Edition TWO : February 2010

NHS SCOTLAND

BETTER HEALTH, BETTER CARE

update

on the National Delivery Plan for Children and Young People's Specialist Services in Scotland

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healthier scotland
SCOTTISH GOVERNMENT

WELCOME

WE HAVE REACHED A PIVOTAL POSITION IN THE IMPLEMENTATION OF THE NATIONAL DELIVERY PLAN AS WE ARE NOW PAST THE HALF-WAY STAGE OF THE INITIAL THREE YEAR COMMITMENT.

NOT ONLY IS THIS AN IMPORTANT TIME TO LOOK BACK TO EVALUATE SUCCESSES ACHIEVED; IT ALSO PRESENTS US WITH THE OPPORTUNITY TO LEARN FROM ANY CHALLENGES ALREADY MET WHEN PLANNING FOR THE FUTURE.

2010/11 sees the largest phase of investment to date. The funds to be allocated stand at £19 million: an additional £10 million on top of the recurring commitments from Years 1 and 2.

As well as augmenting those services previously supported, Year 3 sees investment in several new areas, identified by members of the Implementation Group as those most in need of immediate support. Page 16 offers further details of these areas. The totality of NDP investment across the initial three years puts specialty services in a much stronger position than previously, not only in terms of new appointments but the underpinning infrastructure vital to maintaining these services: education and training, Managed Clinical Networks, telemedicine equipment and more.

I appreciate that there is always more that we wish could be done, and that there are clinicians in some specialty areas who will be disappointed not to have received NDP investment.

However, let us not forget that we have been tremendously fortunate to secure this level of funding and that there will be beneficial knock-on effects for all services from the activity so far. The Implementation Group is closely monitoring our progress against all 55 commitments made in the National Delivery Plan to ensure that they are met.

A tremendous amount of work has gone into making all this happen and I am grateful to all those involved, not only members of the Implementation Group but all those delivering specialist services across the country. Thank you for your advice, enthusiasm and continuing commitment.

We are delighted by the Scottish Government's commitment to continue funding specialist children's services beyond 2011. This should provide the necessary reassurance to Health Boards to make the appointments as set out in proposals, to ensure the sustainability of service which is a fundamental aim of the National Delivery Plan. But this continuing funding is conditional upon our ability to prove, not just anecdotally but with robust evidence, that the investment has led to real, measurable improvement in patient care. To this end we will be asking regions to provide regular progress reports throughout the remainder of the NDP lifespan. The work on clinical outcomes being done by the Information Services Division of NSD will also provide a valuable method for capturing patient outcomes across specialties.

I hope you find this second edition of the National Delivery Plan newsletter positive and informative. It is testament to the contributions which everyone is making towards better care for those most in need.

Best wishes,

CAROLINE SELKIRK
CHAIR
National Delivery Plan Implementation Group

TAKING STOCK:
what have we achieved in Year 2?

Since our last newsletter in summer '09, we have seen the NDP money beginning to make a real impact on frontline services and we are well on the way to meeting the commitments set out in the Plan.

In general terms, the expansion of specialist teams to include AHPs and specialist nurses as well as consultant time has meant stronger, more consistent multi-disciplinary teams. These teams are better able to take part in clinical networks, offer thorough patient assessments and, in some cases, quicker access. Importantly, we are seeing a shift towards more care being provided locally.

Providing staff with the education and training required for these specialist areas is fundamental to the successful delivery of care. NHS Education Scotland (NES) has made valuable progress this year in developing resources to upskill existing staff, providing education and information to those considering a move to specialist children's services and liaising with Higher Education Institutions to expand the training currently available.

The AHP network, launched in October, provides a useful forum for professionals to share expertise, discuss common issues and develop resources. The Managed Knowledge Network, also launched in October, aims to be the 'one-stop' for all those involved in MCNs (see article on page 8). NES now has a representative on every MCN, and is helping them to identify and meet their training needs.

Another notable development is the appointment of a psychologist to develop educational resources to upskill healthcare professionals to deal with the psychological as well as the medical aspect of a patient's condition. This work will complement the regional investment in psychology in Year 3 and build towards a holistic approach to care.

NDP funding has helped expand current services, enabling more patients to be treated (for example, there are now two extra anaesthetic lists provided in Tayside as a result of the appointment of a consultant). Specialist nurse appointments mean that more clinics can be nurse-led, freeing up the time of consultants and using workforce more efficiently. Multi-disciplinary teams are growing: speech and language therapists, dieticians, physiotherapists and other professionals now offer a more comprehensive care package to patients. The increased availability of multi-disciplinary input also means that more effective decisions can be taken.

