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How we created a brighter future for children with serious health needs and their families

wellchild.org.uk



CONTENTS

WELCOME FROM OUR CHIEF EXECUTIVE	2
A MESSAGE FROM OUR PATRON, THE DUKE OF SUSSEX	3
POWER TO CHANGE	5
PRIORITY ONE - HOME IS BEST	8
PRIORITY TWO - CONFIDENT TO CARE	12
PRIORITY THREE - ENABLED TO THRIVE	16
PRIORITY FOUR - A VOICE & A PRIORITY	
WELLCHILD AWARDS 2021	. 23
HOW WE FUNDED OUR WORK	. 24
THANK YOU	. 25

Across the UK, more than 100,000 children and young people are estimated to be living with serious health needs. WellChild is the national charity giving these children and young people with serious health needs the best chance to thrive – properly supported at home with their families.

Welcome

I was proud to step into the shoes of Colin Dyer who moved on to pastures new in April 2022, after fourteen years at WellChild.

Colin was an inspirational leader, notably over the last couple of years, during some extremely testing times for WellChild. He led a huge team effort in rising to the challenges brought by the pandemic, while keeping our focus firmly on the children, young people and families we support. Our amazing supporters and volunteers put their hearts and souls into this effort too, going all out to support us in whatever way they could.

This year the pandemic continued to affect the charity's plans. Once again we tackled challenges head-on, adapting our programmes and services to meet the needs of families. We launched our online Family Information Hub, building on the work we carried out last year. Following on from the success of our COVID-19 Direct Response Service in 2020-2021, we conducted research and scoping work into potential models for a new direct support service for families.

We welcomed the return of some activities and events paused or cancelled during the height of the pandemic.

The Helping Hands programme was able to deliver projects at a more typical rate. And our incredible fundraisers were back in force, helping us to bolster our finances after a difficult year.

In 2022-2023, it's time to press the `reset

button'. The impact of the pandemic was immediate, disruptive and even frightening. But it also showed us how innovative, inventive and inspired we can be. Despite setbacks and obstacles, we have continued to deliver on the key aims of our five-year charitable strategy 'HOME', as you will read in this review.



Matt James is Chief Executive and previously Director of Communications and Engagement

By pressing the 'reset button' we can move forward confidently with a positive attitude towards change, and the knowledge that we can be here for families even in the toughest of times.

I am proud that, thanks to our incredible team, our volunteers and supporters, we continue to keep our promise to children and young people: to give them the best chance to thrive, by being cared for safely at home instead of hospital.



Matt James WELLCHILD CHIEF EXECUTIVE

A MESSAGE FROM OUR PATRON, THE DUKE OF SUSSEX





I want to start by acknowledging the continued determination and resilience of the WellChild community over the past few years. As Royal patron, I know there hasn't been a moment to take a breath, because as long as children and their families are in need, WellChild has been there to step up and do what they do best: provide care, comfort, and support.

I was fortunate to be able to spend some quality time with the 2022 WellChild Awardees recently, and even though we had to connect virtually, it felt as if we were all back in Kew Gardens like last year – sharing a laugh, learning about each other, and celebrating incredible families. Finding comfort, belonging, and even joy during life's most challenging moments is what WellChild is all about. Truly, the power of this community always shines through.

There is no doubt that WellChild families have all faced enormous challenges and major changes – in addition to the complex health needs they already manage on a daily basis – but I have also been struck by their remarkable strength, spirit, and good humour in the face of these challenges. One place where this is particularly apparent is in the WellChild Family Tree peer-to-peer support network where families support each other by offering help, advice, and, when needed, a shoulder to lean on. I am so pleased that this vital online community continues to grow across the UK and is now over 1,000 families strong.

As families up and down the country continue to face difficult times, WellChild remains a lifeline to so many; and as fundraising gets tougher and resources are harder to find, it becomes even more important to support the essential work this charity does to help these children and young people with complex needs.

I would like to thank the entire WellChild team for their fantastic work and dedication over this last year, going above and beyond, and continuing to reach out to more and more seriously ill children and their families. We greatly value the contribution of everyone at WellChild, including the expanding number of Family Tree members, along with the staff, volunteers, nurses, and supporters who are all doing an incredible job to make life better for these most deserving of young people.

