

**JOINT HEALTH SCRUTINY COMMITTEE ON NHS Telford & Wrekin Community  
Children's Nursing Service**

**Minutes of a meeting of the Joint Health Scrutiny Committee on NHS Telford &  
Wrekin Community Children's Nursing Service held on Monday 1st March 2010  
in Coral House, Longbow Close, Shrewsbury**

**PRESENT**

**Telford & Wrekin Council – Members**

Councillors D.R.W. White and Veronica Fletcher, and Val Lindley (Co-optee).

**Shropshire Council – Members**

Councillors Jo Jones, Liz Parsons.

**Other attendees –**

Jo Banks	Deputy Director – SSCYP
Linda Cancelliere	Nurse Manager – Community Children's Nursing
Sharon Boyle	Community Children's Advanced Nurse Practitioner
Rachel Lugg	Community Children's Nurse
Chris Lakin	Community Children's Nurse
Tash Digby	Community Children's Nurse
Fiona Hollands	Community Children's Nurse
Caroline Brewer	Special School Nurse – the Bridge School Telford

Councillor D.R.W. White welcomed all Members and participants to the meeting and requested that everybody should introduce themselves.

The Head of Children's Community Nursing, Linda Cancelliere, gave a comprehensive presentation in response to a number of questions which had been submitted by scrutiny in advance of the meeting. These notes only include supplementary information that was provided in addition to the information provided in the presentation.

Slides 1-4 shows the four components of the service (Long Term Conditions, Acute (H@H), Palliative Care and Respite/Continuing Care) and what common services are provided. The service provides fully integrated individual care packages for children and families, with clinical excellence at the centre.

The organisation chart shows that there is a proportionately small service for Shropshire with a separate service for Telford & Wrekin. Most of the nursing staff are band 6. The Palliative care team and respite care team work as an integrated team.

Long Term Conditions and Acute (H@H) services are both 9am-5pm. (Palliative Care is 24/7 and Respite is 7am-11pm, 7 days per week).

**Q2. What services does the Scheme cover?**

Case studies are provided in the document Patient Stories.

Q3. How many patients does the scheme serve?

It was noted that children with constipation make up a significant number of the Acute service case load. Where possible and appropriate, the team train parents to undertake procedures themselves, for example, children with Juvenile Idiopathic Arthritis need weekly injections and parents can be trained to administer these.

Q4. What population do you serve? (demographics and clinical need)

The Acute element of the service is for referrals from Shrewsbury and Atcham GPs and hospital referrals for Shropshire County only, and there is only 0.8 wte of a post to deliver the service. There is no service for children outside this area, and they have to go to hospital. Any expansion to this service would need to be part of an evaluation and prioritised according to resources.

Q5. How long did it take to plan and implement the Scheme?

Supplementary questions;

**What other areas did you look at as examples of good practice when the service was being set up?**

It is very difficult to pinpoint one model as best practice as not all aspects of one model will apply to another area. There are a number of models nationally that are tailored to specific areas. The service also has to be integrated with existing services so the starting point is not always the same.

**Will there ever be a time when the service would be able to take over A&E and prevention for the whole community?**

This would be very difficult and this would not be within the remit of the service, it would be about working in partnership with acute services including A & E to reduce the number of children with minor illnesses attending A & E where possible and safe to do so. A key principle behind the service is integration with hospital services and a shared workforce. One of the big issues for the community service is recruiting staff as the skill level required to work in the community is specialist and very difficult to recruit to posts. Another element is gender because most nurses are women who may have family responsibilities that are difficult to balance with a 24/7 service.

**How does the service cover neonates?**

There is a very small neonatal outreach service at Shrewsbury Hospital. The service work with the hospital where necessary for neonatal care. They will take on babies with long-term conditions as soon as possible, but the outreach deals with short term neonates. It is up to the hospital to decide how we deal with small neonates, however based on trends the demand is increasing.

