



READY TO RESPOND

How we have responded to an historic period and
how we must ensure our future in 2021 and beyond.

OUR IMPACT 2019-2020



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A MESSAGE FROM OUR CHIEF EXECUTIVE

In 2019-2020 WellChild was embarking on the second year of an ambitious five-year strategy expanding all our core service areas. Little did we know that the COVID-19 pandemic was around the corner. Its impact on WellChild and the families we support forced us to rapidly rethink our plans both for the work we do and the way we raise funds to pay for it.

When the crisis hit we had two choices - scale down our operations and wait for it to pass, or fight the crisis head on for the families who needed our help more than ever. We did the latter.

As we enter 2021, I am immensely proud of the way our team responded and found fresh, inventive ways to make a positive difference for seriously ill children and their families across the UK.

WellChild's programmes have adapted and expanded to take on the challenges presented by COVID-19. The world and the way we work changed, but our mission to give children and families the best chance to thrive at home was more important than ever.

Families caring for a child with complex medical needs have often felt forgotten during this crisis, but WellChild has responded to the largest-ever demand on our services despite the resource and organisational challenges we faced – sourcing and distributing almost 290,000 items of essential Personal Protective Equipment (PPE) to families nationwide, working with key partners at the highest level to lead on guidance and information, and publicly highlighting shortages in vital equipment and support at a national level.

Meanwhile, the investment we have made in our core programmes over the past few years allowed them to go

from strength to strength just when they were most needed. Our WellChild Nurses have carried out vital work for children throughout the crisis, adapting to meet the unique demands of the current situation. Our Helping Hands home and garden projects had to come to a temporary halt, but we found a way to get them back up and running again in a more limited capacity.

We have made every penny count, but inevitably, the way we raise funds for our work has also been dramatically impacted. The cancellation of many events and partnerships during 2020 meant that WellChild faced a 60 per cent shortfall on its fundraising target for the year, forcing us to find new and innovative sources of funding to meet the sudden surge in demand. Thank you to absolutely everyone who contributed, your support has never been more important.

2020 has certainly been an historic year. This report celebrates the great successes from the previous financial year beginning back in 2019, and also the crucial events of the last calendar year.

Thank you again to all of you who have helped us to get to this point. This crisis is far from over and the future is uncertain, but all of us at WellChild are more determined than ever to give families with complex needs children the support they need to thrive at home. We have learned a great deal and must now be ready for the challenges which lie ahead.

Colin Dyer
WELLCHILD CHIEF EXECUTIVE

A MESSAGE FROM OUR PATRON, THE DUKE OF SUSSEX



The world is a very different place today because of the COVID-19 pandemic. We've been forced to collectively reckon with a global health crisis of which there is no modern comparison. It's taken a steadfast, coordinated effort across communities and countries to get ourselves to a point where we can fight this virus, where we can beat this virus. Over the past year, we've seen heroes - both known and unknown - stepping up at every turn. We've seen compassion and care for friends and strangers alike.

I am incredibly proud to say that WellChild has moved with urgency and purpose to tackle the new challenges that children with complex needs and their families have faced because of this crisis. Life for everyone has been tough. For these families, it has been tougher than most of us can imagine.

I've spoken directly to WellChild families during the crisis, and what I've heard repeatedly is that the amazing team at WellChild was able to adapt quickly to meet the moment. Across the United Kingdom, WellChild's COVID Response Team not only delivered much-needed guidance to the communities it serves, but also vital resources like PPE. This energy and dedication to improving the lives of children, young people and their families is precisely why WellChild is so close to my heart.

As we continue to battle this health crisis, the existing needs of vulnerable children should not be forgotten. WellChild is a lifeline for so many people, and has had to redirect many of its funding resources during the pandemic. We must make sure that young people with serious health conditions continue to receive the support they need as we recover, rebuild, and work to return to normal life.

My wife and I have such fond memories of being able to meet the winners of the 2019 WellChild Awards and congratulate them on their achievements. Our hope is that, in 2021, WellChild will once again be able to honour these inspiring young people, their families, and those who care for and support them.

I'd like to offer a heartfelt thank you to the entire WellChild community - to the nurses, carers, staff, supporters, and volunteers - who continue to work tirelessly to care for seriously ill children. Your commitment and dedication will never go unnoticed. And I want to urge everyone to do what they can to support this vital organisation in the year ahead.



RESPONDING TO A GLOBAL CRISIS

When the COVID-19 crisis began in 2020, WellChild and the families we support faced unprecedented challenges. We had to react quickly to meet a sudden and urgent need - from setting up a distribution centre for Personal Protective Equipment (PPE), to expanding our digital services with online information and peer-to-peer support.

