
PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE IN WALES: MEETING FUTURE NEEDS

Report
for Ty Hafan

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FOREWORD

When we started work on this project, we had few preconceived views concerning paediatric palliative care. We have therefore approached it with fresh eyes and many questions.

Possibly our most important finding is that what needs to be achieved has been clearly set out in previous reports, and there is broad consensus on this.

Clearly considerable progress has been made in recent years. But we conclude that, for various understandable reasons, children's palliative care is being given insufficient national strategic attention, which is resulting in clinicians and service providers feeling that they are working against the odds to address the needs they have identified. Although messages about people's needs and experiences of services have been clearly articulated in previous local and national reports and research studies, there is a belief that they have remained largely unheard.

In part, this is because children's palliative care is sometimes equated with adult palliative care. This is misleading because, as we explain in this report, much of children's palliative care is not about the final period of life, but about helping children, young people and families cope better with a series of conditions which may last for many years in childhood, and beyond. Whether these children and young people are in the palliative or the end of life phase, it is right that they have an expectation that service leaders will deliver on their commitments.

This report is therefore not just for that small number of people who are experts in palliative care; it is also for a much wider group who need to understand the issues raised here, and make their contribution to their resolution. We hope this report will be read by a wide range of professionals and decision-makers who, between them, can improve the lot of children and young people who need palliative care.

The time has now come to stop asking people to describe their experiences and increase the pace towards positive, collective and strategic action to deliver equitable and sustainable change.

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SUMMARY

This report presents Phase Two of work commissioned by the Ty Hafan Board. It presents an assessment of the current state of paediatric palliative care services in Wales and an opinion on where further actions need to be taken to ensure continuing improvement. Although commissioned by Ty Hafan, it is written for a wide range of professionals, commissioners, planners and others who share the responsibility for meeting the health and other needs of children and young people in Wales.

Information on the current services and their limitations was sought from families of children and young people with life limiting conditions and professionals involved in the commissioning and provision of those services. The method adopted was a combination of face to face or telephone interviews, questionnaires, stakeholder workshops and a literature review of the key policy documents and recent Welsh focused research.

The changing political and demographic dynamic is explored and its impact upon the divergent directions taken by children's and adult palliative care and the resultant consequences are discussed.

We describe a complex set of statutory and third sector provision which has improved significantly in recent years, as resources and expertise have expanded. The most important finding is that what needs to be achieved has been clearly set out in previous reports and there is a broad consensus on this. But progress now seems to have stalled, and needs new impetus.

We make a small number of recommendations, which collectively highlight the outstanding challenges:

1. Give Paediatric Palliative Care the same status as that for adults by either strengthening the membership of the current End of Life Implementation Board to represent children's needs more effectively, or by establishing a separate Paediatric Palliative Care Implementation Board mandated by the Minister for Health and Social Services and effectively resourced.
2. Develop a Paediatric Palliative Care Implementation Plan to run alongside the End of Life Implementation Plan. This plan should be based upon the specific recommendations from the Sugar Report and local service boards or their equivalents should be tasked with developing regional plans and publishing annual progress reports.
3. Review the role of the vacant specialist consultant (transitions) post in the context of the skill mix required to improve transitional support and the need to provide specialist consultant support to North Wales.

4. Ensure that children's and adult social care are actively involved in the development of plans to address transition to adulthood and end of life care in people's own homes.
5. Explore ways in which communication, information exchange, learning and research can be rapidly shared within the sector including national and international networks and collaborations.
6. Establish child focused performance measures and ensure that data collected by age groups reflects the need to collect data from birth to beginning of transition (0–14) adolescence (15–19) and young adulthood (20–25).
7. Implement the 24/7 specialist telephone advice service to ensure that timely and readily accessible advice for symptom control is available in a manner which is sustainable and not impacting negatively upon those involved in its delivery. Consideration should be given to working with other regions of Britain to develop a national service.

TERMS OF REFERENCE AND METHOD

A Definition of Palliative Care for Children

“Palliative care for children and young people with life limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.”

(ACT and the Royal College of Paediatrics and Child Health, 1993)

Remit

“The lives may be short, however it is important that they are as rich and fulfilled as they can be.”

(Baroness Rennie Fritchie DBE, Chair of the Ty Hafan Review Group - Thinking Together, Working Together, Ty Hafan Review, Final Report of the Review Group, NHS Wales, 21.12.2011)

The Welsh Institute for Health and Social Care at the University of South Wales was commissioned by Ty Hafan to undertake a project to explore the provision of paediatric palliative care services in Wales. The initial objectives were to provide:

- An overview of future service needs, including epidemiological evidence;
- A view on the future orientation of services;
- The views of children and families as well as other stakeholders;
- A route map for improvement and achievement.

As the project progressed and developed, the Ty Hafan Board refined the objectives to provide to the Board and other stakeholders:

- An assessment on the current state of the paediatric palliative care services in Wales;
- A view on where progress is required and the actions which need to be taken;
- A specific report for the Ty Hafan Board providing a view on the options available to it for its future role within a wider health (and social care/education) economy.

Methodology

Phase One: January – November 2013

- A brief review of the relevant literature and available data was undertaken.

- Interviews were conducted with many of the key stakeholders.
- A number of specific themes were identified for further exploration.
- Phase One Report presented to Ty Hafan.

The report from Phase One is included at Appendix 1.

Phase Two: July 2014 – February 2015

- A steering group of stakeholders was established to provide guidance and monitor progress (membership included at Appendix 2).
- A literature review was commissioned and detailed work undertaken to identify the voices of children, young people and their families.
- Focus groups made up of families were established for both Ty Hafan and HOPE house services.
- Further interviews with stakeholders were undertaken both face to face and by telephone.
- A questionnaire (included at Appendix 3) was developed and sent out to 210 families currently receiving services from Ty Hafan and HOPE house. Eleven questionnaires were completed and returned.
- Questions were sent electronically to the Heads of Children's Services sub-group through the Association of Directors of Social Services (Cymru). A response was received from the Gwent Heads of Service Group (Newport, Torfaen, Caerphilly, Monmouthshire, and Blaenau Gwent). (Question included at Appendix 4)
- Letters with questions (included at Appendix 5) were sent to Directors of Education facilitated by the Association of Directors of Education in Wales. Ceredigion and Carmarthenshire provided responses.
- Stakeholder workshops with 23 participants (names included at Appendix 6) were held on the 24th October and 18th November 2014 to consider the information gathered, add to this from their own knowledge and experience, and develop a shared view of what is required for the future.

STRATEGIC BACKGROUND

There are five important documents, which together set the strategic context for this project, and provide something of a baseline against which to assess progress:

1. The Welsh Government's National Service Framework for Children, Young People and Maternity Services. (National Service Framework for Children, Young People and Maternity Services, Welsh Assembly Government, 30.09.2005)
2. The Welsh Government's All Wales Palliative Care Standards for Children and Young People's Specialised Health Care Services. (All Wales Palliative Care Standards for Children and Young People's Specialised Health Care Services, Welsh Assembly Government, 2008)
3. Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services (known as the Sugar Report). (Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services, June 2008)
4. Dying Well Matters (Palliative Care Cymru Implementation Board: Dying Well Matters, One Wales: 3 years on 2008 –2011, 2011)
5. The Welsh Government's Together for Health – Delivering End of Life Care – A delivery plan up to 2016 for NHS Wales and its Partners. (Together for Health – Delivering End of Life Care – A delivery plan up to 2016 for NHS Wales and its Partners, Welsh Government, 2013)

National Service Framework for Children, Young People and Maternity Services (2005)

The NSF is a 10 year strategy launched in 2005 with the explicit aim of transforming services that relate to children's development and wellbeing. Within the NSF chapter 2 sets out the key actions required which are universal to all children and chapters 5 and 7 are particularly relevant to children's palliative care and this report.

Chapter 5 addresses the actions required for disabled children and young people and includes expectations particularly pertinent to this project. For example Action 5.24 clearly stipulates that children and young people who need palliative care, whether in the chronic or terminal phase, should be supported at home whenever possible.