**How can it be cheaper for a nurse to visit/treat children at home rather than in hospital?**

It is not a cheap option, but it's about what is best for the child and family. We will never prevent all admissions, but where it is safe and appropriate, we can prevent short stays such as for D&V. The best option for the child and family is to receive care at home where possible and safe to do so, however we will always need ICU and acute hospital services for children with high dependency needs.

### **How can the team provide care in a safe manner at home when the child may need specialist equipment?**

This is an on-going issue and we work closely with the commissioners so that a stock of equipment has been built up over the years since 1994 e.g. nebulisers, ventilators, Blood pressure monitoring equipment, oxygen saturation monitoring equipment, suction machines, syringe drivers.

### **Do home adaptations cause any problems?**

We work closely with local authorities on adaptations. It is possible to predict some needs e.g. as children get older and need hoists. As technology moves on more children survive and survive longer so the need for support and equipment grows.

### **Do you work with RSLs about integrating services? Some old prefabs in St. Georges in Telford were adapted to incorporate a room for a carer and perhaps this is something social housing providers should think about.**

We do talk to RSLs, and to the local authorities and use Public Health Reports to try to predict future needs but it is very difficult. The other problem is that families move into adapted housing which then becomes the family home and they do not want to move after the death of a child to allow another family in. There needs to be a way to address this.

### Q6. What feedback have you had from children and their families?

The service has very good feedback, and the members of the group were surprised that they had not been aware of its existence!

### Q7. What respite care is available for families?

### **Can it be a relief for parents if the child goes to hospital as it gives them some respite?**

Not usually. It's very stressful for parents looking after the child at hospital instead of at home. Parents will sleep at the hospital to care for the child and they don't sleep as well as at home. There is a lot of nursing research on the effects of hospitalisation available that supports this view .

### **Who provides the respite care?**

Often respite is about sitting in the home to enable parents to go out. Support workers are trained to do this, and there is a competency framework for each individual child. The support workers are trained and supervised by senior nursing staff.

### **Is respite always necessary?**

For the vast majority of families. There is nothing between hospice provision and family care provided by social services, so a number of children fall into this gap. Parents don't always want their children to go into the hospice, due to the association with end of life. We do need to strike a balance between giving enough support and not giving too much which can lead to parents disempowered from their responsibility.

### **How much time do you spend doing this and do you have enough time for each family?**

There is a lot we can do over the telephone, giving advice and support. There is always pressure and new referrals, but parents always know where they can get help and support on the phone. We also provide advice and support to hospital staff for children with long-term complex needs as these children spend more time at home with very few hospital admissions, therefore, there can be certain procedures that the community staff become more competent in managing eg changing gastrostomy tubes, tracheostomy care and we are able to provide training and support to staff within the acute hospital to support the child's admission when necessary. The community team are always involved and doing clinical risk assessments with the patients. It can be a seesaw process with parents needing less support in times of relative stability and more if the situation changes. The idea is for the nursing team to train the parents and then step back when they can safely manage.

### **How does school fit in the care package and do the children access mainstream education?**

We do lots of training with schools but if the child is too unwell to attend then parents can choose to home educate, but children go to school as much as possible. It's really the choice of the parents. We provide support where appropriate. About half the children are in mainstream schools and half are in Severndale or the Bridge.

### **Is there enough respite care provision?**

We have a respite contract and a contract with the hospice but are always challenged to do more. It is about providing parents with enough time to do what they need and this has to be balanced with what is reasonable. It is not possible to please everyone and there are always more children coming into the service.

### Q8. How does the service adapt to the child's needs as he/she gets older? How is the transition to adult services planned?

For the long term conditions we work closely with the local authorities and with district nurses regarding equipment and support. For the acute element of the service there is no need as these children are on the caseload for a short period of time. For Palliative care we work with the hospice and district nurses. Hope House has now extended their service to cover up to age 24 to support families during transition.

### Q9. How is the care for individual children and families monitored? How has the scheme been evaluated?

All children have a plan of care which is regularly monitored. Palliative and respite services have service user questionnaires which are now being done with audit. A questionnaire about Long term and Acute services is being planned. These will feed into the review.