FAMILIES LEFT ISOLATED WITHOUT CARE

Many families were left isolated because of the pandemic, without proper equipment and unable to allow vital carers into their homes due to fear of infection. They became sole carers for their complex needs children 24 hours a day, seven days a week.

Access to PPE for carers and food deliveries whilst shielding became a major problem.

Team members from across the charity rolled up their sleeves to help and in just ten days we set up our COVID Response Team to make sure we were doing everything we could for the vulnerable children and families we support.

PPE LIFELINE FOR FAMILIES

WellChild quickly became a PPE lifeline for families, turning our office into a distribution centre with staff pitching in to get the much needed items packed and shipped out to where they were needed.

Up to the end of December 2020 WellChild sourced and distributed 289,000 items of PPE to more than 1,000 families across the UK including masks, gloves, hand gel, scrubs, visors and more. We also provided families with advice and signposting on issues such as local food and medicine deliveries.

PPE from WellChild meant families could safely open their doors to carers and support once again.

READY TO RESPOND

Thanks to the generosity of many companies and individuals we were able to meet a sudden and urgent need for vital equipment. As we enter 2021, WellChild must be ready to respond again. Your support can ensure we have the resources to meet whatever challenges lie ahead.



MORE THAN
1,000
FAMILIES ABLE
TO LET CARERS
BACK INTO THEIR
HOMES.





WellChild set up the COVID Response Service in just **10 days**.

"We have just taken delivery of the essential PPE supplies. We are overwhelmed by your generosity. **This has brought so much relief and comfort knowing we have vital supplies to keep Emily, ourselves and care givers safe and well!**"

-CLAIRE



"I just wanted to thank you and your suppliers so much for the PPE you provided for us in the summer. **I was extremely nervous about having carers back to care for my daughter during these uncertain times, but receiving the scrubs and protective equipment really helped to ease my concerns and keep us as safe as possible.**"

- DONNA



47,989
masks sent to families and carers.



"I just wanted to say a huge thank you for the PPE I received from WellChild. We are delighted with it and this will now enable us to have our **Nurse back to help us with Matilda's intravenous therapy as well as our PA** knowing we are doing everything we can to reduce the risk of transmission of COVID-19."

- SHARON



21,769
aprons sent to families and carers.



"This is to let you know that the items we recently requested have arrived and I would like to express our sincere thanks for this assistance. **They will go a long way in helping us keep safe during this difficult time.**"

- MOIRA



"Our PPE package arrived today, we can't thank WellChild enough for this. **It's going to help us get our care up and running again, support we need so badly and have found incredibly difficult being without.**"

- NICKY

204,200
gloves sent to families and carers.



DIGITAL SERVICE GROWTH

WellChild accelerated many of its digital services during the last 18 months as COVID-19 forced the charity to expand its online offering to families and pave the way for a new vision for online family support.

PEER-TO-PEER SUPPORT

WellChild's Family Tree, peer-to-peer online support network saw a huge rise in membership this year as more families across the country recognised the value in connecting with one another for mutual support, advice and friendship. The value of being part of this community was brought into sharp focus during COVID-19 as families supported one another through the crisis with information and encouragement.

The online community also became an important listening post for the charity and enabled WellChild to respond quickly to challenges as they unfolded.

INFORMATION AND GUIDANCE

One of the biggest challenges that many families have faced during COVID-19 has been a lack of clear information and guidance specific to their needs. WellChild has worked hard to develop a library of online information and resources to help families navigate their way through the crisis safely – from how to manage carers in the home, to preparing to go back to school.

WellChild hosted a 'Back to School' webinar, an online question and answer session with an expert panel from

Government, health, law and education including Vicky Ford MP, the Parliamentary Under Secretary of State for Children and Families.

The event was produced in association with the South and North Thames Paediatric Networks. A wide-ranging discussion of the issues took place in which the need for clear communication between families, schools and health professionals emerged as the key message.

MEDICINES FOR CHILDREN

Another area of digital expansion saw WellChild further develop its Medicines for Children Mobile App in partnership with the Royal College of Paediatrics and Child Health (RCPCH) and Neonatal and Paediatric Pharmacists Group (NPPG). Work included prototype testing with families to understand future development requirements. Meanwhile, the Medicines for Children information website for parents and carers attracted more than 2.7m users in the year.

DIGITAL SERVICE EXPANSION

During the year, WellChild's digital expansion has been recognised by grants from The National Lottery, People's Postcode Lottery and Fidelity Asset Management. With online support becoming ever more important, the charity plans to expand its digital offering for families further in the next 12 months.

