required each

year. Wirral has adopted the Greater Merseyside Position Statement with an understanding that: “promoting inclusive education involves identifying and removing barriers to the ‘presence, participation and achievement’ of all children, young people and adults... this commitment embraces a fundamental responsibility to place a particular emphasis on those learners who may be at risk of underachievement, marginalisation or exclusion..” This commitment is of particular relevance to children and young people with PMLD.

At a national policy level a number of concerns were identified around the provision of services to people with learning difficulties with: poorly co-ordinated services for families with disabled children especially for those with severely disabled children; poor planning for young disabled people at the point of transition into adulthood; insufficient support for carers, particularly for those caring for people with complex needs; and little choice or control for people with learning difficulties over many aspects of their lives. A number of policy initiatives have since sought to address these concerns. The needs of children and young people with PMLD specifically have been grounded in a national policy context that includes the core principles of *Every Child Matters* and *Aiming High for Disabled Children* (AHDC), which was launched in 2007. Commissioners and policy makers have been seen as not sufficiently addressing the needs of people who had more complex needs, including those with profound intellectual and multiple disabilities. More recently, policy has shown a commitment to improve conditions and opportunities for children and young people with disabilities. This has again been the focus of Government attention with the coalition Government’s reiteration of the principles outlined in these key policy documents. The SEN Green Paper ‘Support and aspiration: a new approach to special educational needs and disability’ in 2011 has focused attention on funding, planning, resourcing and delivery of services for children and young people across the full education health and social care spectrum, proposing a new Education Health and Care Plan which would enable developments across a range of services. The provision of services for people with PMLD has moved away from an institutional model to more community-based and diverse services, accommodating not only the increasingly recognised diverse needs of a heterogeneous group, but also the increasing number of people surviving complex conditions later into life than was previously the case. Thus the extent of service provision is more far-reaching, and presents a multiplication of need for services in the lives of the individual, and their family. AHDC was centred on a core offer that included five standards, in relation to: *information; transparency; assessment; participation and feedback*. These themes and areas of national standards and expectations offer one possible basis for reviewing the nature and quality of provision in Wirral and for guiding the exploration of parent and professional opinion.

### **Data Collection and Analysis**

Research was conducted in two phases; firstly a survey with all parents and carers identified with a child with PMLD in school in Wirral. There were 63 children across primary and secondary schools. There was an overall response rate to the survey of 33% (21/63). The second phase consisted of in-depth interviews with a number of parents who indicated a willingness to take part, alongside interviews with practitioners from a range of services who work specifically with children with PMLD.

## **The first phase - survey findings**

The highlights of the responses from parents indicated that they were broadly satisfied with their child's specialist placement and very satisfied with the safety of their children, responses from staff and interaction between children in those placements. However, they were not as satisfied with the standard of the buildings and accommodation along with extended activities outside of school hours. This reinforced a commonly expressed dissatisfaction with the lack of transport to and from after school activities that effectively reduced participation.

Those parents who responded were asked about the other services that they use, and how satisfied they were with them. The paediatric service received the most positive response and occupational therapy and social services were the least satisfactory. Barely half of parents felt they had received enough information overall about the services they receive, but were broadly positive about their involvement in decision-making. In some responses and in the detail of the interviews concerns were expressed about decisions, in panels for example, that did not appear to take account of their views. There was support for improvements in multi-professional working but little interest from parents in taking more control of personal budgets.

With regard to future provision of services, there was a broad level of support for maintaining the current arrangements. All but one of the parents who responded felt that provision should be kept separate. Those parents who indicated differently were all Lyndale parents, all of whom expressed a wish to see the Lyndale school extended to provide a placement for their child's full educational career, and in some cases, beyond as an adult placement as well. These views echo those expressed in the previous study conducted by Wirral Council in 2009. Given that just over half of the questionnaires returned were from parents of children at Lyndale School, this aspect of the results should be viewed with caution. Their views are clear but cannot be taken as necessarily representing the views of parents in the other schools. The data collected was not in general statistically significant because of the small size of the sample but the views are significant, sometimes very significant, on an individual basis, especially for those who provided examples from their own experience.