Finally, I would like to take this opportunity to say a heartfelt thank you to Colin Dyer for his outstanding service as WellChild Chief Executive for 14 successful years. Colin took WellChild from strength to strength during his time at the helm and left the organisation in a fantastic position to move forward and face the challenges that lay ahead. I wish Matt James, WellChild's new Chief Executive, all the very best as he takes the organisation on to the next level. I know that his significant experience working for WellChild over the years will enable him to do this exceptionally well.

Prince Harry, The Duke of Sussex

2021-2022 Highlights

More than **3,000** children and young people





More than **1,100** parents, carers and professionals trained in vital skills.





2,848 families received peer-to-peer support through the WellChild Family Tree network.





3,627 Better at Home training sessions delivered.













Power to change

For many of us, home is where we feel safe and loved. It offers stability and a foundation. It's the place we belong and thrive.

Home is no less important to our growing population of children and young people with complex healthcare needs and their families too. Many of whom can spend months and even years in hospital because there is a lack of support to get them home. Our vision is that they should be cared for at home instead of hospital, whenever possible and properly supported to thrive with their families.

Every day we strive to make this happen for more children and young people – through our nationwide network of WellChild Nurses, home and garden transformation projects, and family information, training and support programmes. Our vision:

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

How we do it

1- Getting Children Home

Our nationwide network of WellChild Nurses get children home from hospital quicker and support safe care at home.

2- Transforming Homes & Gardens

We create safe, accessible and sensory spaces through our WellChild Helping Hands programme.

3- Supporting Families

Our WellChild Family Tree connects families from across the UK for mutual advice, support and friendship.

4- Empowering Parents & Carers

We provide tools and resources to give families the skills and confidence to care for their child safely at home.

5- Influencing Change

We fund and facilitate research and campaigns to give families a voice, influence policy and practice to improve lives for children and their families.

Thanks to their WellChild Nurse Alex, Benjamin was able to get home from hospital in time for his first birthday. Since being home Benjamin is thriving. He enjoys nursery and has taken up tennis lessons. Alex continues to support Benjamin and his family in the community. For children like Benjamin

For children like Samsondeen

Support from a WellChild Nurse means Samsondeen can live at home with his family and his mum was able to go back to work part time. The family have been supported by WellChild since 2013 and Samsondeen is making great progress.

Priority one - Home is best

WellChild Nurses provide children and young people with the best possible quality of care and support along the often difficult journey from hospital to home and beyond.

In 2021 - 2022



Our priorities in 2022 - 2023



Create new WellChild Nurse posts across the UK and develop more nurse-led projects and collaborations.

Continue to develop the 10 Principles for Complex Discharge project and promote its use among professionals.

Develop a set of national guiding principles and professional resources for improving transition from children's to adults' services and outcomes for young people.

There's no place like home

Families caring for a child or young person with complex healthcare needs at home are under immense practical, physical and emotional strain. This can often come after a long and complicated hospital discharge process.

We're on a mission to change this Our growing network of specialist WellChild Nurses provide valuable, seamless, co-ordinated and high-quality care both in hospital and the

Why was this more important in 2021-2022? Increasing number of children and young people with complex needs means more families need support.

WellChild Nurses

community.

We continued to invest in our network of WellChild Nurses during the year. There are now 50 WellChild Nurses working within children's hospitals and the community in every region of the UK.

Their focus is caring for children and young people with a variety of long term and complex health conditions. They support children and families at every point on their journey – from coordinating their discharge from hospital and providing ongoing care in the community, to supporting the complex transition from children's to adults' services and making referrals for palliative care.



More Nurses, closer collaboration

During the year, we welcomed nine new post holders into existing WellChild Nurse roles. And we continued to develop the WellChild Nurse network and creation of future children's nurse leaders.

We also completed three-year funding for WellChild Nurse posts in Manchester, Gloucestershire, North Wales and London during the year. These Nurse posts will now be established for life within their local NHS Trusts, creating a lasting legacy of support.

Though they are located around the country, WellChild Nurses collaborate as a network, sharing expertise and best practice. To make this easier, we set up five new professional sub-groups. They complement the Transition sub-group which has been successful in helping to produce a Transition Q&A family resource and associated Easy Read Guide for young people.

"I am thrilled to be part of the WellChild network of specialist nurses and hopeful that the patient care I provide, coupled with influencing change, will make a massive difference to the patient and family transition experience and ultimately improve their quality of life."