### Q10. What are the clinical outcomes from the scheme – how does this compare to the previous service provision?

There are no specific clinical outcomes within community children's nursing nationally, other than the benefit of care in the community and close to home. The outcomes are more around increasing the understanding and confidence of families, providing multi-agency services and providing a safe and effective service.

### **Are you involved in End of Life?**

We have the Palliative care team who receive referrals predominantly from the acute hospital wards and from tertiary children's hospitals in Birmingham/Alder Hey. We support families in the choices they make and also provide some bereavement counselling whilst also sign-posting families to other services that can support them.. We work closely with Hope House hospice and the acute hospital oncology nurse specialist providing shared care to support families at home

### Q11. What are the clinical protocols and do nurses have direct admitting rights?

We work within NICE national clinical guidelines. We develop local service guidelines and care pathways. The acute (H@H) nurse can refer directly back to the ward or assessment bay. Referrals from GPs can be referred straight though to the assessment bay. Some of the children on the case-load of the long term conditions nurses have open access to the hospital ward and can therefore be referred directly to the ward or families can go straight to the paediatrician for advice.

### Q12. How many staff support the hospital at home scheme? What proportion of their time is spent travelling?

There's 0.8 wte, band 6 (Sharon Boyle). the post needs a minimum of band 6. Travelling is difficult as the service is so small and there can be long travelling times.

### Q13. What training do staff need to commission / provide this service?

All the staff are trained children's nurses with a minimum of 2 years experience in children's hospitals or children's A&E. All have acute experience. They also work to competencies linked to each child's care plan. A number of staff are training to do acute assessments . The Acute nurse (Sharon) is doing an APNP (Masters level) which is a very advanced assessment/diagnosis/prescribe qualification.

### Q14. How to does the scheme work with specialist tertiary hospitals like the Birmingham Children's Hospital?

Referrals are accepted directly from tertiary hospitals (Birmingham, Alder Hey) but not to the Acute service.

### Q15. How is Hospital at Home funded? What has been the impact of the scheme on the budget for Social Care Services? How does the cost compare to previous service provision?

An initial £20k start up allocation funded by SCPCT. We are not aware of an impact on the social care budget, and there was no previous service provision.

### Q16. Having implemented the scheme what have the benefits been? What are the disadvantages? What was difficult to implement?

The benefits have been to the child and family in terms of empowering parents and helping them to cope better, financial benefits to the family from reduced time off work and less travelling to hospitals, the preventions of admissions and earlier interventions.

The difficulties have been with GP referrals because they need a 24 hour service and the service operates from 9am-5pm. There is a need to keep the service on

GPs radars and to make sure they are confident in the service, and that it is provided consistently.

There is an issue with resources – not for equipment and supplies – but with staff.

What would you do differently?

Request more resources for more staff, target GPs sooner. We would do more training of junior hospital staff because they don't know what can be delivered in the community.

Q 17 What advice would you give to Telford and Wrekin and Shropshire in the development of the scheme?

To make sure that people know about the service, make sure that there are enough staff to deliver the service across appropriate hours and to develop a service that is clinically sound rather than just target driven.

It is good to get the GPs on board as they will only refer if the service is good and available. Developing confidence with GPs and acute hospital staff takes time. A lot of the KPIs are numbers, and that is what the commissioners look at but these don't take into account travel, training and the time that's needed to deliver the best service with robust assessment.

It is critical to build a good foundation – if the assessment and care pathway is developed well at the beginning, it means there is a better service down the line.

The service is being reviewed and this is welcomed. Wallace Pointon (commissioning programme lead) is leading the review of Hospital at Home. The nurses have seen many children at home and have done a good job for years because the service is built on quality. The service in Shropshire is acknowledged at many national and local forums as being a high quality. service. We have a good, professional reputation and the staff continually keep ahead of the game as technology develops. The service is so good that we are aware that some people have moved into county or changed GPs so that they can access it.