Membership grew by **20%** with more than **440 new families** seeking to connect with one another online **for mutual support and advice** during an unprecedented year.

The WellChild Family Tree supported **2,592 families** in 2020.



"it's a chance to talk to others in the same position as us."

More than **1,200 discussions** took place in the online support group with families sharing information and experiences on topics such as **COVID-19, carers, condition management and emotional support.**

93%

of members surveyed say they felt **supported by the WellChild Family Tree** during 2020.



"We have felt supported in so many ways. It's a safe place to talk without judgement. It's been a place where we get our news about things that affect our family medically. It's just a constant we value."



WellChild family tv

During 2020 WellChild funded and produced **38 online videos** that have been **viewed more than 4,000 times** to help families navigate their way through the year including practical information and activities to help protect the emotional wellbeing of themselves and their children.

2.7m users visited the Medicines for Children website to find trusted information on their child's medicine during 2020.

Our online **COVID-19 information & guidance for families** was accessed **more than 57,500 times.**





SUPPORTING FAMILIES ON THE GROUND

Much of WellChild's core programmes have continued during the pandemic. Across the country, WellChild Nurses have adapted their services to support the children and families who rely on them during COVID-19. Their role in delivering WellChild's key vision that every child and young person living with serious health needs should have the best chance to thrive - properly supported at home with their families, has been more important than ever.

NURSE PROGRAMME EXPANSION

During 2019-2020, the WellChild Nurse programme has continued to grow. Two specialist posts were launched to support children and young people with complex needs; one in North Wales to support with discharge home from hospital and another in Cumbria specifically to support young people with the difficult process of transition from children's to adult services. We were also able to fund three new posts across Southampton and South Warwickshire to ensure more children and families have access to the vital support of a WellChild Nurse.

BETTER AT HOME TRAINING

A key area for investment during the year was the WellChild Better at Home training programme. We have committed funding to projects in partnership with children's hospitals in Birmingham, Liverpool, Manchester, Nottingham and Southampton. Those resources will provide home-from-home spaces where parents and carers can learn the often life-saving interventions needed by their child in a safe environment with state-of-the-art simulation equipment.

MAKING HOMES SAFER

We were able to complete 36 Helping Hands bedroom and garden transformation projects around the UK in 2019-2020 – making a direct impact on 65 children and their families. Within this, the Helping Hands team were able to successfully increase the number of bedroom projects. They also delivered a community-based project for a respite centre in Scarborough with the help of a volunteer collaboration between different corporate partners.

SUPPORTING WOLFRAM SYNDROME FAMILIES

26 children and young people were supported by the WellChild Wolfram Syndrome Family Co-ordinator in 2019-2020 to attend specialist clinics at Birmingham Children's Hospital. During COVID-19, the service had to quickly adapt, with many of the clinics moving online. A new information pack for families was developed as well as audio and print leaflets in English and Urdu to raise awareness amongst visual impairment teams and Urdu speaking communities, where the rare condition can often go unrecognised.

A successful Wolfram Syndrome Conference was attended by 79 delegates in 2019 with a virtual conference held in 2020. We also continued our involvement in the progress of the TREATWOLFRAM clinical trial – testing a new use for an existing medicine to hopefully slowdown or halt the progression of Wolfram Syndrome.



46 WellChild Nurses have been funded in the UK including **3 new posts for 2020.**



More than **2,711** children and young people have been **supported by WellChild Nurses** across the UK.



36 Helping Hands projects were carried out up to the end of March 2020, directly **helping 65 children and their families.**



5 new Better at Home training resources funded across the UK.

449 people have been trained through our **WellChild Better at Home** programme including 175 parents and family members, 153 carers and 108 health professionals.



"This has been the hardest and saddest of years for lots of NHS workers, but on the days I myself am feeling low and miss my friends and family, I remind myself of the daily challenges our children and young people with complex health needs and their families face. How hard has life been for them this year, **without the normality of school, carers and respite to support them?** And so I am completely humbled and it has been an absolute privilege to be able to offer them my support."

.....
- JANICE, WELLCHILD TRANSITION NURSE, MANCHESTER

HARI HEADING HOME WITH A GUARD OF HONOUR

The great work WellChild Nurses do in getting seriously ill children home from hospital was summed up this year in one little boy's emotional journey home. Hari who has a rare genetic disease spent 14 months in Alder Hey Children's Hospital cared for by WellChild Nurses Elaine O'Brien and Sue Mounsey.