Janice, WellChild Nurse in Manchester

What are sub-groups?

They bring together WellChild Nurses for peer-to-peer support and collaboration. Sub-groups are a channel for keeping up to date with national issues, and help drive forward new standards and innovative ways of working across child health.

Discharge from hospital

Children and young people with complex needs can spend months, even years in hospital, even if they are medically fit to leave. The process of discharging them home can be very complex.

Support is needed to coordinate all the relevant services, make necessary home adaptations, source equipment, put a care package in place and provide training to parents and carers. Everything needs to be ready so children can be cared for safely at home, with their families.

Complex discharge is often carried out differently depending on where people are in the UK and who or what is available to support the process. While a smooth discharge can be a positive experience, families and carers say a 'bad' experience can affect family life and often have a long term impact.

During the year, WellChild Nurses collaborated to launch the '10 Principles for Complex Discharge Guidance and Toolkit', working with the Pan Thames LTV Collaborative. It is a comprehensive resource for health professionals with guidance and support for managing a complex discharge. It also provides a framework for making the process consistent, safe and timely.

The overall aim is to provide greater support and improve the experience for children and young people requiring a complex discharge and their families.

Celebrating success

WellChild Parent Trainer Nurse, Laura Truscott-Wright won the prestigious Suzanne Goodall Paediatric Royal College of Nursing (RCN) Award. It recognised her outstanding contribution to the care of children and young people with a lifelong or life-limiting illness. Laura is based in Wales, at the Cardiff and Vale University Health Board. Congratulations Laura!



Laura Truscott-Wright, WellChild Parent Trainer Nurse at the Cardiff and Vale University Health Board, Wales.

Samuel's WellChild Nurse, Cat was vital in supporting the family through the transition home from hospital. Cat organised the equipment Samuel needs and liaised with community teams so Samuel can live safely at home with his family.

For children like Samuel

Priority two - Confident to care

We help make a family life at home possible, by providing support and training so that families can leave hospital and look after their seriously ill child safely at home.

In 2021 - 2022



Our priorities in 2022-2023



Expand the Better At Home Training programme to give more families access to quality training and resources.

Listen and learn from families to make sure our Family Information Hub supports their most pressing needs.

Complete phase two development of a Medicines Management App for families working with our partners.

Making a positive impact on family life

For a seriously ill child to leave hospital and thrive at home, families need to have the skills and confidence to care and support them safely. 24-hour care often puts families under immense physical and emotional strain.

We're on a mission to change this

We fund and facilitate high-quality training and information resources so that families have the knowledge and confidence to care for their child safely at home.

Why was this more important in 2021-2022?

Many families continued to isolate at home following the COVID-19 pandemic. Many others struggled without the care they needed because of care staff shortages.

New Family Information Hub

As well as providing hands-on training, we continued to improve and develop our online resources during the year.

We launched a new online Family Information Hub on the WellChild website. It brought together previously published articles along with 32 new online articles on subjects including condition management and wellbeing.

The content we uploaded to our hub was informed by what the WellChild Family Tree network, WellChild Nurse and health professional community tell us they need. In its first year, the Information Hub attracted more than 10,500 visitors.

Tech for good investment

WellChild received funding and mentoring from Comic Relief's Tech for Good programme. With this support, we hope to launch a tool for parents called 'In Your Area' in the new financial year. It is in response to research which revealed that finding local services is a big challenge for families.

Thanks to the support from Comic Relief and the Paul Hamlyn Foundation, we will be able to help families discover and access local services and activities relevant to them quicker.

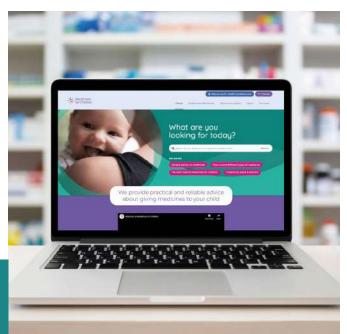
> Medicines for Children is an online library of medicine information for parents and carers produced in partnership with the RCPCH and NPPG.

Working with partners

We continued to work in partnership with the Royal College of Paediatrics and Child Health (RCPCH) and the Neo-natal Paediatric and Pharmacists Group (NPPG) investing further in the development of the Medicines for Children website.

