

Our strategy for giving children and young people with serious health needs the best chance to thrive.

2018-2023





WHERE WE ARE TODAY

38 

WellChild Nurse posts funded across the UK supporting children, young people and families.

Over

300 

homes and gardens made safe, accessible and sensory.

1,500 

families connected for mutual support via the **WellChild Family Tree**.

Establishment of the **UK's 1st**

'Better at Home' parent and carer training facility.

8,000

Visits per day to the **Medicines for Children** information website.

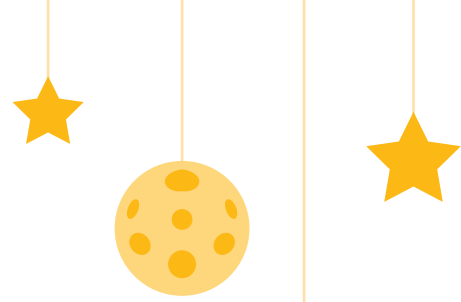
More than

£23m

invested in groundbreaking child health research.

25 

children and young people with Wolfram Syndrome supported at two specialist clinics.



OUR VISION

For every child and young person living with serious health needs to have the best chance to thrive - properly supported at home with their families.

We believe every child, young person and family must have:

- The opportunity to be cared for at home whenever and wherever possible.
- Access to high quality, appropriate care and services whatever their health needs.
- Involvement in all decisions regarding their care.



OUR MISSION

At a time when health and social care resources are under increasing pressure, we will work with innovation and passion to ensure this growing population of children, young people and their families across the UK are not forgotten. Our mission is to:

- Get children and young people with serious health needs home from hospital more quickly and efficiently.
- Ensure that the services they need are in place when they need them.
- Empower parents and carers to care for their children safely.
- Ensure homes are suitable, accessible, safe and encourage development.
- Support families and ensure they are not isolated, or forgotten.
- Advocate for investment and improvements in services where and when necessary.

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“For so many families, organisations like WellChild offer a lifeline that otherwise would not exist”.



WELLCHILD PATRON, PRINCE HARRY



OUR EVOLUTION TO CRITICAL LIFELINE

WellChild's evolution over the past 40 years has taken the charity to the forefront of the provision of services for children and young people with serious health needs across the UK.

This strategy is another step in that development, moving the charity from a background in research to its present and future position – providing direct and vital services to families and their children where and when they need them most.

We live at a time when social care for children and young people with serious health needs lies close to the bottom of the national 'social care' list of priorities. Meanwhile, as medicine and technology advance, children are living longer and more active lives with long term conditions that would previously have been life-limiting. The issue of care at home is a crucial one.

WellChild's strategy could not be more simple. We believe that every child or young person with serious health needs should have the opportunity to have high quality care provided at home.

There is clear evidence that this has a measurable positive impact on the child and the family. It relieves pressure on the NHS and delivers tangible cost benefits to all.

"We believe that every child or young person with serious health needs should have the opportunity to have high quality care provided at home."

WellChild is committed to supporting families every step of the way:

- Enabling co-ordinated, earlier (where appropriate) and less stressful discharge from hospital.
- Pushing for and providing community services to prevent frequent hospital re-admission.
- Parent, carer and professional training to ensure competent and confident care.
- Projects to improve 'home conditions'.
- Giving access to readily available practical and emotional support.

We will continue to push policy and decision makers for greater recognition of these families and their children in health and social care planning – working alongside organisations that share our determination. This starts with a call to urgently address the deeply inadequate and inconsistent national data set on this growing population.

Success for WellChild can only be judged in terms of the improvement across all these areas. Set against a backdrop of an NHS and social care system under increasing resource pressure, a child health workforce shortage, cuts to vital services, less spend on key resources, and with adult care dominating public policy – WellChild's role in supporting this growing population of children and young people to be cared for safely at home is more important than ever.

COLIN DYER, CHIEF EXECUTIVE

A GROWING AND IMMEDIATE CRISIS

It is widely acknowledged that accurate and complete national data regarding the numbers of children and young people living with complex needs or serious conditions in the UK is not available. We therefore believe that planning and prioritisation of future services for these children, young people and their families is seriously affected by a lack of information, awareness and understanding. Through the work outlined in this strategy we hope to support and contribute to a greater understanding of the needs of this growing population.