## **The second phase – in-depth interviews**

### **Findings from Parents' Interviews**

Building on the findings of the initial survey a smaller number of in-depth interviews identified the following themes from responses by parents:

*Concerns about information, transparency and accountability:* as parents became more familiar with the extensive range of services and agencies that they needed to engage with, their concerns grew as they felt that they needed to fight more and more to find out what they were entitled to. For some parents the fact that they have to constantly ask for information was felt to be a degrading process. Emotive terms such as 'belittling', 'frustrating', 'humiliating' were commonly used by parents in relation to their continuous struggle, as they perceived it, in obtaining information and seeking support. A number of parents interviewed questioned the decision-making process in panels, and why parents are

not allowed to attend when decisions are being made. This raised concerns over transparency and accountability when important decisions were being made.

*Improving the way information is provided:* several parents felt that information could be provided in some sort of 'directory'. This was particularly relevant to parents who wanted more of a global understanding of their child's needs at the outset, so that parents could better cope with the potential impact and so come to terms with their situation. Parents stressed the need for honesty and realism when information was being given.

*Importance of continuity of care and child-centred approach:* all parents were focused on the specific needs of their own child, whilst recognising the broader needs of a wider group of children and young people with PMLD, especially in relation to issues of resourcing and maintaining standards of care across services. All parents were keen to stress that individually, practitioners, almost without exception, were dedicated and highly professional in their role. However, it was also considered essential that the individual needs of each child were recognised and a child-centred approach adopted. All parents stressed the reassurance that they felt in the certainty and security of some provision such as that in the primary school where very specific needs were being met because of the presence of specialist staff and continuity of care and development over time was generally available. There were some concerns raised by parents with regard to a number of practical day-to-day issues that impacted on family life and the ability of parents to provide what they felt was an appropriate level of care for their child.

*Suitable home accommodation:* there were considerable difficulties encountered by parents in finding and adapting suitable housing or accommodation, regardless of whether they owned their own home or were in rented accommodation. Difficulties in finding suitable rented accommodation were compounded where parents were not allowed to make any adaptations in the home. Long waiting lists, inappropriate locations and planning delays were raised as stressful and upsetting aspects of the housing issue. All parents had experienced difficulties to varying degrees in seeking to make appropriate adaptations to the home for essential equipment and facilities such as wet rooms, tracking hoists for lifting, stair lifts and widening of doors. Planning decisions were lengthy and it often took over twelve months to secure the alterations required, sometimes resulting in changes that were inappropriate for the needs of the child and the family. There was also concern from parents that the needs of the child change over time, as they grow and develop, and that this was not taken into account, particularly by the local authority, in terms of the planning ahead for what the future needs might be.

*Availability of wheelchairs and other equipment:* parents were concerned that in order to access the service they had to 'put up with what was on offer' and constantly 'battle with red tape' and a perceived lack of understanding from some agencies of the complexities of the family situation. and capabilities of individual parents to seek out and fight for such support.

*Incontinence and toileting facilities:* parents were very critical that they were only provided with three nappies per day for their child, which was considered totally inadequate. Parents then had to source and buy additional nappies themselves, usually without being given information about where to go to do so. All parents of older children expressed very high levels of dissatisfaction with the provision of toilet changing facilities within the Borough. A

lack of appropriate changing facilities at hospitals and clinics was also an issue of great concern. They suggested that there is currently only one location in the area that has a ceiling hoist facility in the public toilets (at Chester Zoo) which enables older/larger children to be changed. In other cases parents have to use changing facilities that are designed for babies or very young children which is not suitable.

*Impact on the family:* The time taken to do everyday things impacts not only on the activities of parents but on those of other family members as well. One of the most significant issues that arose was the emotional impact that families face in coming to terms with their child's condition and the wider implications of this on the whole family. Parents felt that after the initial care that they received from medical practitioners, which was acknowledged to be of the highest standards, they felt that they were very much 'left to get on with things'. Impact is not only a result of the cumulative effect of past experiences but also of the parents' constant need to think ahead and plan for a future in which their health and that of their child may deteriorate and where there may be no other family members upon whom they could rely for future care. Engaging with some services is described in confrontational terms, although there is recognition of good practice by individuals within services, and for most parents there are key practitioners who they and their child have developed long-standing relationships with which are described in positive terms.

