

Southern Derbyshire Service for People with Profound and Multiple Learning Disability

Debbi Cook

In Southern Derbyshire we have 5 locality teams serving the Adult Learning Disabled population. We take people from transition at 18 to the end of life. Each team has a nurse, a physiotherapist, an occupational therapist, a speech and language therapist and a psychologist. Our PMLD population is a small percentage of our overall work, but some of the most complex and rewarding work we do. The service we provide for our clients is based solely on the principle of being Person Centred. This is never more self-evident than in the work we do with our profound and multiply disabled clients.

In our experience the PMLD clients we see:

- Have a profound learning disability
- Have a severe physical disability
- Need skilled carers to understand and interpret their communication
- May have difficulties with eating and drinking and may be PEG (Percutaneous Endoscopic Gastrostomy) fed
- Often have additional sensory problems e.g. sight and hearing.
- Often need exceptionally high levels of support with all aspects of their care due to their multiple complex health needs
- May have episodes of behaviour that are difficult to understand, interpret and manage.
- Often have epilepsy
- May have autism and/or additional syndromes

Currently in Southern Derbyshire, there are approximately 159 clients with PMLD. These numbers reflect those who are permanent wheelchair users and those who are ambulant (often with assistance i.e. gait trainers and walking frames). While these numbers do not seem particularly high, the amount of input these clients need is exceptional as they often have complex, multiple, life-limiting conditions, and many are still being cared for at home by family. Prospective numbers coming into the service are high, increasing rapidly, and the conditions people present with are more complex. Over the last 20 years neo-natal care has improved and children with conditions that would have previously precluded them from surviving into their teens are now being managed effectively, prolonging their survival. Services need to consider the resource implication of so many children with complex needs coming into Adult services.

The motivation for all our work

The driver for all our work with this client group is that we value them for being themselves, not for what they can do, not for what we wish they could do, not for what society thinks they should do. Our service hinges on the ability to respond and communicate with our clients on the most instinctive level, using techniques such as Intensive Interaction to create a bond of acceptance that allows us to provide an empathetic and compassionate service that meets their individual highly complex needs. This client group depends on total care and support given by others and is therefore the most vulnerable group of people the service provides for.

We also engage and support the carers, both families and professionals as they are the lynch pin in identifying, treating and supporting this very special client group. Professional carers need intensive training and support to keep their clients safe and healthy. Parental and familial carers need even more support and understanding of the care they provide. Parents, siblings and other relatives are often providing cradle to grave care for this client group and dealing on a daily basis with emotional, often distressing and physically draining activity. They need our assistance and understanding to manage the enormity of the tasks they undertake, twenty four hours a day, 365 days a year.

'Families caring for a son or daughter with profound intellectual and multiple disabilities face an exceptionally heavy responsibility of care'. Mansell (2010)

Within the Learning Disability Service, we operate in episodes of care. This means that clinicians work on specific goals and once these goals have been achieved they will be discharged. However, due to the complexity of the needs of people with PMLD we work

differently, and individuals often remain open to us for a substantial period of time. Clients with PMLD are often supported by our staff for the whole of their lives as their health needs are ever changing and their wellness hangs in a balance that can be tipped into life-limiting by something as simple as a small misjudgement in giving a drink or even a change of weather. This has a profound effect on staff that consequently need the close support of their fellow team members to help them cope with the emotional highs and lows that arise from dealing with this client group.

The community teams work closely with other agencies e.g. Social Services, Primary and Secondary Health care to provide seamless, optimal care. We also have the Complex Needs Clinic for clients with PMLD. The Complex Needs Clinic was started in 1999 and was required because most clients with PMLD were seeing multiple medical practitioners both from Primary and Secondary care and there was a lack of communication between Medical Services. The clients with PMLD were also not having a regular "overall" review, which in view of their complex health needs was deemed essential. The Clinic is now seen as a National example of Good Practice.

The Clinic is run on a weekly basis by Dr Xia Lin, Consultant in Rehabilitation medicine, and clients with PMLD from all over Southern Derbyshire are reviewed yearly or more often if appropriate. Clients are supported by carers or family and staff from the Learning Disability team, usually the Physiotherapist or the Nurse. Dr Lin looks at all aspects of the client's health from management of conditions like epilepsy, spasticity and orthopaedic problems, to aspects of basic care such as bowel management and posture. The Service has proved invaluable over the years as Dr Lin is able to "fast-track" clients into appropriate departments, and also monitors their on-going health problems.

Outcomes of an internal audit

In November 2013 the Service undertook an internal audit. This revealed that hospital admissions in Southern Derbyshire among this group of clients, with such complex needs, were significantly lower than in other parts of the country (10.5/1000 as opposed to the National Average of 70/1000). The Health needs of this client group are varied, multifactorial and often life-limiting. For example, if a client has a dislocated hip they may be unable to side-lye, so they can't have their chest treated on that side.

If they get a chest infection the coughing increases their spasticity, making their back deformity worse, which misaligns their head so that when they drink they become distressed and aspirate. Their treatment often involves the whole team supporting the client and their

carer, with overlapping roles in order to maximise the efficiency and efficacy of service delivery.

The intended overall outcome for all PMLD clients is for them to be Healthy, Happy and Safe. All Services for this group, regardless of profession have this as an end goal. The fact that we have much smaller numbers than the National Average being admitted to Hospital in Southern Derbyshire proves that the Service is effective in maintaining the health of these people with such multi-faceted life-limiting conditions.

What must be taken into consideration when looking at Outcomes is that for PMLD clients we are looking at 24 hours a day, on-going life-long management of complex life-limiting conditions. Services are predominantly provided through carers and families with support from the appropriate professionals.

We pride ourselves in Southern Derbyshire with working closely with client, families and paid carers to provide the best service we possibly can for this small but important group of people.

Our treatments need to be flexible, individual, compassionate and creative, holding the client at the centre.

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