In this funding cycle National Services Division has established four new Managed Clinical Networks: for Cystic Fibrosis, Children with Exceptional Healthcare Needs, Endocrinology and Rheumatology. Regular meetings with all MCN managers provide a useful opportunity to exchange ideas, promote best practice and address common issues. NSD has also been funded to develop a minimum dataset which all MCNs can use. This, in conjunction with the simultaneous work into clinical outcome indicators being progressed by ISD, will help to provide networks with valuable data to capture patient information and measure the impact of care.

TAKING STOCK:
CONTINUED

Telemedicine is increasing in profile and uptake, as new equipment is installed and training offered to ensure staff are comfortable using it to liaise with colleagues across the country. 2.5 FTE nurse specialists have recently been appointed and will be looking specifically at the role of telemedicine in cases of unscheduled care, care at home and to support clinical decision-making by colleagues in different locations. Furthermore, fruitful discussions are taking place with colleagues in remote and rural areas to look at how education can be delivered remotely using telehealth equipment.

All the above demonstrates the breadth of work underway as a direct result of NDP funding. Whilst the benefits can clearly be seen, this work has not been without its challenges. Recruitment has continued to be slower than anticipated due to Agenda for Change banding discrepancies and the time taken to put posts through the process. In some cases it has proved difficult to recruit to split posts or partial posts, and fixed-term appointments have been challenging to fill. The confirmation by the Scottish Government of the continuance of NDP funding beyond 2011 should help provide the financial reassurance necessary to encourage Health Boards to offer posts on a permanent basis. Establishing new permanent medical and AHP posts should move the services onto a more secure footing and help ensure that the NDP funding is aiding stability rather than providing a short-term boost which cannot then be sustained.

In light of the recruitment issues evident in Year 2, the North of Scotland has taken a new approach to plans for 2010/11: starting from a position of workforce planning they have identified the staffing required across all specialties. They plan to appoint generalist posts which are then given training in specific specialties, moving away from the previous model of partial posts e.g. 0.2 of a dietician, thus creating full-time jobs and increasing chances of successful recruitment. We will watch with interest in 2010 to see how this fresh approach takes shape.

The foundations laid in 2009 will stand specialist children’s services in very good stead for the future, and thanks once again to everyone who has worked tirelessly to make sure that the care we offer our patients is the best that it can be.

THE NATIONAL MANAGED CLINICAL NETWORK (NMCN) for CHILDREN WITH EXCEPTIONAL HEALTHCARE NEEDS (CEN)

DR PATRICIA JACKSON, CEN LEAD CLINICIAN
DR MARIT BOOT, CEN NETWORK MANAGER

THE NETWORK SO FAR INCLUDES OVER 300 PROFESSIONALS FROM HEALTH, EDUCATION AND SOCIAL WORK AND MOST IMPORTANTLY PARENTS AND CARERS OF CHILDREN WITH COMPLEX AND EXCEPTIONAL HEALTHCARE NEEDS FROM ACROSS SCOTLAND. THE NETWORK AIMS TO IMPROVE SERVICES FOR A GROUP OF CHILDREN AND YOUNG PEOPLE DEFINED BY THEIR COMPLEXITY OF CARE RATHER THAN THEIR DIAGNOSIS.

Working groups of the CEN Network

Dr Marit Boot (CEN Network Manager) and **Dr Patricia Jackson** (CEN Lead Clinician)

NDP funding has facilitated setting up the network for children with complex and exceptional healthcare needs (CEN) to provide improved services and to build on the experience and expertise of the Scottish Complex Needs Group. The managed clinical network actively encourages professionals from health, education, social work, voluntary sector and parents and carers of children with complex and exceptional healthcare needs to discuss and become involved in service improvement. Because of the large range of underlying diagnoses in children with exceptional healthcare needs, links with other existing networks are essential. The enthusiasm of the large number of motivated professionals and parents engaged in network meetings and events has been very encouraging.

A key priority for the network is the implementation of care co-ordination and the specialised keyworker training as described by CCNUK, which fits well with the child centred approach and the emphasis on sharing information central to the *Getting it Right for Every Child* (GIRFEC) structure. The implementation of a named keyworker by 2008 was prioritised in *Delivering a Healthy Future* (SG, 2007). The network is keen to support further implementation of keyworkers/lead professionals across Scotland.