The site provides parents and carers with practical and reliable advice about giving medicines to their child. It was redesigned and relaunched during the year with a better, more accessible user experience. Medicines for Children received more than 2.8 million page views.

We also kick-started phase two of the development of a Medicines Management App aimed at making complex medication management easier for parents and carers.





Better At Home Training programme

We continued to invest in our Better At Home Training programme and have funded 11 projects across the country to date. During the year, 3,627 training sessions were delivered to more than 1,100 individuals including parents, carers, wider family members and child health professionals.

Our seven innovative parent training suites now operate within seven NHS Trusts. Set up like a child's bedroom, the suites are calm, dedicated spaces away from busy wards, so parents can focus on learning the skills they need in a home from home environment.

In some areas, sessions are delivered or coordinated by our six specialist WellChild Parent Trainer Nurses who work across England, Scotland and Wales.

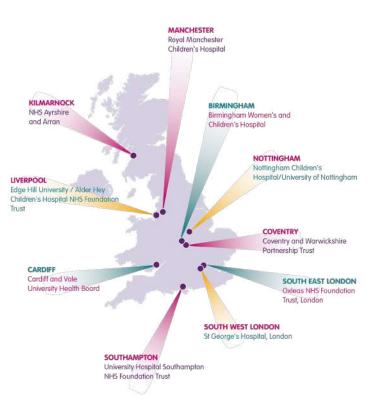
Inside our training suites

Set up like a child's bedroom, these are supportive and safe environments where parents and carers can learn the invaluable specialised skills required to care for their child at home, using state-of-the-art simulation equipment.

Examples of skills taught include basic life support, gastrostomy training, tracheostomy tube training, oxygen saturation monitoring and seizure management. "My role is to train parents and carers in clinical skills and techniques. The aim is to help them learn to take care of their seriously ill child so they can go home, often after spending months in hospital.

I'm proud to call myself a WellChild Nurse and to help families navigate the challenges faced by having a child with a severe illness."

Charlie Perth- WellChild Nurse



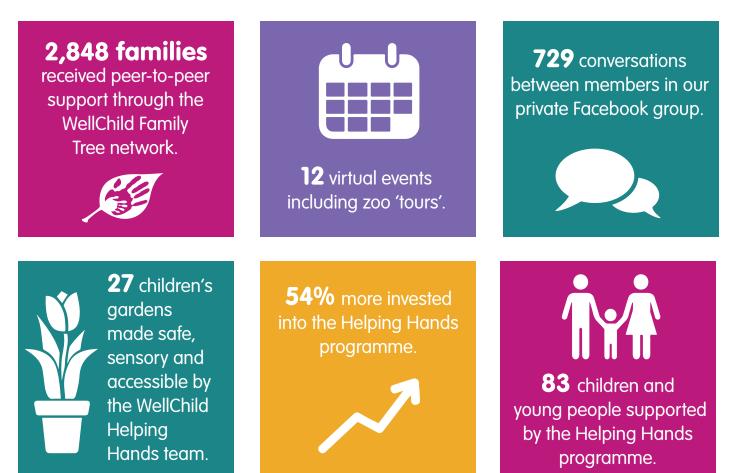
Wanda and her family are supported by WellChild Nurse, Billy. Billy was vital in the transition home from hospital and continues to support the family in the community. Since being home, Wanda is thriving, she has taken her first steps, has developed her communication skills and is full of smiles.

For children like Wanda

Priority three - Enabled to thrive

Once home, children, young people and their families must be properly supported and enabled to have the very best chance to thrive.

In 2021 - 2022



Our priorities in 2022-2023



Launch an 'In Your Area' online tool to help families find and access local services quicker.

Develop and expand our family events and engagement programme, including 'Giddy Up for Good'.

Deliver more Helping Hands projects and carry out 'Follow Up' visits to past projects to evaluate their longer-term impact

The power of togetherness

In hospital, families have the reassurance of around the clock support for their seriously ill child. But when they leave, they face many practical and emotional challenges of being at home with a child living with complex health needs.

We're on a mission to change this

We lay the foundations for a safe, stimulating and happy home life for children, young people and their families. Why was this more important in 2021-2022? Families continued to network online but also welcomed back much needed in-person support after COVID-19.