*Good practice identified by parents:* two services in particular received numerous positive comments, notably the portage service, and the continuing care team at Clatterbridge Hospital. Within each service parents were keen to identify key practitioners who they felt had made continued extensive efforts to support parents, often, as was described, over and above their normal duties. In addition, there was praise for many consultant staff working at Arrow Park and Alder Hey hospitals who had provided parents with much support and advice early on in their child's lives. Often these practitioners provided signposting to other services, and were able to give some reassurances at a time when parents described themselves as being low, vulnerable and uncertain. Fear of transition emerged as a prominent theme throughout discussions with parents. These fears were most tangible when discussing the changes that parents felt would be experienced when their child moved from what they felt was a safe and secure environment in primary school, to a more risk-prone and less accommodating environment in secondary school. The important role that the portage service played in allaying the fears at the primary stage may be one area where good practice can be replicated to improve other transition stages. Finally, the operational features of the Lyndale School were cited by many of the parents interviewed as being an example of good practice, something that was also supported by practitioner interviews. Specifically, the ethos of the school was highlighted in relation to the extensive care and support that both teaching and non-teaching staff demonstrate towards the children. In addition, parents felt that there was greater emphasis on non-academic aspects of their child's development which was considered more important than academic achievement. (

### **Findings from Practitioner Interviews**

In total eleven interviews were conducted across services including; education (head teachers); health and social care; the local authority; and non-statutory services. Practitioners were asked a range of questions broadly in line with what parents discussed, around issues of how existing services work together; provision of information; transition

services; parental partnership and involvement in decision-making, and what they thought about developing future provision.

What emerged was a strong sense that individual professionals are committed and passionate about their work, with empathy for family's needs.

One area that was recognised as a cause of difficulty for families and practitioners alike was that of transitions. It was clear from discussions with a number of practitioners that there were historical problems in the transitions service, however, recent changes were being implemented and it was also suggested by the DASS Transitions team that problems had been recognised and were being addressed, for example through beginning the transition process much earlier (at age 14), introducing a protocol that would include the active participation of all services early on, and providing multi-media information to parents early on. The work of the Aiming High team emerged as an area that had achieved some success in addressing parental concerns and practical issues, especially in relation to short breaks services. The service also is essential as a main point of contact through which information can be disseminated about the range of services available.

A concern was raised about the consistency of service provision, specifically in relation to the provision of play schemes or extra-curricular activities in out-of-school hours through the Aiming High scheme. It was noted that there was variability in the secondary schools did not run activities for the same length of time as other schools during holidays. This was one area that a number of practitioners felt could be improved.

A number of practitioners that were interviewed mentioned their involvement in 'team around the child' meetings and how regular multi-agency meetings were an integral part of improving support to children and their families. This, however, was not always recognised by parents interviewed, some of whom felt that services repeatedly failed to communicate effectively and to work in unison in support of their child's needs. This might indicate a tension between the effectiveness of individual practitioners working within service boundaries It was suggested that not all practitioners are always included in team meetings (the example provided was that of the Speech and Language Therapy service) and therefore there is a break in the continuity of service.

A number of practitioners were keen to endorse the way that some of their colleagues in their own and other services go over and above their professional remit to ensure that information is communicated, but it was also recognised that cross-agency communication was variable. An example of good practice in relation to cross-agency communication and team working is the portage service and the continuing care team who have developed strong and trusting professional links.

There were some concerns expressed by several practitioners about the arbitrary nature of using the categorisation of PMLD, which resonated with comments that some parents had made. Different practitioners had differing emphases on what they felt were the most important issues. Some felt that the issues extended more widely and concerned all children and young people with special needs. In addition, there was a concern expressed by some practitioners with the notion of providing services on age-specific criteria where chronological age was not a determinant of ability or future orientation.