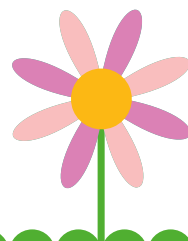
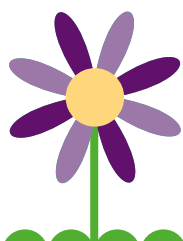
According to a 2016 report by the Council for Disabled Children and True Colours Trust¹, the numbers of school children living in the UK with complex needs has increased dramatically by over 50% since 2004 from 49,300 to around 73,000. It is thought however that this figure is an underestimation of the true picture.

With a clearly increasing demand, access to quality services for these children, young people and families is currently both inadequate, inequitable and in some areas, not available.

WellChild is firmly focused on the many complex challenges surrounding the care of this group of children and young people who too often fall through ever widening gaps in health and social care, and face an increasingly uncertain future.

“The neglect of children with disabilities in data systems is stark.”

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH 'STATE OF CHILD HEALTH' 2017



¹Understanding the Needs of Children with Complex Needs or Life-limiting Conditions. What can we learn from national data? Exploratory analysis commissioned by the Council for Disabled Children and the True Colours Trust, Anne Pinney, 2016

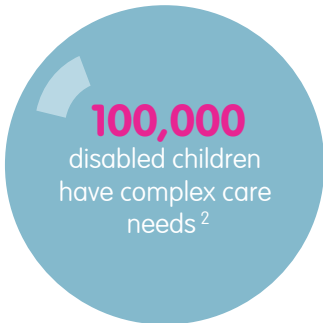
WHAT WE DO KNOW

The following estimates, from a range of sources and time periods help us build an overall picture of this growing population.



30,000

babies (1 in 25) are diagnosed every year with a genetic or rare disorder. (Genetic Disorders UK)



100,000

disabled children have complex care needs²



49,000

children and young people are currently living with a life-threatening or life-limiting condition.³



1 in 8

babies born each year in the UK will need neonatal care. (Bliss)



6,000

children and young people are dependent on assistive technology.⁴



1,500

children require long-term ventilation.⁵



6,000

children and young people are living with an undiagnosed genetic condition. (Syndromes Without A Name)



² Aiming High for Disabled Children: Better Support for Families, DfES 2007

³ Fraser L.K. et al. Life-limiting and life-threatening conditions in children and young people in the UK. Final Report for Together for Short Lives, Leeds University 2012

⁴ National Service Framework - Standard 8, Disabled Children & Young People and those with Complex Health Needs, DH & DfES 2004

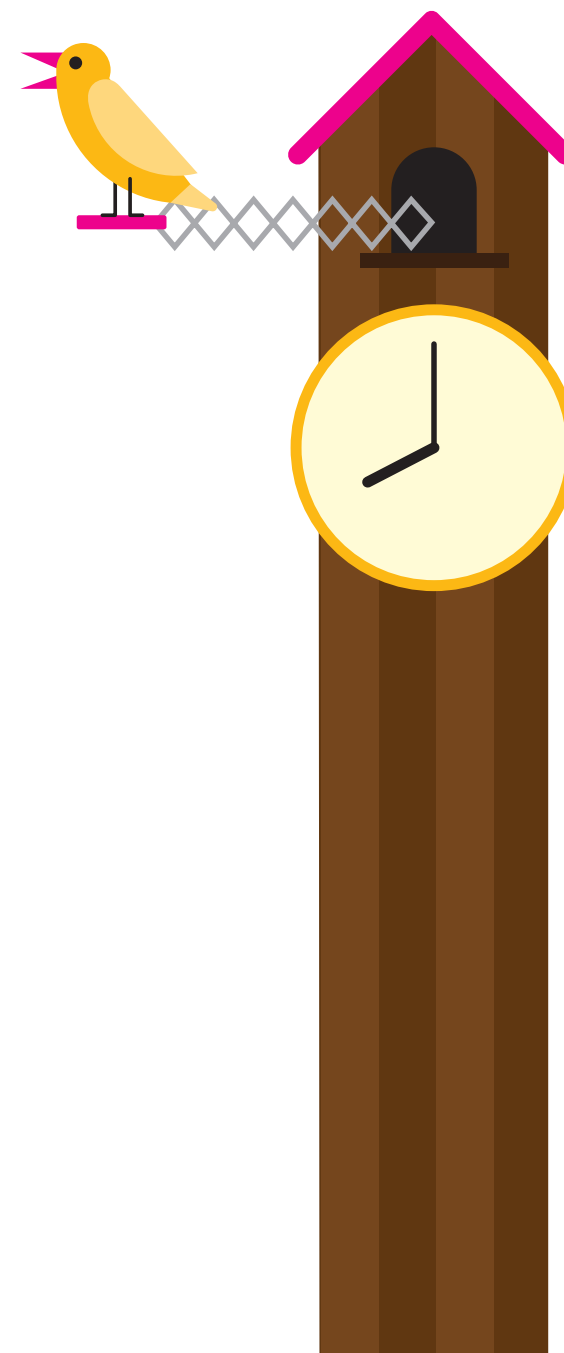
⁵ Paediatric Critical Care CRG, NHS England