**Do you have any records to demonstrate how it was built up on these high standards?**

The service was set up in 1994 and in the early days was ad hoc and this kind of documentation was not systematic so we don't have those kind of records over the whole period. The climate now is completely different and a good system of service development has evolved. The challenge is to maintain high levels of care and do the number crunching.

There is an impression that the H@H is a new service and the terminology used is not helpful. Children's conditions change so they don't; fit neatly into boxes like Acute or Long Term because they move around so much and fitting things into one box isn't helpful. Hospital at Home has become a buzz word for what the service has always done, but we would like more resources to provide the service to more children.

The question for scrutiny members is how do we make sure the service is properly funded, sustainable and good quality?

### **How would you be involved in the development of the service?**

Wallace Pointon is the project lead for the joint commissioning review of the service, working with Shropshire and Telford & Wrekin and chairs the Steering Group. Linda sits on the steering group along with clinical specialists, and local authority representatives.

### **How are the Palliative nurses supported?**

It is an emotionally demanding role. There is support built in within the team which has weekly meetings. They also meet the safeguarding team and staff at Hope House and have links with the clinical psychology team. There is also clinical supervision available to all staff within the PCT. The members were shown a case study dvd of baby Jack who was referred to the service following surgery at Alder Hey and moved home with ventilators, a tracheotomy and oxygen so all the equipment was at home and the parents were supported to manage acute episodes at home. There was a big package involved, including training carers. Jack is now in mainstream school.

### **Can you account for the high levels of constipation – is this poor diet?**

The children's constipation service was set up in Telford in 2009 following the acute (H@H) nurse for Shropshire identifying high numbers of referrals for children with constipation. This led to the development of a steering group including staff from community and acute services looking at the management of children with constipation across both Telford and Shropshire. Diet is only one aspect of the problem, there can be many factors that may cause childhood constipation. Within the clinic the nurse will provide advice and support to the child and family regarding diet, fluid intake, behaviour management, exercise and prescribe appropriate laxative treatments. The clinic is nurse-led and since January there have been 20 referrals in Telford. A clinical psychologist works within the nurse-led service providing advice and support to the nursing staff regarding behaviour management as well as direct support to families where required. There is no like-for-like service in Shropshire currently. The nurses also provide education sessions to GPs using NICE guidelines on the management of childhood constipation and provide advice on the nurse-led service.

### **How far do you see the service going?**

The real problem is with the workforce and where to get staff from. There are strong foundations here, but the skill set required to provide a comprehensive service for children at home is very high.. There can be a perception that the skill set of nurses in the community are out of date, but this is not true in Shropshire where the nurses have a good reputation for having very high level skills. They are experts at meeting children's needs at home. The team works very hard to make sure they keep up to date with new technology and are ahead of the game. The community nurses train the acute staff in the hospital in some clinical procedures and are acknowledged as being the experts for children with long-term conditions.

The other difference with the community nurses have a completely different relationship with parents than the hospital staff do. The nurses are guests in people's homes so the dynamic is different from a hospital environment where parents are not on their own territory and tend to be less empowered..

**Where will extra staff come from?**

There are a number of positive incentives – good salary, working in the community can be a favourable option, it is more rewarding than working on a ward. The team is very passionate and committed which means that turnover is very low and there is a solid foundation. We also see parents blossom as their knowledge grows, and we give them emotional support, but this cannot be measured.

**Do you have any other view on how an extended H@H would work?**

With the reconfiguration plans, there is a risk that services could become a football between the 2 hospitals and we would not want to see that happen. We would embrace expansion of the service and having a bigger, well developed, well resourced service with clinical excellence at the centre; working along side the hospital.

Next steps:

- The joint committee to meet Wallace Pointon, and to find out the results of the commissioners review due to be completed at the end of April
- To visit Northamptonshire to explore their model – a rural/urban mix – which is bigger and further developed than Shropshire
- To review the results of the national Community Children's Nursing Review underway

At the end of the meeting Derek White and the other scrutiny members thanked the community nursing team for attending the meeting and answering the questions, and moreover thanked and congratulated them on their hard work in providing an excellent service.