## Conclusion

The Aiming High for Disabled Children (AHDC) programme (DCSF, 2007) set out three priority areas for responding to the needs of children and young people with disabilities: empowering disabled children, young people and their families; promoting more responsive services and timely support; and improving quality and capacity through boosting the provision of vital public services. In Aiming High for Disabled Children the report went on to identify a core offer for disabled children, young people and their families which was set out again in a progress review of 'Best Practice to Common Practice', (DCSF, 2009b). This core offer covered detailed recommendations but broadly in line with the following outline:

**information:** disabled children and their families able to access appropriate information at every stage of a child's life;

**transparency:** levels of support for disabled children and their parents determined on a fair, understandable and transparent basis, with social care;

**assessment:** disabled children and their families to benefit from integration of assessment processes, with shared information, shared basic assessments;

**participation:** families to take more control e.g. of budgets for care packages;

**feedback:** a clear and published complaints procedure for all families who are not happy with the services they are receiving.

The findings of this research have been mapped onto these 5 standards and although it is not the purpose of this research to make *recommendations for action* by the Council in relation to its review, some *key issues for consideration* have emerged which the Council may wish to bear in mind when reaching its decisions in due course. These need to be read in conjunction with the detailed accounts of the concerns and priorities of parents and the perspectives of practitioners, some of which may be addressed relatively easily by adjustments to management and procedures or by policy review in one or more partner agency. It may be concluded that these areas for potential action should be considered and resolved before embarking on organisational or structural change to services which might produce unforeseen or unintended consequences in the complex systems of support for children and young people with PMLD and their families and carers.

## ISSUES FOR CONSIDERATION

**better information** – Information and knowledge about the child and their current and future circumstances as well as the services available is not moving sufficiently freely and effectively between parents and agencies and between agencies. How can different levels of information, appropriate for and targeted on the individual child or young person be made available in a timely and accessible way such as to ensure fully informed decisions by all concernedV ;

**more transparency** – The ways in which the range and level of support for parents and carers is decided by the agencies involved is sometimes too opaque. What support can

parents expect, how do they access it, what are they expected to do on their own, where are the discontinuities and who is there to help to bridge the gaps?

***more personalised and coordinated assessment*** – There is still some tendency on the part of some agencies to regard children and young people with PMLD as a homogeneous group but each individual has a unique set of needs and more account should be taken of these differences between children in the PMLD category - confusion around different professional and working definitions of PMLD do not help and should be clarified;

***more participation*** – Parents do feel that they are able to give their opinions but quite often they are frustrated because this seems to have little impact on decisions. Although they are not currently enthusiastic about taking more direct control through personal budgets some do feel excluded when decisions about services are made “behind closed doors” in panels or meetings and these should be more open and accessible.

***improved feedback*** – Procedures and practical relationships between parents and agencies do not recognise sufficiently the confusion that can result from the complex range of professional feedback that makes some parents and carers feel lost in the system – a situation that may be associated with the capacity, training and level of involvement of the practitioner working with the family.

***service development*** – In spite of strong professional commitment by many individuals in the agencies involved with each child or young person, there are concerns about lack of continuity and coherence - a more effective “key worker” approach, offering multi-agency and multi-professional coordination and, if necessary, advocacy might help parents to feel that they were not fighting alone and against the system. This in itself might help to identify and address potentially unhelpful or dysfunctional policies, procedures or practices in the support services including for example, transport for after school or out of school activities, planning and installation of adaptations and equipment in the home. Consideration could be given to a more strategic, multi-agency commissioning approach that reviews current and future provision of education and other support services from first principles before “tinkering” with the current arrangements.

***capacity and resources*** – it is recognised that the issues set out in this summary do not take account of financial or other resource implications and the need to secure necessary staff capacity. This information would need to be provided at a later stage. However issues raised by parents and, in some cases practitioners, should be the focus of careful consideration and it may be that some concerns might be addressed by adjusting or reconfiguring the relevant services without additional resources. Such responses could emerge from a strategic commissioning approach.