Mutual support

The WellChild Family Tree is a network of parents and carers where individuals find mutual support, information and advice from one another on emotional and practical issues. The network grew by five per cent during the year, to 2,848 members.

We hosted 12 virtual events including two virtual 'zoo tours', seven parent-led coffee mornings and a transition Q&A webinar. We also saw a return to face-to-face family activities with the inaugural Giddy Up for Good riding event in partnership with The Jockey Club and Cotswold Riding for the Disabled.

During the year, 960 parents and carers were in the charity's private Facebook Group. Here members talked about a range of topics, from condition management and COVID-19 to emotional resilience and celebrating positive moments.

As planned, we continued to enhance the joining process for our WellChild Family Tree and Facebook group to make it easier for families to access relevant peer-to-peer support quicker.

What do WellChild Families ask one another?

"Does anyone have any tips on easier ways to clean syringes?"

Condition management

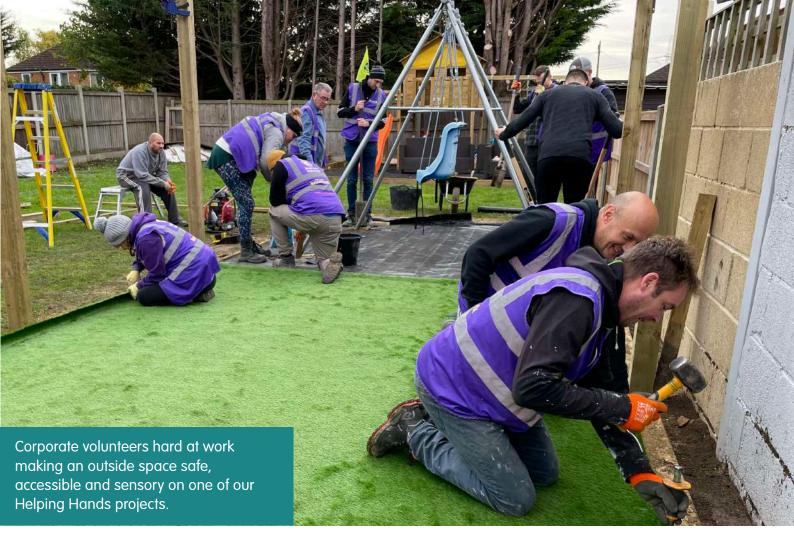
Carer management "Can the carers still come and care for my child if I've tested positive for COVID-19?"

> **Emotional support** "We would love be able to talk with someone to help us understand the pain our daughter is in."

Positive news

"Finally we now have some amazing care support and my child's condition has improved!"

WellChild Ambassador Sir AP McCoy joined us at the inaugural 'Giddy Up for Good' riding event at Cheltenham Racecourse.



WellChild Helping Hands

Our team works with hardworking and enthusiastic corporate volunteers to create safe, accessible and sensory garden spaces for children and young people with complex health needs.

The pandemic and associated restrictions were changeable during the year. But our programme continued, balancing the needs of families with the safety of our staff and corporate partner volunteers.

We are proud to report that, with the help and support of eight different corporate partners, the team delivered a total of 27 garden transformation projects throughout the year, for an estimated 83 children and young people.

What our corporate partners do

Our partners allow their employees to take paid time off to become WellChild Helping Hands volunteers. As well as helping us build some incredible spaces for children and young people, it builds teamwork too.



A new sensory outside space for Harrison, in County Durham.

Since being at home Wyatt has been able to go to school and is currently learning to swim. WellChild Nurse, Rachel was vital in supporting the family to transition home from hospital and continues to support them in the community.

TRA

For children like Wyatt

Priority four - A voice & a priority

Ensuring that the needs of families are recognised publicly and at the highest levels.

In 2021 - 2022



Our priorities in 2022-2023

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To take forward the Care Crisis campaign and use the voice of families to inform decision-makers and improve awareness of the challenges faced by families.

Promote and encourage more opportunities for families to contribute to national research and projects aimed at improving outcomes for families caring for children with serious and complex health needs.

Build on the WellChild Awards programme and explore ways to provide longer term support and development to WellChild Award winners.

Influencing change

For a growing population of children and young people with complex needs and their families, the services they need are currently under funded, under pressure and, in some areas, not available.

We're on a mission to change this

We aim to raise awareness about what it is really like to care for a child with serious health needs, influence decision makers and make sure there is funding and investment in place so that services are available.