Parents and carers are essential in identifying training needs and developing education together with professionals in the network. The initial focus will be on training to:

- Recognise the emotional issues related to enteral feeding in an online education module and an education day on 24 February 2010
- Improve communication between families and professionals
- Extend the knowledge of local professionals to facilitate care closer to home for children with exceptional healthcare needs

With the initiation of education and training, data collection and audit and the development of specialised pathways of care and care standards, the network is on track to fulfil the ambitions of the NDP to improve services for children with complex and exceptional healthcare needs.

More information about CEN assessment criteria, data, education and events on: www.cen.scot.nhs.uk

NESCAN (North and East Scotland Child and Adolescent Neurology Network) – does a network work?

DR MARTIN KIRKPATRICK, CONSULTANT PAEDIATRIC NEUROLOGIST, NESCAN LEAD CLINICIAN

Dingwall, 6 February: Snow and ice forecast, high winds. Another trip with Fraser and his wheelchair to Glasgow. Have I got enough changes of clothes? Where will I change him? What if he has another fit in the car like he did last time? My mum can drop off the other two at school, but I've had to ask my neighbour again if she'll pick them up. Hope they don't play up too much; my neighbour's getting pretty frail now. Last time was awful.

Only a small proportion of Highland's 40,000 children need to go to a paediatric specialist clinic every year but we should not underestimate the cost to families that this brings. Not just the financial costs of needing to take another day off work but the costs of disruption to what should otherwise be a reasonably normal family life. For families of a severely disabled child this disruption is magnified hugely.

The North and East Scotland Child and Adolescent Neurology Network (NESCAN) began its life in 2002 but has remained largely embryonic until recently. Rather than travel all day to a teaching hospital to be seen for a 30 minute appointment, children and their families are now being seen much closer to home. Twice monthly clinics in Inverness, for example, means less travelling for families. Perhaps at least as importantly these are done as joint clinics with the local paediatrician. Families see and participate in the decision making about further follow-up, who is doing what and when, and who to contact if things are not going to plan. The children's epilepsy nurse is there as well, to help advise parents how to cope; for example if their child was to have a fit on the way to the clinic.

NDP funding is, for the first time, allowing us to develop these services properly. There are now more clinics in more places with more support staff in places that are closer to the child's home. Inefficient use of limited resources, you might say? We, and our patients' families, resolutely disagree. We believe that we can and should make progress with a principle that we should deliver specialist paediatric care as close as possible to the child's home.

WITH THANKS TO FRASER AND HIS MOTHER

Things are much better now. Fraser still has lots of appointments but they're almost always in Inverness. I can drop the kids at school in the mornings and be back in time to let him get to school in the afternoon. Life's still not a bed of roses but it is easier and Fraser's still well looked after.

ADOLESCENT HAEMATOLOGY

DAVID DANIELS
PROJECT MANAGER, WEST OF SCOTLAND PAEDIATRIC TERTIARY INTERFACE SERVICES

CORAL BRADY
BUSINESS MANAGER, RHSC, NHS GLASGOW & CLYDE

As a result of Year 2 NDP cancer monies, the RHSC Glasgow and the West of Scotland Cancer Centre (Beatson Unit) have been able to appoint to the new and unique post of Consultant Haematologist with an interest in teenagers and young adults.

Dr Nicholas Heaney took up the new position on 1 January 2010, and will split his time equally between the TCT (Teenage Cancer Trust) Units at both hospitals. He has been acting in a locum capacity since October 2009.

The main purpose of this exciting new role is to lead the care for teenagers and young adults with haematological cancer, including the development of transitional care and a late effects service. In time it is anticipated that Dr Heaney will participate in a national role in service development for teenagers and young adults with haematological cancer in Scotland.

Dr Heaney said, "I am delighted to be taking on this new position that will be both challenging and rewarding. Teenagers and young people have told us that they would like a service designed for them that will give them equitable and age appropriate levels of care across both sites. I am pleased that we will be able to directly help and advise the young people during their difficult journey".

Dr Brenda Gibson, Lead Clinician for Children's Cancer Services at RHSC said, "This is the first post of Consultant Haematologist with a specific interest in teenagers and young adults in the UK. We are exceptionally pleased to be able to provide a service that meets the needs of this patient group and to deliver age appropriate support at a time when it is most needed".

The Teenage Cancer Trust Unit at RHSC was sponsored by the Teenage Cancer Trust. The Unit opened on 23 November 2009.