There is an expectation that assessments for equipment are undertaken within 4 weeks of referral, the equipment is supplied within 6 weeks of that assessment and there are dedicated resources for children, which are distinct from adult resources (Action 5.14).

A key transition worker should be appointed to all disabled young people at age 14 (Action 5.33). One role for this worker is to coordinate the planning and delivery of services before and after the process of transition and will continue to monitor and have contact with the young person until the age of 25 years (Action 5.35). As part of this process a joint organisation transition plan should be produced for each young person, which forms the

basis of the Unified Assessment within adult services and specifies arrangements for continuing support and services.

The aggregated information derived from these transition plans should then be provided to the Young People's Framework Partnerships to inform strategic planning (Action 5.37).

Chapter 7 addresses acute and chronic illness or injury and includes the expectation that children and young people are able to access treatment and care close to home and that there are an appropriate range of outreach services provided as close to home as possible, particularly to meet the needs of families living in rural areas (Action 7.5).

Equipment used should be the correct size for each child, and its design is tailored to the different needs at different ages and stages of development (Action 7.13) and every lead health professional has adequate arrangements for transfer of young people to adult services, preferably via specific transition clinics involving staff from both paediatric and adult services (Action 7.28).

It is Welsh Government's intention to evaluate this NSF during 2015/ 2016.

The Welsh Governments All Wales Palliative Care Standards for Children and Young People's Specialised Health Care Services (2008)

The Specialised Service Project was established in 2003 to enable equity of access through effective managed clinical network models for all children and young people in Wales requiring specialised services. This report was accepted by the Welsh Government in 2008. The report set out six standards, each with rationale and key actions. These actions also detailed the responsible organisation and timescales.

Standard 1: Access to Palliative Care Services. All children identified as needing to access palliative care have access to high quality, evidence based care provided by appropriately trained multi-professional teams in the most appropriate environment and with as little disruption as possible to the child, young person and family.

Standard 2: Staffing of palliative care services. Palliative care services are staffed with appropriately trained, multidisciplinary professionals with access to other resources to ensure that children and young people have no delay in receiving palliative care services.

Standard 3: Facilities for Palliative Care Services (including equipment). Appropriate facilities are available to care for children who require palliative care and their families. This will include provision of care in their own home.

Standard 4: Care of the child and family. The child and the family receive comprehensive, holistic and child and family-centred care as close to home as possible and with ease of access to specialist centres when this care cannot be provided locally.

Standard 5: Communication. Effective communication mechanisms are in place to ensure the smooth delivery of palliative care services to children and their families in a timely manner.

Standard 6: Education and Training. All members of the multi-professional team are trained to the required standard to deliver a high quality service safely. Care will be delivered based on the best available evidence.

Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services. The Sugar Report (2008)

The All Wales Palliative Care Planning Group chaired by Vivienne Sugar presented its report to the Minister for Health and Social Services in June 2008.

The terms of reference for the group were:

1. To specify the elements of a core palliative care service including end of life care for (i) adults and (ii) children, which should form the basis of a commissioning specification to underpin funding considerations by the Welsh Government and Health Boards.
2. To develop a means of formally measuring the quality of a core palliative care service which the Welsh Government and LHBs can use to inform funding considerations for individual providers.
3. To take evidence from organisations, service providers, individuals and written documents as it is deemed necessary to inform this work.
4. To conclude this work in time to inform commissioning and funding decisions from 2008-09.

The report was based upon three core principles, namely:

1. Good end of life and palliative care should be available universally across Wales.
2. Fairness of service provision is fundamental to raising the standards of end of life care. This needs to be achieved without jeopardising evaluated evidence based service developments by the specialist palliative care service providers in Wales.
3. Close integration of services in an area, whether provided by the NHS or by voluntary sector providers, is essential for high standards of care.

The following seven objectives were outlined:

1. Access for patients with complex needs to specialist palliative care on a 7 day per week basis, with advice available to all clinical teams in Wales on a 24/7 basis.
2. A funding formula that would determine how to fully fund core, evidence based services, delivered by statutory and voluntary sector organisations that was fair and equitable, while taking into account variables such as access to specialist care in rural

areas and the demand on services in areas of urban deprivation and social isolation. The funding formula would endeavor to ensure a minimum level of specialist services across Wales.

3. Development of CaNISC as an electronic patient information system that would improve care through access to patient information.
4. Standards that would determine a set of Quality Outcome Measures to ensure the services delivered were fit for purpose and appropriate to the needs of the population. The standards should be applied universally to monitor the quality of care in all settings.
5. Service specification to clarify the expectations on those delivering the services and act as a method of performance management, ensuring service delivery meets expectation and the services meet the requirements of the agreed standards.
6. Public engagement, using patient/carer and public feedback to monitor that services continue to meet the needs of patients, using this information to modify or change services as necessary.
7. Establish a Palliative Care Research Network. Driving up standards of care through evidence, and to provide a focus of enquiry, providing solutions to problems encountered by patients with advanced disease.

The report echoed the existing recommendations and principles contained within the National Service Framework and the Specialised Services Project and stated clearly that:

“In order to achieve the core service standard, planning and commissioning must adhere to the standards set out in these two reports, specifically in relation to staffing, quality and audit and transition for adolescents.”

(Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services, June 2008, page 25)

The specific recommendations made for an All Wales Core Palliative Care Service for Children and Young People was that it must be holistic, put the patient at its centre and should include (Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services, June 2008, page 29):

1. Timely and open communication and information.
2. Choices/options in all aspects of care, including complementary therapies.
3. Death in place of choice.
4. Coordination of services at home, where this is the chosen place of care, including a fully staffed Palliative Community Nursing Service.
5. Expert symptom management.
6. Access to 24 hour specialist advice and expertise.
7. Emotional and practical support for all family members.
8. Respite care with medical and nursing support, when required.

The report concluded that this could be achieved by having in place the following elements:

1. A specialist multidisciplinary team (MDT) led by a key worker.
2. The key worker role to include the management of transition for adolescents.
3. A directory of services should be introduced for Wales, including local contacts.
4. Care should be delivered through a care pathway by a team comprising of the following elements:
 - a. Paediatric Consultant (level 3).
 - b. Clinical Nurse Specialist.
 - c. Community Paediatric Nursing Support.
 - d. Rehabilitation and Play Support Worker.
 - e. Social Worker and Welfare Support.
 - f. Administrative Support Team.
5. The MDT should then be supported by the following services:
 - a. Bereavement and Counseling.
 - b. Access to respite.
 - c. 24/7 access to medication.
 - d. 24/7 access to equipment.
 - e. Access to specialist advice.
 - f. Psychological support for staff.
 - g. Access to education.

In terms of general palliative care for children and young people, the report states that as much support for them will take place in the home and there needs to be a sufficient staffing level of community nurses to allow this for all. It also stated that the MDT must be supported by the necessary medical expertise through 24/7 access to tertiary level advice and care. Out of hours care must be supported by a 24 hour rota with a single point of contact. The report was specific that this should be organised in a way that supports staff and does not place an excessive workload on them.

In respect of quality measures, the report recommended that there should be a single regulatory authority for inspection and that when delivering services, providers should adhere to the quality measures set out by the NSF for Children and Young People.

There was also a recognition that the specific needs of adolescents and young adults requires further exploration which was beyond the remit of the report.

Finally the report also recommended the:

1. Development of CaNISC as an electronic patient information system.
2. Public engagement, using patient/carer and public feedback to monitor services.
3. Development of service specifications.
4. Establishment of a Palliative Care Research Network.

Dying Well Matters (2011)

In 2011 the Palliative Care Implementation Board published its report “Dying Well Matters – One Wales: 3 years on (2008 -2011)” which presented the board’s assessment of the progress that had been made against the objects set in the “Sugar Report” (Palliative Care Planning Group Report: 2008)

The progress report concluded that by 2009 the medium and short term objectives had been achieved. It also identified areas not addressed in the Sugar Report including:

- The needs of bereaved children.
- Wheelchair services for palliative care patients.