Why was this more important in 2021-2022?

Families caring for children with complex care needs have a constant battle for the recognition and support that they need. Many families this year continued to struggle without carers, or appreciation of their circumstances.

Raising awareness to change lives

During the year, our families continued to suffer disproportionately from the impact of the COVID-19 pandemic. We continued our drive to raise awareness of the issues facing seriously ill children, young people and their families, who find themselves isolated and forgotten.

WellChild is a founding member of the Disabled Children's Partnership (DCP), a consortium of more than 68 disabled children's charities. Together we campaign for improved services and support for disabled children and their families.

This year the DCP played a key role in researching and communicating the impact of COVID-19 on disabled children and their families. The DCP actively campaigned for improvements to disabled children's services and funding, and challenged decision making and public policy at the highest levels.

Care Crisis campaign

Our campaign revealed the huge impact of care staff shortages on families. WellChild's research found 88 per cent of families are being expected to cover staff shortages and deliver round-the-clock care routines alone.

We called for a 'New Deal' for families caring for a seriously ill child at home. We highlighted the immense pressure that many families are under, and this was reported on both Sky News and across regional media. We shared this with a number of regional continuing care networks and working groups.

Making the headlines

BBC Newsnight

One of our Helping Hands projects, in Manchester, featured in a BBC Newsnight report on the issues around the lack of adequate housing available for children and young people with complex health needs and their families.

The Evening Standard

We celebrated the work of our most recent nurse posts in Gloucestershire, Manchester and for the Parent Trainer and first Better at Home Suite in London at St George's hospital, which was featured in The Evening Standard.

Proactive partnerships

The year also saw WellChild families directly contribute to a range of national research projects aimed at improving understanding and professional practice.

Development of a Long-Term Ventilation (LTV) ethical framework and resources for parents in partnership with the PAN Thames LTV Collaborative.

Swallowing and Feeding outcomes for children on LTV in partnership with a researcher from University College London and Evelina London Children's Hospital

Medicines Management App in partnership with the Royal College of Paediatrics and Child Health (RCPCH) and Neo-natal Paediatric and Pharmacists Group (NPPG).



Widespread coverage

WellChild enjoyed a second successful year as a partner with The Jockey Club for The Festival at Cheltenham Racecourse. Here we announced that popular chaser, Smad Place, had become WellChild's first equine ambassador, representing The Festival and The Jockey Club.

Smad Place 'helped' Grand National-winning jockey Rachael Blackmore, Cheltenham Festival ambassador Barry Geraghty and ITV Racing presenter Ed Chamberlin to open the WellChild Walkway. The partnership generated widespread news coverage for WellChild's work.

WellChild Equine Ambassador Smad Place opening the WellChild Walkway at The Festival 2022 at Cheltenham Racecourse





WellChild Awards 2021 And the winner is...

The WellChild Awards, in association with GSK, returned in the summer of 2021 with a celebration at Kew Gardens in London.

Many of the vulnerable children, young people and families supported by WellChild struggled immensely during COVID-19. The Awards shone a light on the challenges many have faced, whilst bringing some much-needed hope and positivity to their lives after such a difficult year.

The event was attended by WellChild Patron, the Duke of Sussex along with a host of celebrity guests including Ed Sheeran, Ronnie Wood and Anne-Marie. The real stars of the show were the remarkable children and young people and hard-working professionals from across the UK who were named winners.

"I could not be prouder to be here, to meet this year's WellChild Award winners, to thank the nurses and doctors for all they do, and to celebrate these amazing families."

Duke of Sussex



How we funded our work

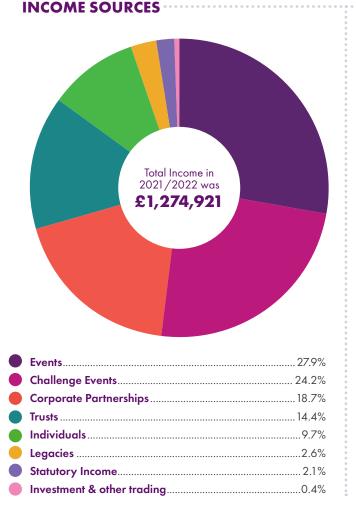
The COVID-19 pandemic continued to affect our plans across all areas throughout the year. We adapted our services and working practices to meet the needs of children, young people and families. At the same time we built resilience to protect the charity ahead of an expected difficult fundraising period.