CHILDREN AND YOUNG PEOPLE'S SERVICES MANAGED KNOWLEDGE NETWORK

NHS Education for Scotland (NES) is a national organisation which aims to support better patient care by offering educational solutions for workforce development. Within the National Delivery Plan NES is charged with leading on a variety of projects to support the implementation of the policy. One of these has been the development of a Children and Young People's Services Managed Knowledge Network (MKN) website. The MKN is for all staff working in NHSScotland with an interest in children and young people's health. It provides educational networks for key service areas and allows professionals to exchange information across services.

The website was officially launched in October 09 and its main principles are to:

- Facilitate education and enable practitioners to share and access education resources online
- Offer access to expert information and support for personal and professional development
- Enable specialist communities to set up and manage their own websites and learning environments
- Enable staff to collaborate with colleagues in other areas

The Child Health team is working in partnership with Managed Clinical Networks (MCNs) to support education and the development of 'communities of practice' on the website. These enable access to guidelines, educational material, pre-defined literature searches and resources available through NHSScotland e-library. Currently cancer, cystic fibrosis, gastroenterology, inherited metabolic diseases, palliative care and renal and urology have communities on the website and we will be supporting other MCNs to develop pages in the forthcoming months.

> **"THIS IS AN EXCITING RESOURCE FOR CHILDREN AND YOUNG PEOPLE'S SERVICES WHICH ENABLES TRAINING AND EDUCATION MATERIAL TO BE SHARED BY ALL PROFESSIONALS"**
>
> **JENNIE KING**
> **PROJECT LEAD, NHS EDUCATION FOR SCOTLAND**

The MKN also hosts additional projects which NES is working on to support the NDP. These include an Allied Health Professional and an Advanced Practice Network as well as an Education Toolkit to support MCNs.

Finally, to ensure sustainability a sub-group has been established to manage and plan how the development of the website can be taken forward. This consists of key stakeholders from across Scotland. Representatives from MCNs are also responsible for maintaining the content of their ‘communities of practice’ and ensuring it is current and up-to-date.

For more details please visit: www.knowledge.scot.nhs.uk/child-services

For additional information please contact:

JENNIE KING
PROJECT LEAD CHILD HEALTH
Email: jennie.king@nes.scot.nhs.uk

> **“A USEFUL RESOURCE FOR STAFF TO ACCESS INFORMATION ABOUT CHILDREN AND YOUNG PEOPLE’S RESOURCES IN ONE WEBSITE. I REALLY LIKE THE LAYOUT AND ACCESSIBILITY OF MATERIALS”**
>
> **MANAGED KNOWLEDGE NETWORK USER**

Welcome

Welcome to the NHS Scotland **Children and Young People's Services Managed Knowledge Network** (MKN). The purpose of the MKN is provide specific information and resources for NHS Scotland staff working with children and young people.

The website is designed to be updated and monitored by its members with the aim of achieving shared ownership and responsibility.

To **login** please use the link above. You will need your NHS Scotland Athens username and password. If you do not have a username or have forgotten your password **click here**.

News

Launch of the MKN website: October 2009

The website will be launched on the 7th October at the RCPCH Paediatric Frontiers education conference. To help you navigate around the website please look at the 'Introduction to the Children and Young People's MKN' presentation on the Help page.

MCN Education Toolkit: 30th Septmber 2009

A toolkit to support Managed Clinical Networks to identify their educational needs and provide guidance for developing an education strategy, action plan and resources has been developed. This can be accessed in the **Education** page.

WHO Growth Charts: 20th September 2009

New growth charts for all babies born on or after the 1st January 2010 are to be used. 4 Training the Trainers study days have been planned for 2009 in Scotland along with guidance produced by the Royal College of Paeditrics and Child Health (RCPCH). Further information can be accessed in the Education page: Events and Training/Education Resources.

Information Search

Journals and ebooks can be found by using the search box (top right above). This searches the NHS Scotland e-Library (Please note the search results pages are under development and will improve).

If you are searching for information on a conditon, look in the **Communities of Practice** link and click on the relevant community. Here there are also journal and article links relevant to the specialities.

The **Guidelines & Evidence** and **Resources** pages contain links to other guidelines, organisations, professional bodies, charities, national Managed Clinical Networks and hospitals.

OUTREACH SERVICES:

3 Case Studies

Accessibility is a fundamental indicator of service quality. Having to travel to access care can cause substantial disruption to family life and a child's education as well as being a considerable burden financially. This is a particular problem for patients in the more remote parts of Scotland. The National Delivery Plan states increased accessibility as one of its primary aims.

Through NDP funding, a number of outreach clinics have been established in order to minimise travel and provide the same quality services closer to home. This makes it much more convenient for patients and families. New outreach clinics have been established across all regions of Scotland - from the Scottish Borders to the Highlands and Western Isles, with plans to extend services to Orkney and Shetland. These services are essential in helping us achieve an equitable service across the nation.