With specific reference to services for children the progress report stated:

“Paediatric and transitional care of children and young people with life limiting conditions have been a focus of service development with each Health Board having one or more named paediatricians and specialist nurses with sessional commitment to end of life care. These paediatricians and specialist nurses have all started training on the Cardiff University MSc in Palliative Care (paediatric modules). A paediatric PCIG has been established to ensure cohesive developments, including cross cover arrangements across Wales.”

£3,162,500 was made available for the implementation of the “Sugar” objectives, with £258,000 (8%) being allocated to children’s services for:

- 1 consultant to lead for transitional care for teenagers.
- 1 session per week for paediatric leads in each health board.
- 4 specialist paediatric palliative care nursing posts.

The Palliative Care Implementation Board commissioned a report on access to wheelchairs. This report revealed unacceptable delays for patients, particularly those with advancing neuromuscular disease, accessing the wheelchairs and other adaptations which “they need to allow them to continue to live and function as independently as possible in society.” The deficits identified were accepted as needing urgent work in order to be resolved within 2 years (i.e. 2013).

Together for Health – Delivering End of Life Care – A delivery plan up to 2016 for NHS Wales and its partners (2013)

This plan sets out the Welsh Government’s expectations of NHS Wales, working with its partners, in particular the hospice and social care sector. Although in his ministerial forward Mark Drakeford AM makes reference to “good end of life and palliative care should be available across Wales” this plan focuses primarily upon end of life services.

The plan presents delivery aspirations and specific priorities for the period 2013 – 2016. The delivery aspirations are mainly generic and pertain to children as well as adults ((Together for Health – Delivering End of Life Care – A delivery plan up to 2016 for NHS Wales and its Partners, Welsh Government, 2013, page 8). This being said the following are specific or make reference to children:

1. Greater awareness among paediatricians and other professionals caring for children with life limiting conditions of the need for timely discussion of the preferences for care at and around the time of death.
2. Ensuring for children, where the terminal phase is likely to be long, continuous support and opportunities.
3. Strong communication between local and tertiary palliative care teams, and non-statutory services such as children's hospices.
4. Transition processes are in place from children to adult palliative care services.
5. Families facing bereavement particularly those with children are supported in coming to terms with their impending loss with additional support in bereavement where needed.
6. Key information on all patients seen by the specialist palliative care team (adult or paediatric) is recorded on CaNISC and accessible to others who have clinical responsibility for the patient.

The children specific priorities for 2013 – 2016 are to:

1. Ensure paediatricians are aware of the Advance and Emergency Care Planning.
2. Work with GP practices to encourage the use of Palliative Care registers for patients, including paediatrics, with less than one year life expectancy and in particular, non cancer patients.
3. Ensure transition arrangements from child to adult palliative care services are in place.
4. Put in place 24 hours paediatric palliative care telephone advice rota.

The Local Health Boards are responsible for the delivery of this plan through their own specific delivery plan and they have to report annually on the progress made to the End of Life Implementation Board, previously the Palliative Care Implementation Board which produces its own annual report and has ultimate responsibility for the delivery of the plan.

Numbers and patterns of disease

Estimating the numbers of children and young people who actually require palliative care is problematic because it is defined, not by organ system, but by the needs of an individual child and family.

Noyes J et al (Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V. (2014) Bridging the Gap: Transition from Children's to Adult Palliative Care, Bangor University, United Kingdom) describe four categories of life threatening and life limiting conditions:

1. Life threatening conditions for which curative treatment may be feasible but can fail, for example cancer or irreversible organ failures.
2. Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal lives, for example cystic fibrosis and Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years, for example Batten disease and mucopolysaccharidoses.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death, for example severe cerebral palsy and multiple disabilities.

Historically adult palliative care service models have provided care to individuals with foreseeable terminal care needs, often with cancer and requiring symptom relief and psychological support towards the end of life. In the opinion of the clinicians and service providers interviewed, only about 20% of the children identified as having palliative care needs have a cancer. The majority of the remaining children fall into categories "2" and "3". Ty Hafan for example has a cohort of young people with Duchenne muscular dystrophy. The service deals with a large number of different conditions each of which may involve a relatively small number of children. Some conditions are so rare that they are named after the child who has them.

The Palliative Care Planning Group Wales – Report to the Minister for Health and Social Services (June 2008) quoted from the Association of Children's Palliative Care and the Royal College of Paediatrics and Child Health guidelines, which estimated that in 2005 there were around 600 families across Wales who have children with needs pertaining to life limiting conditions.

The generally accepted estimated prevalence rate for children and young people likely to require palliative care services is 15 per 10,000 population aged 0–19 excluding neonatals

(Palliative Care Statistics for Children and Young Adults, Department of Health, 2007), which results in a figure of 1054 children and young people requiring palliative care services in Wales during 2014. Of these it is estimated that 10% (105) will die during the year.

There was an alternative view expressed during our interviews that the prevalence rate is similar to that of adults at 40 per 10,000. This results in an estimated population of 2811 with 281 deaths during the year. Although this is considered to be an overestimate, it does illustrate both the lack of robust and reliable data and the potential level of need.

Annual reports and plans

In 2014 the End of Life Implementation Board (previously the Palliative Care Implementation Board) published its first Delivery Plan Annual Report.

The report recognised the role of the Paediatric Palliative Care Network (also referred to as the paediatric palliative care clinical network) and the centralisation of the management of the network within the Cardiff and Vale University Health Board.

Particular reference was made to clinical delivery remaining as local as possible with consultant led teams based in Swansea and Cardiff supporting the consultant leads in each of the health boards.

Specific progress was reported in the following priority areas:

1. An out of hours all Wales telephone advice service for paediatric palliative medicine has been developed and an all Wales out-of hours rota will start on 1st November 2014.
2. End of life care planning documentation has been completed, and will be rolled out across Wales in the next few months. Dissemination remains an issue until adequate administrative support is in place.
3. An end of life 'just in case' box for children has been designed and agreed on an all Wales basis.
4. Considerable progress has been made with respect to an all Wales approach to transitioning children to adult palliative care. However it is recognised that services for younger adults and the processes required to support them through the challenges of transition are in their infancy and a big push is required to improve the situation for these young people.

In addition this report reflects upon the establishment of a shadowing programme for the specialist palliative registrars in adult palliative medicine to improve information flows and patient care for those young people moving from children to adult services.

Each Local Health Board is expected to provide the End of Life Implementation Board with an annual report on progress made in respect of their own local implementation plans.

Three of these were accessed for the Cardiff and Vale, Abertawe Bro Morgannwg (ABM) and Cwm Taf health boards.

Cardiff and Vale provided the most detail with the following achievements being described:

1. The provision of support to paediatricians to participate in the rolling programme of education to support Paediatric Emergency Care Planning.
2. The promotion of the use of Advance Care Planning in paediatric palliative care and now 50% of children who are under the care of the palliative care service utilise advanced care plans.
3. Training is provided by the Paediatric Palliative Care Team to carers (usually parents) if children are terminally ill.
4. The creation of a central register of children with life limiting conditions, for whom GPs have access to their records.
5. Plans in place to improve the transition arrangements between children and adult palliative care services.

ABM identified that the formal establishment of a paediatric palliative care service was a high priority and Cwm Taf reported that its Palliative and End of Life Care Strategy Group, which had previously focused on adults, now had additional representatives from paediatric palliative care services. Cwm Taf also made reference to the All Wales Paediatric Palliative Care Network developing an All Wales Delivery Plan specific to End of Life care for children and young people.

Children's and Young People's Framework Partnership Plans (most were for 2008–2011 although a number were for 2011–2014) for all the 22 local authority areas were analysed for specific references to children with life limiting or palliative care needs.