WellChild's income for the 12 months covered by this report was a third lower than in the previous year. This was due mostly to a reduction in donations from trusts and legacies which is a reflection of the challenging fundraising landscape. Thanks to the incredible response of supporters and partners, the impact was eased in part by an increase in challenge fundraising.

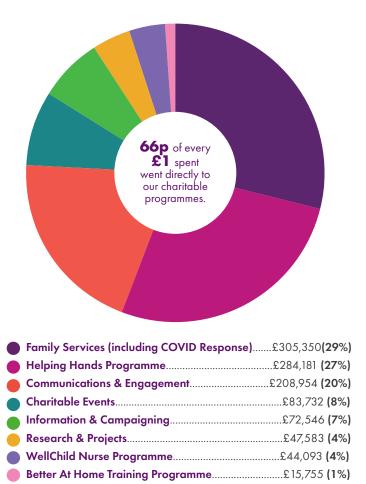
We are so fortunate to have many incredible fundraisers and supporters. Like many charities who rely on voluntary income, WellChild will need to count on their dedication and drive more than ever in the year ahead, to continue to invest in the services which are vital to so many families. In addition, the flexibility of some existing WellChild funders in allowing the charity to re-direct funds to key areas towards securing the organisation's future, was especially important.

The contribution made by so many to help WellChild at such a crucial time has been inspirational – and has helped as we shifted our charitable expenditure priorities as this impact report demonstrates.

However, fundraising remains a huge challenge and will do so for many months or years to come – and WellChild will need support more than ever to help us continue to invest in giving this growing population the best chance to thrive at home.



CHARITABLE EXPENDITURE





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THANK YOU!

WellChild can only support children, young people and their families, thanks to a wide range of amazing people who put their hearts and souls into raising funds and awareness. Thank you, your support makes our work possible.

From running marathons to baking cakes, our supporters raised vital funds for our work. We are so grateful for their energy, dedication and kindness. WellChild believes in partnership working and we create bespoke partnerships with companies, working together to meet clear objectives with mutual benefits. During the year we were delighted to work alongside 137 volunteers. These dedicated individuals gave many hours of their time and contributed significantly – from helping in our head office in Cheltenham to assisting at fundraising events throughout the UK. We feel very privileged to have such a fabulous team of celebrity ambassadors and supporters who are committed to raising awareness of what we do.



WellChild 3





CORPORATE PARTNERS·····

Advent of Change • Allianz • Armstrong Fine Art • Ascot Racecourse • Avalon Fashions Ltd • Bazaar Events Boddens. Legal and Corporate • British Fine Foods • Build-A-Bear • Carrs Billington • Cayman Islands Government Christie's • Continuity Marketing • Creed Foodservice • Crowe U.K. LLP • CubicWorks • Davidson Kempner Capital Management DontSendMeaCard.com • ecclesiastical • Ellenborough Park • Enterprise Rent-A-Car • Fletcherwilson • Fortnum & Mason GSK • HELLO! • Hilti • Horse Racing Ireland • Idiliq Group • Irwin Mitchell • Katherine Rhodes • KGJ Insurance • Kingsley Napley LLP • Lycetts Insurance Brokers • M & D H Insurance • Martin & Co. • Maven Securities • MRE Group Limited Paragon Group • Pickfords • Propp • Racing Post • Rhodar • Salesforce • Savills • ServiceMax • Seven Barrows Ltd Siemens Mobility • Sky Betting & Gaming • Speedy Services • St Nectan's Glen State • State Street Global Markets Stitchfinity • Systems Integration (Trading) Ltd. • Talbot Underwriting Ltd • Thames Water • The Chocolate Libertine The Entertainer • The Jockey Club Cheltenham • The Property Race Day • Warner's • West Way Nissan

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Get involved

From challenge event places and garden transformation projects, to sponsorship opportunities and celebrity golf days, WellChild has a wealth of corporate social responsibility opportunities for you and your organisation that will help you to...

- Increase staff engagement
- Boost PR and brand profile
- Entertain clients and prospects
- Grow your social impact

Contact our corporate team today. Email Abby at abbyguilding@wellchild.org.uk













Patron: The Duke of Sussex



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