The clinics span a broad range of service areas and a number of success stories have emerged:

- In the North, 50 neurological patients now receive additional nursing support locally.
- In South East and Tayside, the appointment of a consultant paediatric surgeon in Royal Hospital for Sick Children Edinburgh to provide an outreach service to District General Hospitals has resulted in over 350 children being seen locally in NHS Fife. As well as minimising disruption and travel for the patients, this has the added benefit of freeing up capacity at the RHSCE.
- In the West, the surgical outreach service in Wishaw has reduced inpatient wait from 18 weeks to 3 weeks and outpatient wait from 18 weeks to 9 weeks.

We asked the regions to give us their perspective on the benefits such a service can bring, using general surgery as a model:

1. FROM THE NORTH. . .

The North of Scotland has a unique set of problems with delivery of general surgery of childhood. There is small volume delivery in a number of remote and rural sites and a specialist centre that is not located close to the centre of the geographical area supported. There is however a cohort of adult general surgeons who are motivated to continue delivery of this service locally.

The proposed solution for the North therefore is to deliver outreach support to the hospitals around the region. Each service has a different set of potential issues and we have been working with the local clinicians to define their needs.

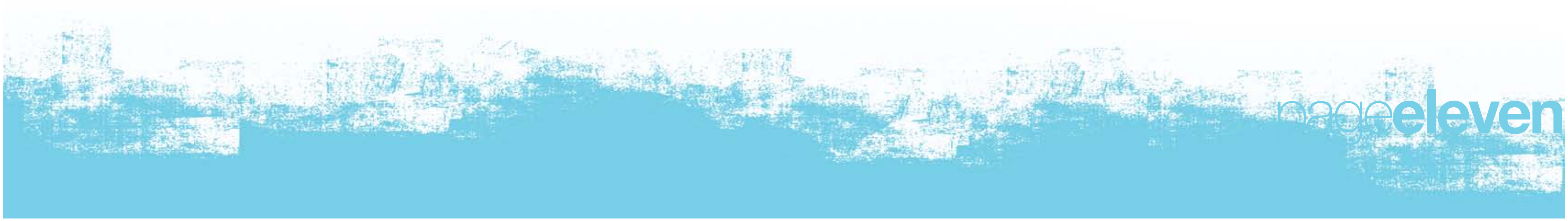
We have adopted a step wise approach spreading out from the centre to engage with local services. Initial work focused on reassuring local surgeons that there was no intent to “take over” services but an aspiration to enable continued – and perhaps enhanced – delivery locally.

We have to date started outreach clinics in Inverness and Elgin in general paediatric surgery but directing referrals made to Aberdeen to local clinics rather than diverting referrals made locally. In Inverness we have also started operating sessions and there is a programme now in place for joint operating sessions with local surgeons. The aim is to facilitate development of surgical skills and attitudes for new appointees who will take the service forward.

The next stage is to spread this model out further to Shetland, Orkney and perhaps Fort William as required and invited. An individual model is required for each unit but key to the development is robust communication and local engagement. We have made a point of discussing local needs and wishes before starting clinics to ensure there is no perceived threat to the local service, and of giving each centre a consistent point of contact to facilitate communication.

This model of care is time intensive for a visiting team and the appointment of a paediatric surgeon from NDP money has permitted this development. The future may be joint operating, development of regional protocols of care and utilising the specialist service as resource for CPD for both surgical and nursing staff. We should however be in a position to maintain general surgery of childhood as a locally delivered service in the North of Scotland.

CHRIS DRIVER
CONSULTANT PAEDIATRIC SURGEON
NHS GRAMPIAN



2. FROM SOUTH-EAST AND TAYSIDE. . .

The general surgery of childhood encompasses the common surgical problems seen in children. Most of the surgery is carried out on a day case basis. In the past this was done by specialist paediatric surgeons in the children's hospital, and by general surgeons in the local district general hospitals across the South-East of Scotland. In recent times there has been a movement of much of this work towards the children's hospital with many families travelling considerable distances both for outpatient appointments and day surgery procedures. This is a trend that has also been seen across the rest of Scotland and the UK.