CHALLENGES OLD AND NEW

Families caring for a child or young person with serious health needs are under immense practical, physical and emotional strain - with an often relentless, 24-hour care routine, too often after an unnecessarily long and complicated hospital discharge process.

Many families simply don't have the support they need to care for their child when they need it and, most disturbingly, when there is a crisis. The challenges are complex, with wide-reaching implications.

- Unnecessarily long stays in hospital for children and young people.
- Inadequate, inconsistent, or unavailability of services.
- Lack of access to quality training (for parents, carers and professionals).
- Poor focus on the emotional impact.
- Lack of information or advice on practical issues (e.g. housing, or financial support).
- Slow or poor transition to adult services.
- Lack of suitable respite care (including short breaks).



LONG STANDING ISSUES UNRESOLVED

In 2009, we published our 'Better At Home' report, produced in conjunction with the Royal College of Nursing that included results from a Freedom of Information request to 582 hospitals and local health authorities across the UK.

The exercise highlighted a number of barriers preventing children leaving hospital quickly and with a plan in place for quality care and support once at home. Barriers included a lack of children's nurses (including community children's nurses), along with issues surrounding equipment, housing and ongoing packages of care.

That Freedom of Information process was repeated in 2017 to help inform this strategy, and has plainly shown that exactly the same issues are facing families now as they were then.

TRAINING & WORKFORCE PRIORITIES EMERGE

The process has also identified a common theme of poor parent and carer training which has become more prominent at a time when families are being left to carry out increasingly sophisticated elements of their child's care at home.

Meanwhile, children's nurses account for just six per cent of the total nurse population in the UK with 63% of NHS providers reporting vacancies.

EMOTIONAL SUPPORT SEVERELY LACKING

The relentlessness of 24/7 care regimes can impact a family in many ways – work, financial, social, leisure and quality time with other children. The effects are long lasting and research is mounting into the impact of such a regime on emotional wellbeing and mental health.

Research from various sources has shown that 32% of those parents presented with acute stress with 21% subsequently diagnosed with Post Traumatic Stress Disorder (PTSD). Meanwhile 47% of parents have been to see their GP with 62% of them being prescribed medication.



“Rogan is doing really well at home now. Our WellChild Nurse was fantastic in helping us coordinate everything needed to have him come home to us. It’s such a comfort to know she is on the end of the phone whenever we have any concerns”

.....
WAYNE, ROGAN'S DAD

HOME IS BEST

Our plan to overcome barriers to hospital discharge.

While nurses are not the only barometer or solution for the gap between the needs of children, young people and families and the support available to them – our continuing investment in our network of WellChild Nurses has had significant impact – particularly in preventing delayed discharge from hospital and ensuring community support.

Many children and young people are being delayed by months (even years) when there is no medical requirement for them to remain in hospital. The emotional impact and financial cost to these families is significant.

On-going barriers to hospital discharge for children and young people remain due to avoidable issues such as lack of support for families at home, housing, equipment and financial issues.

WellChild Nurses provide a valuable, seamless, co-ordinated, effective and high quality model of care at a challenging time for the children’s nursing workforce across the UK. They are instrumental in driving forward with new and innovative ways of working.

We plan to grow this expert network of support, whilst working with others to eliminate the inequities of discharge planning across the UK and enabling better communication between relevant services to improve efficiency during that planning.

OUR STRATEGIC AIMS

Increase the impact of the WellChild Nurse programme through the creation of further posts – including new and innovative models.