5 of the plans made reference to children and young people with a disability or additional health needs, particularly those with complex health needs being target groups for their plans. Only one plan made specific reference to palliative care:

"In this section we are particularly concerned with...(b) children and young people with long term conditions, life threatening illness, palliative care and complex health needs."

(Swansea Strategic Plan for Children and Young People 2011–2014)

Recent research (Wales)

Two relevant research papers were published in 2013 and 2014, both by Bangor University.

Noyes et al (Noyes J et al; Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar, BMC Palliative Care 2013, 12:18) in their research on evidence based planning and costing of palliative care

services for children found important gaps in service provision and the clinical network within their exemplar locality, North Wales. In particular they found that:

1. Choice of end of life care at home is not currently universally available.
2. If children who need specialist palliative care are to be able to have the same access that adults currently enjoy, then service developers must engage commissioners with appropriate evidence.
3. There is no current directory of palliative care services.
4. There is no national database of children with palliative care needs.
5. There is no advance care planning framework available to ascertain child and parent preferences before the end of life stage.
6. No appropriate costing methodology.
7. Only 23% of the children in this study died in their own homes. As children got older they were more likely to die at home.
8. Young people and parents experienced fragmented services with insufficient choice and options and described the same gaps as healthcare professionals.
9. The most important service attribute was access to specialist advice and support 24 hours a day.
10. The importance to families to be able to access children's community nursing support for routine complex care and end of life care in their own homes. This was a stronger preference for families than it was for the healthcare professionals interviewed.
11. The most important professional gaps identified were a specialist consultant for North Wales and the resources available within the children's community nursing service.
12. Professionals had little time for planning ahead, and frequently provided end of life care over and above their contracted hours.
13. Approximately half of the identified resource committed to children's palliative care was funded by charities with the costs of hospice services and continuing care packages representing approximately 83% of the total cost.
14. Those living in rural areas have to travel considerable distances to access services, or, practitioners have to travel distances to get to them.

In their report "Bridging the Gap: Transition for Children's to Adult Palliative Care, Noyes et al (Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V. (2014) Bridging the Gap: Transition from Children's to Adult Palliative Care, Bangor University, United Kingdom) concluded that adult services are too complex for young people with life threatening conditions to negotiate and that adult services need to extend their scope to better meet the needs of young people and their families. Many young people did not have a "key worker" or someone to support them in organising their transition so it was easy for young people to get lost and fall through the gaps.

What families told us

A questionnaire was sent out to 210 families who currently use Ty Hafan and HOPE House services. From these, 11 questionnaires were returned predominantly from North Wales but also one from Mid Wales and one from West Wales. Although this represents a low response rate the issues raised by the parents reflected those raised by practitioners and those identified within the literature review and the parent focus groups undertaken in Phase One. One reason given for the low response rate was that parents were beginning to suffer from “questionnaire fatigue” with those involved with Ty Hafan having just completed a quality assurance questionnaire (results not available in time for this project) and families in North Wales having been involved in research conducted by Bangor University in “transition”.

Families felt that services let them choose what type of information they wanted and when to receive it, although there was an issue about how well the choices available to them were explained. There were mixed views about the quality of the general information available, particularly that concerned with their child’s particular developmental issue. However they did report that they were provided with specific information about how their child was doing and his/her progress.

Information tended not to be available in a variety of forms and advice on how to get information, or how to contact other parents, was generally not available.

Services were reported as looking at the needs of the child as a whole and they made sure that at least one member of the team worked with the family over a long period of time. There was a consensus that professionals and families were planning and working together to the same aims and the information provided to them was consistent.

The parents reported that they felt that they were made to feel competent as parents and services provided a caring atmosphere and they were given enough time not to feel rushed.

As a contrast the following comments were made by parents in answer to the question concerning suggestions they would make for change:

“Can’t change anything as no help provided in the first place.”

“There’s no other care provided in [county] area so without [hospice] life would be harder than it is.”

“No one ever speaks to my family.”

“More respect as a parent caring 24 hours a day, 7 days a week.”

“Someone who understands why we feel the way we do.”

“Someone in charge who has actually been in our position so they can totally understand how we feel.”

“The services at our child development clinic are shambolic and disorganised and parents of disabled children are actively discouraged from returning to work. It all needs a shake up!

What professionals told us

The current specialist paediatric palliative care service comprises one full time consultant based in Cardiff and one consultant based in Swansea on a contract of 2.5 sessions. This will increase to 6 sessions (including 3 sessions for strategic development) in due course. The Cardiff based consultant splits his sessions equally between providing tertiary and secondary services. There is also a senior registrar and a part time secretary. Both of these posts split their time equally between tertiary and secondary services and although the funding for the secretarial post was originally for full time this has not been fully realised. The team is completed by a full time specialist paediatric palliative care nurse.

The Swansea based consultant is supported by a full time specialist paediatric palliative care nurse.

Additionally all the health boards, other than Powys, have specialist palliative care support comprising one session each from a consultant paediatrician and, with the exception of Powys and Betsi Cadwaladr UHB, each has a specialist paediatric palliative care nurse (this includes the 2 posts referred to previously).

The stakeholder workshops and interviews, in both phases of the study, highlighted five major themes, as being the main issues from their and their families perspectives which need to be addressed as a priority. These are discussed below:

- Leadership;
- Working across boundaries;
- The transition into adulthood;
- Symptom control (including access to equipment particularly wheelchairs);
- Networking.

Leadership

In terms of leadership (defined as being the process of social influence in which one person can enlist the aid and support of others in the accomplishment of a common task) there was a very strong feeling expressed that, outside of the core group of interested professionals paediatric palliative care was not given adequate priority by the End of Life Board, the Welsh Government or those who plan or purchase services primarily within the Welsh NHS but also within Welsh local government. This was illustrated by the lack of

robust data to inform commissioning, the limited numbers of specialist staff available and the challenges of providing a specialist tertiary care service across Wales with the capacity available within the Cardiff team. There was also concern expressed that Powys does not have its own specialist acute and community services and is thus reliant upon other areas for these. The concern was that children, young people and their families were not consistently able to access support. In North Wales the three District General Hospitals were reported as having services, which are at different stages of development and the region and reliance upon clinicians with generic rather than specialist skills. As a result, it was suggested that the region was reliant upon Alder Hey Hospital for specialist acute and community services, although the latter is only available to those children who are current patients of the hospital and provided through good will rather than by means of a formal contract. The concern expressed was that this was resulting in an inequitable access to services across the region.

Three priorities were identified in this area:

1. To identify the leaders who are able to provide new impetus.
2. Persuading political and other decision makers to take action.
3. To identify who is actually responsible for driving the standards.

The participants felt strongly that children's palliative care needed to stop being in the shadow of adult services and that the service would not progress sufficiently unless people started to stand up for the rights of children and develop a specific strategy for children's services.

Working across boundaries

In respect of working across boundaries (defined as thinking and collaborating outside of institutional, professional and current thinking to develop new ways of achieving agreed goals) two main issues were identified. The first was that the specialist nurses felt that they were not allowed by their managers to work outside of their specific geographical areas and duties as detailed in their individual job descriptions. The inference was that this made it very difficult for them to maximise the potential benefits of working more closely together. The second concerned working across boundaries with other agencies particularly education and social services within local government. Working with the third sector, particularly with the hospices was well developed but could be further built upon.

Three priorities were identified:

1. Ensuring an inclusive, equitable approach.
2. Identifying and removing the barriers to good collaboration in the commissioning and provision of this set of services.
3. Developing an accessible, safe, multi agency IT system.

Most of the participants felt that there needed to be a concerted push away from protectionist working practices and the silo mentality. There was a serious concern that management decision making was increasingly being made based upon financial imperatives at the potential risk of patient and service need. Examples included the concern that the recently vacated specialist consultant post for transitional care would not be filled in order to contribute towards cost improvement targets. This was made more difficult by the development of isolated IT systems, which could not “talk” to each other. Health Boards in particular were felt to be too insular and needed to start sharing their resources for palliative and end of life care to, at the very least, ensure that 24 hour support was available.