In 2009 a consultant paediatric surgeon was appointed to support the local delivery of children's general surgery in the South-East of Scotland. This post was wholly funded from the National Development Plan. The surgeon appointed has duties at the RHSC Edinburgh and in Fife. This has allowed the establishment of a weekly outpatient clinic and day surgery operating list at the Victoria Hospital in Kirkcaldy. The appointment has also allowed time for one of the existing paediatric surgeons at RHSC to begin an outreach clinic in the Borders, together with a regular day surgery list. The service in the Borders is run in conjunction with one of the local general surgeons, who has a specific interest in children's surgery.

The outreach clinics also allow children with complex surgical problems to have more of their follow up locally. This development has meant that, for many families, all their surgical care can be provided at their local hospital, whilst for those requiring more complex surgery or highly specialist anaesthesia, outpatient care is provided locally with surgery at the children's hospital. Travelling and disruption for families is therefore minimised whilst maintaining a high and uniform standard of care.

FRASER MUNRO
CONSULTANT PAEDIATRIC SURGEON
RHSC
EDINBURGH

3. FROM THE WEST…

Following Forth Valley's successful bid for NDP funding in Year 1, a very effective model of shared care has been established between RHSC Yorkhill and Stirling Royal Infirmary. This model allows paediatric patients within a District General Hospital to receive a seamless and complete paediatric package of surgical care, which would normally only be available from a specialist paediatric tertiary centre.

The Child's Journey

Following referral, the child and their family are seen by the paediatric surgeon in an outpatient clinic in Stirling Royal Infirmary. Although the clinic is in an adult setting, it has a designated play area and is supported by qualified play staff. After assessment, if surgery is deemed necessary, the child will be given a date for an operation within 6 – 8 weeks. The child attends the Paediatric Inpatient ward for a pre-assessment clinic and then returns on the morning of surgery. In most cases the child will be allowed to go home within four hours of surgery. This avoids the need to travel repeatedly to RHSC Yorkhill, some 30 miles away.

There are currently 3 visiting surgeons to Stirling Royal Infirmary, who rotate weekly every Thursday. Their schedule is a theatre list in the morning with a scheduled list of 5 patients, followed by an outpatient clinic where approximately 14 children are seen. The surgery carried out is general surgery of childhood and the children treated range from 6 months to 14 years of age. Recent figures show that the types of surgery now carried out are more varied than in the past. Previously, few adult surgeons were happy operating on children and, as a result, few procedures were carried out. With a visiting paediatric surgeon far more can be done. In the long-term, such work will ultimately increase the range of procedures that will be offered at Stirling Royal Infirmary.

In addition, NDP funding has provided local staff with an opportunity to learn new skills and gain vital experience, as the surgeons involved host four teaching sessions a year. Stirling Royal Infirmary previously had no dedicated paediatric surgeon – there was only an adult surgeon with an interest in paediatrics. Now the ultimate aim is for there to be a suitably trained person to take on local paediatric surgical service supported by colleagues at Royal Hospital for Sick Children.

So far, the feedback from parents has been very positive. A mother of a recent patient said, "I can't believe that he is ready to go home so soon. The whole experience was great. I don't know why I was so anxious about him coming in".

Another parent said, "When the GP said she would need an operation I thought I would have to go to Yorkhill. It's been great that she could be treated here in Stirling".

This service is a strong example of the move towards local care, putting patients' and families' needs first and providing quality care closer to home.

HELEN BAULD
SENIOR NURSE, PAEDIATRICS, STIRLING ROYAL INFIRMARY

DAVID DANIELS
PROJECT MANAGER, WEST OF SCOTLAND PAEDIATRIC TERTIARY INTERFACE SERVICES

PLAY THERAPY SERVICE

TO SUPPORT CHILDREN WITH LIFE-THREATENING CONDITIONS

A FAMILY'S EXPERIENCE OF CARING FOR A YOUNG CHILD AFFECTED BY A VERY RARE FORM OF CANCER AND THE DIFFERENCE THE PLAY THERAPY SERVICE MADE TO THEM.

ANNE WILSON
ACTION FOR SICK CHILDREN

> **"Play therapy is a way of helping children, young people and adults suffering emotional and behavioural difficulties to express their feelings and deal with their problems, using play as the main communication tool . . . Rather than having to explain what is troubling them, as adult therapy usually expects, children use play to communicate at their own level and at their own pace, without feeling interrogated or threatened."**
>
> **– British Association of Play Therapists**

Condition

A rare form of bone cancer, 2 operations, 14 weeks in a cast, 18 weeks of chemotherapy, a metal plate and screws in the leg, a further 24 weeks of chemo, considerable pain, 8 months in hospital, regular insults to her body and life both in hospital and at home as a result of the treatment, including daily sub-cuticular injections, finger pricks to draw blood samples and the rigours of a naso-gastric tube over many months.