Collaborate in the development of a national discharge database – creating a standardised and monitored approach to discharge.



Explore the use of digital technology in providing on-demand and dedicated 24/7 support to families at home by WellChild Nurses.





“The WellChild Training Unit is such a lifeline for so many families, not just ours. It gives families that comfort of knowing that they’ve got a facility they can come to, train and be confident enough then to take their child home and care for them safely.”

.....
HAYLEY, PARENT AND USER OF THE WELLCHILD BETTER AT HOME UNIT

CONFIDENT TO CARE

Our plan to improve the accessibility, quality and consistency of information and training for families.

All parents and carers must be confident and competent to care for their children at home. Access to high-quality, individualised and flexible parent-training programmes – with regular reviews and updates – is essential.

'BETTER AT HOME' TRAINING UNITS

Parents and professionals already have access to the UK's first, pilot WellChild 'Better At Home' Training Unit based at Edge Hill University and in collaboration with Alder Hey Children's Hospital. This provides simulation training in a safe and supportive home-from-home environment. We plan to replicate this successful model of training across the UK.

NATIONAL TRAINING PRINCIPLES

We believe that training models should work to nationally agreed principles so that all families expect and receive consistent and high-quality support. Training should also be available using different media such as simulation, and in different environments including the home.

IMPROVING INFORMATION

Parents and carers must have access to a wide range of information, using different media, on different aspects of care in a way that is most beneficial to them – covering issues such as housing, medicines, equipment and financial support.

OUR STRATEGIC AIMS

Establish a network of new 'Better At Home' Training Units across the UK.

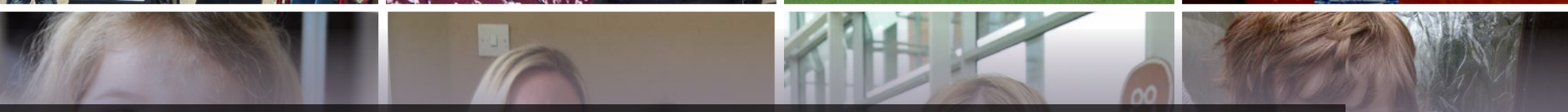


Collaborate in the development of new national training principles for parents, carers and professionals.



Explore the use of digital technology in delivering more, improved and co-ordinated training and information resources.





“WellChild has really helped us grow as a family. We have been able to reach out from feeling very isolated and alone, to join with other families. It has been so important to feel part of a network that understands how hard the journey is.”

SIAN, WELLCHILD FAMILY TREE MEMBER

ENABLED TO THRIVE

Our plan to lay the foundations for a safe, stimulating and happy home life for children, young people and their families.

Getting home and being able to provide the right level of care is often just the first part of the journey for many families. Once home, children, young people and their families must feel properly supported and enabled in order to have the very best chance to thrive. This means overcoming many of the practical and emotional challenges of simply being at home with a child living with serious health needs.

MAKING HOMES SAFE, ACCESSIBLE AND SENSORY

WellChild's Helping Hands programme has carried out more than 300 projects to improve the suitability of family homes and outdoor spaces for the care of children and young people living at home with long term illness or severe disability. We want to ensure that all children and young people have access to a space for play and for themselves at home to help their development.

REDUCING FEELINGS OF ISOLATION

Peer-to-peer support through the WellChild Family Tree has created a network of more than 1,500 parents and carers, with many of them active in an online forum for mutual support and advice. The group has become a vital source of emotional and sometimes practical support for many and an opportunity to make new friends, memories as well as creating a platform for change.

ADDRESSING THE NEED FOR EMOTIONAL SUPPORT

We believe all families (including siblings and other carers) must have access to emotional support as soon as possible and for as long as required. This includes both formal and informal support which must start as early as possible and be available within the community for as long as the family need it.

OUR STRATEGIC AIMS


Expand the WellChild Helping Hands programme to satisfy growing demand.




Enhance support available through the WellChild Family Tree network.




Establish a face-to-face emotional support service for families.