The transition into adulthood

Although there has been a real improvement in the transitional arrangements between children’s and adult palliative care services (defined as being the planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults as they move from child-centred to adult orientated systems), the real issue, which all participants felt was not being addressed, was between generic children’s services and generic adult services, particularly adult social care services.

Two priorities were identified in this area:

1. Identifying and removing the barriers to transition.
2. Enabling adult health and social services to contribute to services’ redesign rather than focusing on case by case involvement.

It was considered important that lessons learnt from research, such as the benefit of having specific keyworkers to support individuals through transitions, should be implemented. Other issues were also identified, such as multiple assessments, trust, and supporting those in adult services to understand the needs of young adults with life limiting conditions.

Symptom control

The discussions on symptom control (defined as preventing or treating as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and the psychological, social and spiritual problems related to a disease or its treatment) raised two important issues of concern. The first was timely intervention. Examples of the impact on children and young people of not having timely and effective symptom control were shared, including no access to specialist advice over a weekend resulting in real distress for both the individual, family and support staff.

The following priorities were identified:

1. Ensuring all areas of symptom control are addressed.
2. Improving symptom control for neonates at end of life.

3. Improve the medical response for emergency control out of hours.

Many participants argued that children were not getting good symptom control out of hours because of the lack of specialist services. There was also a view expressed by some that subjecting a child to significant curative medical intervention when the outcome for that child cannot be changed, was not enhancing his/her quality of life, and that services needed to ensure that parents and children were always effectively engaged in such decision making processes. A number of participants also felt that there should not be an assumption that families want end of life care on a neonatal unit. This is an important aspect of prudent healthcare. The important role of GPs in providing effective symptom control in the community was also highlighted together with their need for additional training and 24/7 access to specialist advice. Finally there was also a view expressed that the Welsh NHS was becoming too inward looking and that in order to provide 24/7 access to telephone based specialist support, relationships with specialist hospitals in the rest of Britain should be developed, for example Alder Hey Hospital.

The second issue of concern was timely access to specialist equipment, especially wheelchairs, which are appropriate to the physical and also emotional and social needs of the children and young people involved. Examples were shared of how it can take up to 12 months for a wheelchair to be delivered to a child/young person by which time the individual's needs had changed, if only due to physical growth.

Networking

The priorities for networking (defined as being the process of developing and using your contacts to improve your service, enhance your knowledge, expand your sphere of influence or serve your community) were:

1. Ensuring that networking is effective i.e. actually improves the provision of paediatric palliative care services.
2. Expanding the network beyond the existing managed clinical network within Wales.

The consensus was that people needed to think of networks as being beyond Wales, or even Britain, and that they should concentrate upon sharing good practice, developing partnerships and finding solutions. There was also a view that those working in the field needed to learn and develop new skills in order to engage with and educate others and also undertake a lobbying role for children and their families. There was an appreciation that, as a group, the participants could do more to engage with policy and decision makers to develop a robust evidence base for the development of services in the future.

There were two responses from education departments and a response from Gwent Heads of Children's Social Service Group representing five local authorities.

The education responses highlighted the work authorities undertake to ensure that children receive an education including the provision of home tuition when a child is unable to attend school.

For children's social services the feeling was that children's needs were addressed through the "Child in Need" process.

Both sectors stated that joint working was essential, but that "each sector remains aware of their individual responsibility" (Education) and that all those involved with a child should adopt a person centered approach to planning. This later point was also mentioned as being an important element of an effective service by a number of those professionals interviewed especially during periods of transition and was linked to the importance of developing a keyworker system.

Twenty six professionals from a variety of professional backgrounds, roles and responsibilities were interviewed separately as part of this project. There was a consistent concern about the sustainability of the current system and a majority view that there are insufficient human resources to provide all or even some of what is expected.

The specialist capacity previously detailed is not considered, by those who deliver it, to be enough to provide a workable rota for a 24/ 7 specialist telephone advice service let alone a practical support service. The current arrangements are not sustainable because they are based upon the good will, and the good health, of a small number of practitioners.

The provision of an out of hours GP service to the hospices, and to children at the end of life phase at home, is also very vulnerable, either because it is provided outside of contract and based on good will, as in the case of the support to Ty Hafan, or because of the lack of knowledge and experience of GPs generally to provide end of life care in the home. The GPs interviewed also expressed the view that although end of life care is now part of how their performance is measured, (they are being asked to reflect upon each death and the Royal College of General Practitioners is developing a teaching resource on Advanced Care Planning) the reality is that the average GP would not see many children with life limiting conditions or end of life needs and the ability to provide more home based end of life care within current capacity is very limited.

The concentration of specialist capacity, limited as it is, in Cardiff and Swansea means that it is very challenging to provide support to mid, west and north Wales. Powys is reported as being without any specialist provision and North Wales is reliant upon Alder Hey but without sufficient formal agreement.

Transitions are problematic in areas other than that between paediatric and adult palliative care services, which are generally improving and effective. The real issue described by practitioners, is the difficulty experienced by young people who do not meet the criteria for social care services for people with learning disabilities: in particular those young people

who have respiratory or neurological conditions which result in high support needs combined with aspirations for opportunities for further education and independent living. Supporting young people and their families through local authority systems takes much of the consultant's time.

Navigating through the complexity of support after full time schooling was a rationale for the implementation of the keyworker system, although it was recognised that supporting young people and their families through transitions was time consuming and challenging. One element raised by a number of interviewees was that one transition that is not necessarily recognised is the change of focus from working with the family to working with the individual. It feels as if there is this shift in attitude by professionals on the young person's 16th birthday when the parents are no longer able to make the decisions or have the influence they were used to having.

The other issue for children with palliative care needs is the transition from being under the clinical care of a paediatrician, who understands the needs of the child and family as a whole to adult specialists who are primarily interested in their specific specialist clinical area. This is a particular issue for those young people with complex multifaceted conditions, which do not fall neatly into one specific discipline.

The specialist paediatric nurses both in the workshops and in interviews described how challenging it was for them to plan end of life care, access continuing care funding and mobilise the resources required to enable a child to die at home.

During the second workshop, an approach developed in West Wales was described which took advantage of paragraph 32 of the Welsh Government's guidance on Children and Young People's Continuing Care (2012) to develop a rapid response approach utilising continuing care funding:

“Children and young people who require fast tracking because of the nature of their needs, such as a prognosis indicating end-of-life care needs, should be identified early and the child or young person's needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care for children and young people who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place.”

(Welsh Government, Children and Young People's Continuing Care Guidance, 2012.
Paragraph 32)

This has enabled the Paediatric Oncology Outreach Nurse Specialist and the Paediatric Palliative Care Nurse with active support from their line managers to implement the Hywel Dda Palliative Care Outreach Nursing Service.

The service provided is determined by the needs of the family and planned and coordinated by one of the specialist nurses utilising their own capacity (the role is contained within their job descriptions) and the capacity of bank nursing staff to provide, for a maximum of 3 weeks, the support required for a child/young person to die at home.

CONCLUSIONS

The effectiveness of leadership in delivering change is fundamental to any discussion about the current state of paediatric palliative care services in Wales.

Much has been written about leadership in management texts and three factors would appear to be important for this discussion. The first is that leadership is fluid in that it does not have to sit with one individual or group of individuals all of the time. It can be dynamic and move between these dependent upon circumstances. The second is that those in leadership positions have to have a mandate. This can either be a formal mandate such as a ministerial appointment or an informal mandate where the role is acknowledged and accepted by others within the system. Thirdly when there is a leadership vacuum, as with any other form of vacuum, actions will be taken to fill it.

The “Sugar” report of 2008 was fundamental to moving children’s palliative care forward. It provided clear recommendations concerning the model and outcomes to be achieved and there was resource provided to make things happen. A clear mandate was given to the Palliative Care Cymru Implementation Board by the then Minister for Health and Social Services, and a chair and board members were appointed. There is no doubt that this resulted in important developments within children’s palliative care.