Many of the strongest of us would have buckled under the strain of coping with this onslaught, yet these are just some of the challenges faced by this little girl of only three and a half as she and her family battled Ewing's Sarcoma, a rare form of bone cancer which is normally only seen in adolescence. Rosa is one of a group of only 4-5 children throughout the whole of the UK.

The impact on the family

One could be forgiven for thinking that the person suffering most in all of this was Rosa but as a parent to watch your child suffer, to fear for their continued survival and then to be the recipient of all that child's anger, because they feel you let it happen or did nothing to stop it, must be intolerable.

When she was first referred to play therapy Rosa represented a pathetic little figure with no hair, tubes everywhere and grossly underweight. She had regressed in some of her milestones and was displaying challenging behaviour which was becoming increasingly difficult to manage. The range of her emotions ran the whole gamut from fear and sadness to anger and aggression. Her mother describes it:

"When a child is diagnosed you are put on a speeding train and you have to go with it. Your child has to lie on a scanner and is refusing to get on – as her mother you have to persuade her to get on. You don't have a choice"

While still undergoing treatment, she was referred to the Play Therapy Service to support children with life-threatening conditions within the Child and Adolescent Mental Health Services team at the RHSC Edinburgh, from which the family benefited immeasurably.

For her parents the service was a life-line; not just in coping with the day-to-day management of their child and her treatment but also in their confidence as parents. For them too there is a range of troubling emotions from distress at witnessing their child's trauma, their own fear, guilt and associated concern at whether it is still appropriate to maintain discipline and boundaries. These are uncharted waters and this is behaviour that does not fit with the experience they have of their child. The therapist can explain that this is normal in the circumstances and thus the responsibility for the child becomes shared with a professional, easing the burden on the parents. Rosa's mother describes the therapist as

"the only person who could engage with us on an emotional level"

For Rosa's little sister, under 2 at the time, it was a baffling, distressing world compounded by having one parent missing as they took it in turns to be with Rosa in hospital. The support the parents received from the therapist gave them the confidence to know how to deal with the impact on Rosa's little sister.

Her father points out that

"without the support of the service our other child would have suffered."

The benefits of the service

The benefits of play therapy have far reaching implications not only in the acute setting of a hospital environment but also within the broader community for families, schools and local services.

These are outlined as follows:

- Support to parents to help understand and manage their child's behaviour against a background of strain
- In turn parents are helped to manage and support their child through treatment in hospital and at home
- Facilitation of normal family functioning and support to siblings in a welter of confusing emotions
- Preparation of child for potentially traumatising difficult medical interventions
- Preparation of child for transition to normality – in school, home and community life
- Therapist helps child work through difficult experiences by eliciting responses which they otherwise may be unable to express
- Therapist helps child explore emotions, contain those safely and teach coping mechanisms
- Therapy promotes child's emotional well-being, which aids their physical recovery

"We would have struggled to cope and I do believe that the most positive outcome was achieved in the shortest space of time for everyone involved."

With many thanks to Action for Sick Children (Scotland)

Helping sick children and young people meet their healthcare needs in partnership with parents, carers and professionals

YEAR 3

A LOOK AT THE YEAR AHEAD

The National Delivery Plan recognises the requirement to undertake work to ensure that issues of sustainability, access and quality are identified and addressed across the full range of specialist services for children and young people. A number of new service areas, both on a regional and pan-Scotland level, will receive NDP funding in Year 3.

Clinical Psychology

One service that is to receive a significant increase in investment on a regional level is Clinical Psychology. For many children with chronic medical conditions in Scotland, the psychological support they receive is often insufficient and, at times, non-existent. Whilst the physical requirements of the patient are clear, the mental and emotional impact of suffering from acute or chronic medical conditions can be underestimated or relegated in importance. The NDP states a commitment to "ensure that when investing in specialist children's services psychological support is recognised as a key component in the care of children and young people with serious or long-term conditions".

The lack of funding in this area has created an absence of much-needed psychology provision and has made the service that is available largely reliant on the goodwill of psychologists. In the North of Scotland shared posts will be recruited in Grampian, Highland and Tayside, spread across a number of specialties including respiratory, neurology and renal.

The West of Scotland plans to invest over half a million pounds to boost psychology services. This will fund clinical psychology posts in Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Lanarkshire and Great Glasgow & Clyde (amounting to over nine WTE).

SEAT plans to appoint two WTE clinical psychologists in Year 3, one to supplement the play therapy work in Lothian and the second to serve the Borders.