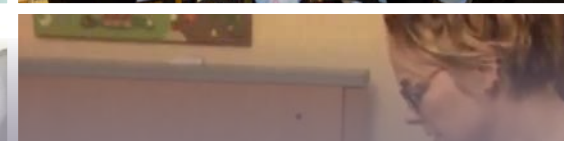
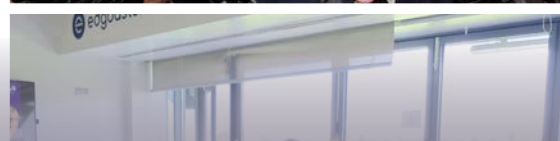


Collaborate on the provision of further professional support posts for families – including focus on psychological and social care.



Explore new support services for rare conditions based on the success of the WellChild Wolfram Syndrome Family Co-ordinator model.





“Being a WellChild family has given us amazing support, and also the strength to have a voice for our complex needs child in a world that is very overwhelming”.

.....
VICTORIA, WELLCHILD FAMILY TREE MEMBER

A VOICE & A PRIORITY

Our plan to ensure the needs of families are recognised publicly and at the highest levels.

With adult social care dominating health and social care policy and public debate, the needs of this growing population of children, young people and families must continue to be placed firmly in the public spotlight.

ESTABLISHING A STRONG VOICE FOR FAMILIES

Through campaigns such as #notanurse_but and the high profile WellChild Awards, WellChild has used innovative and wide-reaching strategies to illustrate and communicate the need for solutions to the issues facing families across the UK.

MAINTAINING PRESSURE ON KEY ISSUES FACING FAMILIES


At a time when there is so much uncertainty regarding services, it is important to monitor the impact of an NHS and social care system under increasing resource pressure, a child health workforce shortage, cuts in vital services and less spend on key resources. It is critical to maintain pressure on the organisations responsible for providing effective care, and to ensure they understand the issues facing families.

Those issues include a fully integrated approach to the planning of care for children and young people in their homes, better integration across health, social care and education, and commissioning models which are focused on addressing the needs of children, young people and families at both national and local levels.

Collaborative approaches to campaigning enable organisations working together to provide a strong and unified voice. As one of the 28 founder organisations of the Disabled Children's Partnership there will be scope for WellChild to continue to push for action on the most important of issues.

OUR STRATEGIC AIMS


Continue to develop campaigns and projects such as the WellChild Awards and #notanurse_but to increase awareness of key issues.




Engage with regional and national child health policy and decision makers.



Create a more powerful voice by exploring new, and developing existing, campaigning collaborations.



Support and contribute to better national data and understanding of the needs of families.



ABOUT WELLCHILD

WellChild is the national charity for seriously ill children, young people and their families. More than 100,000 children and young people are living across the UK with serious illness or exceptional health needs. Many spend months, even years in hospital simply because there is no support enabling them to leave. Meanwhile those who are at home face inconsistent and inadequate levels of support.

Through a UK-wide network of children's nurses, home and garden transformation projects and family support services, WellChild exists to give this growing population of children and young people the best possible chance to thrive – properly supported at home, together with their families.

HELP US DELIVER OUR STRATEGIC AIMS

WellChild is entirely reliant on the fundraising support of individuals and organisations, without whom none of what we plan to achieve will be possible.

Find out how you or your organisation can help us deliver our ambitious plan for children and young people with serious health needs. Visit [wellchild.org.uk](https://www.wellchild.org.uk).



OUR VALUES

WE ARE PASSIONATE ABOUT WHAT WE DO

We are passionate about our purpose and our work – from ensuring that families get the support they need for every step of their journey, to raising funds and awareness.

WE EMPOWER OTHERS AND WE ARE NOT AFRAID OF LETTING GO AND EMBRACING CHANGE

We empower everyone from our staff to the families we support to enable them to make their own decisions. We are not afraid of letting go and enabling others – from funders through to partner charities – to help build on our ideas.

WE GO THE EXTRA MILE

We are ambitious and committed, determined to go the extra mile to ensure the best for the people we support, our funders and anyone else who comes into contact with us.

WE INNOVATE AND CHALLENGE THE STATUS QUO WHENEVER WE CAN

We foster an environment where creativity thrives. We are not afraid of doing things differently.

OUR WORK IS SHAPED BY THOSE AROUND US

We ensure all our work is informed by the voice of the people we support and work with.

WE ARE CARING AND RECEPTIVE

We are approachable and supportive and we treat everyone with mutual respect. The WellChild environment is always warm, friendly, open and honest.



Patron: Prince Harry



Follow us on Twitter and Instagram - @WellChild
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