The evidence presented in this report from clinical practitioners presents a view that the needs of children are not being given adequate attention and there is insufficient leadership to resolve this. Those who have been tasked to provide this leadership would undoubtedly take issue with this view referring to reports charting the progress that has been made. Can both be right?

The evidence from this project suggests that there are two forces at work which may explain the dynamic occurring within palliative care services.

The first concerns the policy priority for ensuring appropriate ‘end of life’ care. The discussions with professionals have involved, interchangeably, terms such as palliative care, end of life care and life limiting conditions. Back in 2008 this confusion of terminology was probably not significant and reflected the nature of the service they worked within. However by 2013 the use of language has become fundamentally important with the Palliative Care Cymru Implementation Board morphing into the End of Life Implementation Board with the responsibility to deliver the “Together for Health – Delivering End of Life Care” plan (Welsh Government; Together for Health – Delivering End of Life Care – A Delivery Plan up to 2016 for NHS Wales and its partners, 2013). In addition, Health Boards have been given a very clear responsibility to produce their own plans for implementation and publish annual progress reports.

What has changed significantly during these five years is that whereas the Sugar Report made explicit reference to children's services, with a dedicated section, and a clear conclusion about what actions needed to happen, "Together for Health" reads as being focused upon adult palliative care services with limited reference to children's services where they interface. An example of this is the transition from children's to adult services, which has in effect become focused upon the transition from paediatric to adult palliative care services.

Where previous reports and plans recognised the crucial differences between children's and adult services, this has now become blurred. Nobody is at fault for this and it could be said that what has developed has done so as a result of strong leadership providing a vision with expectations for delivery. The problem is that those working in children's services have become somewhat distanced and disenfranchised from this process and conclude, understandably if not correctly, that the needs of children are not recognised, understood or prioritised.

It would also be fair to say that the End of Life Implementation Board has recognised this dynamic by identifying the role of the Specialist Clinical Network to develop a specific plan for children and manage its implementation. There is also evidence of Health Boards, having initially established adult-only implementation boards, extending membership to those working in children's services. All of these developments have helpfully recognised the distinctive needs of children in relation to palliative care; but nevertheless, this has not translated into sufficient recognition, and more importantly into the development of an adequate infrastructure to ensure that children's needs are always – and equitably – met.

This first force is therefore driving activity to focus upon 'end of life' care, and not sufficiently supporting those children and young people who have life limiting conditions which result in them requiring supportive or palliative care for many years.

The second force concerns the changing demographics of the population group. As previously mentioned, there are four categories of children and young people who may require palliative care services in the broadest sense:

1. Life threatening conditions for which curative treatment may be feasible but can fail, for example cancer or irreversible organ failures.
2. Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal lives, for example cystic fibrosis and Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years, for example Batten disease and mucopolysaccharidoses.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death, for example severe cerebral palsy and multiple disabilities.

Paediatric palliative care is a relatively recent specialty with hospice services being about 15 years in place and specialist consultant led teams being less than 10 years old. From the evidence provided by clinicians, about 20% of the children receiving palliative care services have a cancer and they will receive the majority of their services from oncology specialists.

Until relatively recently the children with conditions where premature death is inevitable would have died young and it would have been rare for them to have lived through transition into adulthood. With the advances being made in medical treatments and technologies, this is no longer the case. These children now have a much greater chance of living through transition and into adulthood, thus delaying the requirement for end of life care. The same applies for those children and young people with progressive conditions without curative treatment options. Whereas previously they would have died at a young age, this is no longer the case.

The children and young people with irreversible but non-progressive conditions often have associated learning disabilities and, although increasing numbers are living through transition to adulthood, they are able to access adult services specifically designed to meet their needs.

As a result of these changes, out of an estimated population of 1,054 children requiring palliative care only around 105 will require end of life care during the year.

From the perspective of those working in this field, there are at least 1,054 children who require specialist palliative care services, which is not an insignificant number of children, young people and their families. For this cohort the evidence from this project is that more needs to be done to improve specialist services.

However when the two forces are applied, the result is that only around 105 children and young people may fit the criteria for end of life services. This then provides an explanation as to why the End of Life Implementation Board is focused upon the interface between paediatric and adult palliative care because it is very important to any individual who is on that end of life pathway to get this right. The problem is, where does this leave the remaining 90% of the children and young people, and the identified service issues?

There was no evidence presented that would indicate that it is the intention of either the Implementation Board, Welsh Government or Health Boards to move away from the definition of palliative care for children presented at the beginning of this report. However there is a concern that without some reflection this may be an unintended consequence.

There was a view shared at the final meeting of the project steering group that those children who are not in immediate need of end of life care experience issues which are similar to those children who are categorised as having severe physical disabilities and/or chronic health conditions, which impact upon their day to day lives but are not life limiting.

For example they experience similar issues concerning timely access to wheelchairs and other aides and adaptations, transition from childhood to adulthood and accessing support to live as independently as possible. Should children with palliative care needs therefore be regarded as a sub-set of all children with severe physical disabilities?

This argument has some merit. One advantage of this approach would be that it would facilitate the engagement of other partners, particularly those in local government because, while there is little reference to 'palliative care' in the children and young people's plans, there are clear statements concerning those with complex disabilities and medical conditions. It is certainly the case that if the actions detailed within the National Service Framework for children with disabilities and complex medical conditions were fully realised, this would improve the experience of all of these children. However, such an approach would not take account of the "life limiting" fact, that, even with the advances made, these children and young people experience. There is also some concern that even the National Service Framework is hardly a panacea for any of these groups, given that several of its objectives have not been fully realised (for example, the implementation of a key worker system, and performance targets for wheelchair services).

This discussion on leadership also influences the approaches to the remaining four priority areas identified.

With the limited specialist resource available, irrespective of the numbers of children and young people supported, the combination of low density, large geographical coverage and complexity of condition, means that the current working arrangements are not sustainable. For example five specialist paediatric palliative care nurses covering the whole of Wales means that priorities have to be made and it appears, from the evidence they gave, that planning and providing end of life care, especially in the home, is a major challenge for most. While the quantum of resource is very limited, there is some scope to improve its effectiveness, and the example from west Wales - where professionals networking and working across boundaries are better able to meet need - deserves study elsewhere.

The expectation that two consultants, plus the paediatricians with one session dedicated to palliative care, can provide a robust 24/7 telephone advice facility also appears unrealistic, and at the current time this is being partially provided, out of contract through good will. No evidence was presented that Health Boards were working together to address this issue and even if they did there would be no easy resolution to the capacity shortfall. One approach, which might have merit, would be to form networks with specialists elsewhere in the UK. At the very least Health Boards could adopt an all-Wales perspective to use resources nationally rather than locally, thus maximising the intellectual capacity available; this may also assist with the capacity issues for Powys and North Wales. However, even working in this way, there is a limit to what can be achieved with the resource as it currently stands.

This leads to the issue of transition, and specifically the future of the recently vacated consultant post for transitions. Although the emphasis for the Implementation Board is to ensure effective transition between paediatric and adult palliative care services, a main activity of the consultant, when in post, was to support individual young people and their families in exploring the options available to them and helping them through the education and social care systems. She also sought to identify potential partners to develop new service models to support these young people into independent living.

With this post becoming vacant, there is an opportunity to review how this resource is utilised. One potential option could be to focus upon implementing the key-worker model, as described in other documents, and target the consultant capacity into providing specialist cover for North Wales, working in collaboration with colleagues from Alder Hey Hospital. These options require detailed consideration.

Symptom control is a key element of palliative care and is not solely applied at the end of life. It is at times of crisis, usually over a weekend or bank holiday, that the fragility of the system is highlighted. Although such crises were described as being infrequent, they are very serious and upsetting for the individual and those around them when they occur. For this reason, if no other, it is imperative that the matter of 24/7 specialist advice cover is resolved.