Benefits of psychological support include improved treatment adherence and health outcomes and shorter hospital stays.

The total proposed investment in Year 3 is approximately £800,000. This represents a significant boost to current provision and is a welcome move towards offering a fully comprehensive patient care package.

YEAR 3 CONTINUED

Nephrology

An aspect that all Nephrology and Urology conditions have in common is the need for accurate diagnosis at an early stage of disease presentation and local ongoing management of care. Since 2004, the Scottish Paediatric Renal and Urology Network (SPRUN) has enabled the local management of conditions, improved standards of care and has bettered patient self-management. The aim is to build multi-disciplinary teams capable of delivering local care. At present many patients with more complex problems are reliant on receiving their care only at specialist centres. This in turn leads to de-skilling of staff in District General Hospitals. To address this, Year 3 investment will fund the expansion of multi-disciplinary teams at a local level, as well as the enhancement of services through regional networks. All regions have put forward plans to invest in additional staff (nurse specialists, pharmacists, dieticians and consultant time).

PID/HIV

Children with Primary Immune Deficiency and HIV represent a vulnerable group of children with a rare, complex set of disorders who benefit from earlier diagnosis and treatment in specialised clinical pathways. The current provision of care and access to specialised clinical teams varies across Scotland and has developed on an ad hoc basis. The proposed model includes the establishment of a nationally managed clinical network, the appointment of a pharmacist (a crucial role given the complexity and expense of drug regimes for this patient group) and the expansion of current provision in all regions. Additional consultant sessions, nurse specialists in the North and West and administration to support the model of care will be provided in Year 3.

YEAR 3 CONTINUED

Allergy

Allergies have increased dramatically in prevalence over the last 3-4 decades. Now about 30% of children suffer from allergic diseases in Scotland, with around 2-3% of all children (between 19,000 – 28,000) suffering from severe allergic disease. For these children, lack of support when managing their condition can dramatically reduce their quality of life. There is an urgent need for work to be undertaken to set national standards for the diagnosis and management of allergies; to define patient pathways from primary to secondary and tertiary care and from paediatric to adult services; and to provide greater education and research facilities for doctors treating allergies. The Implementation Group has agreed to provide funding to support this project. Regionally, SEAT plans to invest in additional nursing and dietetic resources to support sustainable secondary and tertiary care. The West similarly intends to support nursing and dietetic resource as well as the services of a specialist paediatric allergist and a consultant paediatrician. The North is also investing in allergy as a Year 3 priority.

Critical Care

The provision of paediatric critical/high dependency care is fundamental to the sustainability of devolved paediatric surgery and underpins the model of local paediatric care. The High Dependency Care (HDC) Audit was published in January 2009 and reinforced the importance of coordinated planning, co-operation and resourcing to ensure equitable access to a minimal standard of high dependency care. Hospitals receiving critically ill and injured children require the expertise and resources to resuscitate, stabilise and maintain children. The pan-Scotland proposal, based on these recommendations, aims to ensure that HDC is delivered to agreed standards, that clear care pathways exist and that staff are adequately trained and can participate in regional networks. These networks are important as a means of enhancing communication between local hospitals and making effective clinical decisions. It also recommends the establishment of a national steering group, to include the regional clinical leads. A national coordinator will liaise between the three regions and lead on the national audit to monitor standards and patient outcomes. The creation of a database (built upon the system being developed for NMCNs) will improve national clinical audit and allow Scotland to take part in the UK-wide data system, thus being able to benchmark performance.

The three main components of the critical care plan are increased nursing staff, training and equipment. A proposed investment of £1.25 million is planned for Year 3.

YEAR 3

REGIONAL PRIORITIES

In addition to national and pan-Scotland commitments, each region has identified a number of service areas it will prioritise in Year 3. These include:

The North:

The North have taken a new approach this year which includes prioritising cross-cutting areas. These include:

- MEDICAL STAFF
- PAEDIATRIC PHARMACISTS
- ALLIED HEALTH PROFESSIONALS
- PAEDIATRIC NURSING
- REMOTE AND RURAL NETWORKS
- CHILD PROTECTION
- PSYCHOLOGY*

South East & Tayside:

- NEUROLOGY*
- PSYCHOLOGY
- CHILDREN WITH EXCEPTIONAL HEALTHCARE NEEDS*

The West:

- CLINICAL PSYCHOLOGY*
- PALLIATIVE CARE*
- NEUROLOGY
- LONG TERM VENTILATION*
- RADIOLOGY*
- DIABETES*

* = Newly added in Year 3

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