Finally what is weakening any argument for the development of paediatric palliative care services is the absence of robust need, activity, outcome and cost data on a Wales-wide basis. Individual Health Boards are reported as having made progress in terms of patient data, most notably Cardiff and the Vale, but this is not a national system. Activity data for the health service is not structured to assist planning for children's services. For example it is not possible to identify the numbers of children in the transition phase between the ages of 15 and 19 years of age. From the research undertaken by Bangor University, cost data is at its infancy but needs to be developed if the most efficient use of resources is to be achieved.

RECOMMENDATIONS

The importance of leadership for the future of children's palliative care is obvious and beyond question. It needs to command the confidence and support of service users and professionals, to coordinate scarce resources at the all-Wales level, and to span the sectors and organisations which all have a crucial role to play. Above all, it needs to focus on the specific palliative care needs of children and young people, which are often quite different from those of adults.

The Specialist Clinical Network is working to provide child-centered direction and there is an opportunity for the membership to broaden to include those who manage, plan and purchase services, and a suitable resource provided to ensure the expert coordination and management which such networks require. There will also be a need for additional capacity to enable the formulation and monitoring of plans to take place.

The future role of the third specialist consultant needs to be considered in the light of the skill mix required to deliver effective transitional arrangements and the need to address the capacity to provide cover for Powys and North Wales.

The lack of specific data is also a problem as it is both difficult to plan for and deliver new service models, argue for resource and know if a difference is being made without it.

Finally, the one inescapable conclusion reached from this project is that greater emphasis needs to be given to fully implementing the recommendations from previous reports, because the answers to the problems identified are already contained within them.

Recommendations

- 1. Give Paediatric Palliative Care equal focus as that for Adults by either strengthening the membership of the current End of Life Implementation Board to represent children's needs more effectively, or by establishing a separate Paediatric Palliative Care Implementation Board mandated by the Minister for Health and Social Services and effectively resourced.**
- 2. A Paediatric Palliative Care Implementation Plan should be developed to run alongside the End of Life Implementation Plan. This plan should be based upon the specific recommendations from the Sugar Report and local service boards or their equivalents should be tasked with developing regional plans and publishing annual progress reports.**
- 3. The role of the vacant specialist consultant (transitions) post should be reviewed in the context of the skill mix required to improve transitional support and the need to provide specialist consultant support to North Wales.**

4. Children's and adult social care should be actively involved in the development of plans to address transition to adulthood and end of life care in people's own homes.
5. Ways in which communication, information exchange, learning and research can be rapidly shared within the sector should be explored, including national and international networks and collaborations.
6. Child focused performance measures should be established and data collected should include data from birth to beginning of transition (0 – 14) adolescence (15 – 19) and young adulthood (20 – 25).
7. The 24/ 7 specialist telephone advice service should be implemented to ensure that timely and readily accessible advice for symptom control is available in a manner which is sustainable and not impacting negatively upon those involved in its delivery. Consideration should be given to working with other regions of Britain to develop a national service.

APPENDIX 1 – PHASE 1 REPORT SUMMARY

ISSUES EMERGING FROM THE SCOPING WORK

Seven key issues emerged from the initial work, which are relevant to the terms of reference. These are briefly set out here, and many are inter-related. They are included here if they were perceived to be of relevance to several of the stakeholders. Each requires further exploration, but collectively they represent the scope of the further work now required:

1. Changing need

- a. Patterns of disease, numbers, needs – the causes of the need for palliative care are changing
- b. Increasing complexity of care needs – the nature of the support required is changing e.g. neonates, medically unstable children
- c. Survival times – the improving response of healthcare to these conditions is leading to markedly different expected survival times
- d. End of life care – people’s expectations of end of life care are changing, as is the ability of clinicians and carers to respond
- e. Uses of epidemiology – the changing epidemiological data allows for discussion both normatively (e.g. what would stakeholders like to see provided?) and comparatively (e.g. what is ‘best practice’?)

2. Types of service response

- a. Models of care:
 - i. Types/elements (respite, palliation, family support, counseling, bereavement support, care for siblings, etc),
 - ii. Settings (outreach, community, “hospice at home”/home nursing, NHS, hospice, Young People’s Unit/ ward), transition between services (including child to adult)
- b. Integration with other services, particularly NHS
- c. Service characteristics – specialist/non-specialist, level of training, unidisciplinary/multidisciplinary
- d. Standards for services:
 - i. use of beds
 - ii. medical input
 - iii. out of hours service
 - iv. care planning
- e. Family accommodation
- f. Wellbeing/broader life experience/holistic care

3. Access to services

- a. Criteria for admission (by service), including age, condition, severity
- b. Equality/equity – ensuring ‘fair’ provision by geography, socioeconomic status, religious group, ethnicity etc
- c. Minimum level of provision for different areas in Wales
- d. Cross-border issues between England and Wales
- e. Funding under continuing health care guidance

4. Workforce

- a. Achieving an optimal multiprofessional/multidisciplinary/multiagency skill mix
- b. Appropriate skill levels
- c. Training and support for generalist staff – eg communication about death
- d. Access to specialist medical input e.g. paediatric palliative care specialists

5. Partnership working

- a. Optimal operational links between third sector, NHS, education, social services, and others
- b. Ensuring the strategic coherence of services across Wales – e.g. commissioning, role of PCIB
- c. Cross border issues

6. Clinical Governance

- a. Governance systems
- b. Audit/ Quality of care (assurance)
- c. Safeguarding

7. The rights of children and young people

- a. A rights-based approach might offer a different framework for expressing the future needs for children's/young people's palliative care.
- b. In addition, some specific issues were raised in this context:
 - i. Consent/ Advocacy/ Involvement in decision making
 - ii. Access to IT and education

APPENDIX 2 – STEERING GROUP ATTENDEES

Andrew Fletcher, Together for Short Lives

Andy Goldsmith, Hope House Children's Hospices

Catherine Thompson, Ty Hafan

Cerilan Rogers, Welsh Institute for Health & Social Care, University of South Wales

Chris Dawson, Welsh Government

Jayne Saunders, Ty Hafan

Jo Griffiths, Abertawe Bro Morgannwg University Health Board

Jon Skone, Welsh Institute for Health & Social Care, University of South Wales

Kathryn Macsorley, Cardiff & Vale University Health Board

Marcus Longley, Welsh Institute for Health & Social Care, University of South Wales

Mervyn Ham, Ty Hafan, Representing Ray Hurcombe

Paula Davies, Cardiff & Vale NHS Trust, Representing Ruth Walker

Ray Hurcombe, Ty Hafan

Richard Hain, Cardiff & Vale University Health Board / University of South Wales

Veronica Snow, Powys Local Health Board

Vivienne Collins, Welsh Government

APPENDIX 3 – QUESTIONNAIRE FOR PARENTS

Palliative Care for Children and Young People in Wales Project Parent Survey

SECTION A: YOUR VIEWS

We would like to hear about your views on the current palliative care services for children and young people in Wales.

A1. To what extent do the people who work with your child.... Please tick one answer for each question						
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not Applicable to me/ my family
1. Help you to feel competent as a parent?						
2. Provide you with written information about how your child is doing?						
3. Provide a caring atmosphere <u>rather</u> than just giving you information?						
4. Let you choose when to receive information and the type of information you want?						
5. Look at all the needs of your child (e. g., at mental, emotional and social needs)?						
6. Make sure that at least one team member works with you and your family over a long period of time?						
7. Fully explain service choices to you?						
8. Provide opportunities for you to make decisions about the type of service you receive?						
9. Provide enough time to talk so you don't feel rushed?						
10. Plan together so they are all working in the same direction?						
11. Treat you as an <u>equal</u> rather than just as a parent of a child on their caseload?						
12. Give you information about your child that is consistent from person to person?						
13. Treat you as an individual rather than as a "typical" parent of a child with a long term condition?						
14. Provide you with written information about your child's progress?						
15. Tell you about the results from Assessments?						

A2. Please give reasons or examples to explain the answers you have provided above.

A3. To what extent do the organisations where you/ your child receive services.....

Please tick one answer for each question

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not Applicable to me/ my family
16. Give you information about the types of services offered within the area in which you live?						
17. Have information available about your child's condition (e. g., its causes, how it progresses, future outlook)?						
18. Provide opportunities for all your family to obtain information?						
19. Have information available in various forms such as booklet, kit DVD etc?						
20. Provide advice on how to get information or to contact other parents?						

A4. Please give reasons or examples to explain the answers you have provided above.

A5. To what extent would you agree/ disagree with the following statements?

Please tick one answer for each question

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not Applicable to me/ my family
21. Staff responsible for the care and support of my family have the appropriate knowledge and skills.						
22. My family has been able to access specialist medical input when required.						
23. The number of staff provided across the services has been appropriate.						
24. Staff responsible for the care and support of my family listen to us and respond appropriately to our concerns.						
25. We have confidence and trust in staff across the services.						

A6. Please give reasons or examples to explain the answers you have provided above

A7. What three things would you change about the services you receive or are provided?

1.

2.

3.

A8. What might make, or has made, the biggest difference to the quality of your family life?

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A9. Is there anything else you would like to add?

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SECTION B: ABOUT YOU AND YOUR FAMILY

B1. In which local authority area do you live?

Please tick

Anglesey	<input type="checkbox"/>	Monmouthshire	<input type="checkbox"/>
Blaenau Gwent	<input type="checkbox"/>	Newport	<input type="checkbox"/>
Bridgend	<input type="checkbox"/>	Neath Port Talbot	<input type="checkbox"/>
Caerphilly	<input type="checkbox"/>	Pembrokeshire	<input type="checkbox"/>
Cardiff	<input type="checkbox"/>	Powys	<input type="checkbox"/>
Carmarthenshire	<input type="checkbox"/>	Rhondda Cynon Taf	<input type="checkbox"/>
Ceredigion	<input type="checkbox"/>	Swansea	<input type="checkbox"/>
Conwy	<input type="checkbox"/>	Torfaen	<input type="checkbox"/>
Denbighshire	<input type="checkbox"/>	Vale of Glamorgan	<input type="checkbox"/>
Flintshire	<input type="checkbox"/>	Wrexham	<input type="checkbox"/>
Gwynedd	<input type="checkbox"/>	Other (please specify below)	<input type="checkbox"/>
Merthyr Tydfil	<input type="checkbox"/>		<input type="checkbox"/>

B2. Are you a.....

Parent of a current service user*	<input type="checkbox"/>	Bereaved parent	<input type="checkbox"/>
Parent of a recent service user	<input type="checkbox"/>	Other (please state)	<input type="checkbox"/>
*In this context, the term 'Service User' is used to describe a child or young person who is receiving palliative care support/ services in Wales			

B3. How old is your child?

Please tick

0-2	<input type="checkbox"/>	6-10	<input type="checkbox"/>	16-18	<input type="checkbox"/>	Over 25	<input type="checkbox"/>
3-5	<input type="checkbox"/>	11-15	<input type="checkbox"/>	19-25	<input type="checkbox"/>	Not applicable	<input type="checkbox"/>

B4. What gender is your child? <i>Please tick</i>			
Male	<input type="checkbox"/>	Female	<input type="checkbox"/>

B5. What types of services have you/ your family accessed? <i>Tick all that apply</i>			
Respite	<input type="checkbox"/>	Bereavement support	<input type="checkbox"/>
Pain and symptom control	<input type="checkbox"/>	Care for siblings	<input type="checkbox"/>
Family support	<input type="checkbox"/>	Other (Please state)	<input type="checkbox"/>
Counseling	<input type="checkbox"/>		

B6. In which settings have you/ your family accessed services? <i>Tick all that apply</i>			
In your home	<input type="checkbox"/>	In a young people's unit/ ward	<input type="checkbox"/>
In your community	<input type="checkbox"/>	In an adult unit/ ward	<input type="checkbox"/>
In a children's hospice	<input type="checkbox"/>	Other (Please state)	<input type="checkbox"/>
In an adult hospice	<input type="checkbox"/>		

B7. Who provides the services you access? <i>Tick all that apply</i>			
National Health Service	<input type="checkbox"/>	Private/ for profit	<input type="checkbox"/>
Local Authority	<input type="checkbox"/>	Other (Please state)	<input type="checkbox"/>
Voluntary/ not for profit	<input type="checkbox"/>		

And finally.....

B8. Would you be willing to be interviewed by a researcher from the University of South Wales?			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
If you answered YES above please could you provide the following contact details?			
Name:	<input type="text"/>		
Contact Telephone Number:	<input type="text"/>		
Contact Email (optional):	<input type="text"/>		

Thank you for taking the time to contribute to the Palliative Care for Children and Young People in Wales Project.

The WIHSC Project Team



APPENDIX 4 – QUESTIONS TO DIRECTORS OF SOCIAL SERVICES

1. How do you see the current role for the local authority children's social services in supporting children who have life threatening or life limiting conditions?
2. What do you see as the future role for the local authority children's social services in supporting children who have life threatening or life limiting conditions?
3. What are the priorities around transition to Adult Services for the same groups of children and young people?
4. What is your view of the role of children's hospices?
5. Do you have any thoughts on partnership working between health, the third sector and local authorities to better support these specific groups of children and young people?

APPENDIX 5 – LETTER AND QUESTIONS TO DIRECTORS OF EDUCATION



Welsh Institute for Health and Social Care
Lower Glyntaf Campus
University of South Wales
Pontypridd
CF37 1DL

September 2014

Dear Colleague

Palliative Care for Children and Young People in Wales: Meeting Future Needs.

The University of South Wales is currently undertaking a piece of work for Ty Hafan Hospice which will inform the future provision of services for children and young people who have life limiting conditions and require palliative care.

We would like this project to be as consultative as possible and we would very much welcome your input and should be grateful if you could take the time to respond to the following questions:

1. How do you see the current role for the local authority education services in supporting children who have life threatening or life limiting conditions?
2. What do you see as the future role for the local authority education services in supporting children who have life threatening or life limiting conditions?
3. What are the priorities around transition to adult services for the same groups of children and young people?
4. What is your view of the role of children's hospices?
5. Do you have any thoughts on partnership working between health, the third sector and local authorities to better support these specific groups of children and young people?

It would be very helpful to have your input by Friday the 26th September. You can send your answers to these questions by e-mail to marina.mcdonald@southwales.ac.uk

Thank you very much for your help.

Yours sincerely

Jon Skone
Associate, Welsh Institute for Health and Social Care

APPENDIX 6 – WORKSHOP PARTICIPANTS

Andy Goldsmith, Hope House Children's Hospices

Anne Williams, Hope House Children's Hospices

Catherine Thompson, Ty Hafan

Cerilan Rogers, Welsh Institute for Health & Social Care, University of South Wales

Elizabeth Bendle, Cardiff and Vale University Health Board

Jack Robinson, Together for Short Lives

James Cooper, Together for Short Lives

Jayne Saunders, Ty Hafan

Jayne Thomas, Hywel Dda University Health Board

Jo Griffiths, Abertawe Bro Morgannwh University Health Board

Jon Skone, Welsh Institute for Health & Social Care, University of South Wales

Kate Jones, Carmarthenshire County Council

Kath Jones, Hope House Children's Hospices

Kathryn MacSorley, Cardiff and Vale University Health Board

Lynette Thacker, Abertawe Bro Morgannwh University Health Board

Marcus Longley, Welsh Institute for Health & Social Care, University of South Wales

Marina McDonald, Welsh Institute for Health & Social Care, University of South Wales

Patricia O'Meara, Aneurin Bevan University Health Board

Paula Davies, Cardiff and Vale University Health Board

Sally Jenkins, Newport City Council

Sian Thomas, Aneurin Bevan University Health Board

Vera Clement, Cwm Taf Health Board

Viv Collins, Welsh Government

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