When he left to go home to Caegwyn in Wales hospital staff gave him a guard of honour and he was escorted by police officers with dogs, cars and bikes to speed him on his way.

Mum Ellen was full of praise for the WellChild Nurses and the rest of the Alder Hey Children's Hospital staff, she said:

"We want to say a big thank you for everything they've done and for getting us to where we are today. We're very excited to get home but we'll miss everyone here."



MAKING THE VOICES OF FAMILIES HEARD

Often during the COVID-19 crisis families with complex needs children have felt forgotten, isolated and hidden more than ever before.

WellChild has repeatedly raised awareness of the specific challenges they were facing with Government in the national media to make sure they get the attention they demand and pushing for the families to get solutions to their problems.

WellChild also continued to work as part of the Disabled Children's Partnership, a coalition of more than 80 organisations campaigning for improved health and social care for disabled children, young people and their families.

APR 2020	FAMILY COVID-19 FEARS AND VULNERABLE LISTS WellChild Patron the Duke of Sussex conducted a video call with WellChild families to understand the challenges they were facing and in particular, the difficulties in getting on the 'vulnerable lists' for food deliveries whilst shielding. The story generated wide spread news coverage with families appearing across national TV and newspapers.	
MAY 2020	ACCESS TO PPE With many families unable to access the PPE required to let carers safely into their homes, WellChild raised awareness of the problem within national and online media and through its COVID-19 Response work.	
JUN 2020	LEFT IN LOCKDOWN The Disabled Children's Partnership released their 'Left in Lockdown' report which identified that 76% of families with a disabled child had seen support stop altogether during COVID-19. The report received widespread national coverage and called for practical plans for this group to be put in place.	
JUL 2020	VENTILATOR SUPPLY SHORTAGES WellChild Nurses and families reported a shortage in ventilator supplies for children reliant on ventilators to help them breathe. WellChild raised awareness of the story through national media leading to direct meetings with the teams responsible for sourcing ventilator supplies to help understand and rectify the problem.	
AUG 2020	BACK TO SCHOOL Many families were unsure how to prepare for returning back to school and what provisions were in place for complex needs children, particularly for those requiring Aerosol Generating Procedures (AGPs). WellChild hosted a webinar discussion attended by 150 people, including families and a panel with Children's Minister Vicky Ford MP and other SEND representatives from the Department of Education. WellChild also directly fed into the changes required to AGP school guidance so that more children could return to school when it was safe to do so.	
DEC 2020	FORGOTTEN FAMILIES The Disabled Children's Partnership released a report highlighting how 24% of children are still not in school. WellChild also worked with BBC News to reflect on the challenges that many families had accessing vital ventilator supplies and how families had felt forgotten and more isolated than ever during COVID-19.	



WELLCHILD AWARDS 2019

The 2019 WellChild Awards ceremony, in association with GSK, was a wonderful event for our winners which they will remember for many years to come. The event made a major impact in the media both at home and abroad, spreading WellChild's message far and wide.

Our Patron the Duke of Sussex, who attended the Awards with his wife the Duchess, spoke movingly about how the Awards affected him in a new way now that he had become a father himself.

Our WellChild Award winners met a host of WellChild celebrity supporters at the event which was presented by Radzi Chinyanganya and Gaby Roslin. Pixie Lott performed for the guests.

The event received significant coverage across television news and the national and regional press, spreading the word about WellChild's commitment to raising the awareness of the growing population of children with complex needs and their families across the UK. HELLO! Magazine were media partners at the event. We also reached millions of people through our social media posts from the awards.

"It has been over a decade since I first came to these Awards and every year they never fail to surprise and inspire me. Yet this year, it resonates in a different way, because now I'm a father."

- THE DUKE OF SUSSEX



Media reach more than **310m** across national, regional and online media.



10,000 people watched the ceremony on Facebook Live.



More than **72,500** social media likes, comments and shares.

OUR FUNDING AND OUR FUTURE

Like many charities reliant on voluntary income, this year has been an incredibly tough one for fundraising, with 60 per cent of WellChild's projected income lost due to the impact on traditional funding sources caused by the COVID-19 pandemic.

However, thanks to the incredible support of some long-standing partners and the response of so many people and organisations to our calls for help, the charity has fought back strongly.

Early in the crisis, WellChild launched a Resilience Fund which became the focus of many creative fundraising activities and an opportunity to communicate the need for increased support to meet ever-growing demand as widely as possible. That Fund exceeded its target very quickly and was a huge help in allowing the COVID Response Team to be started with such urgency.

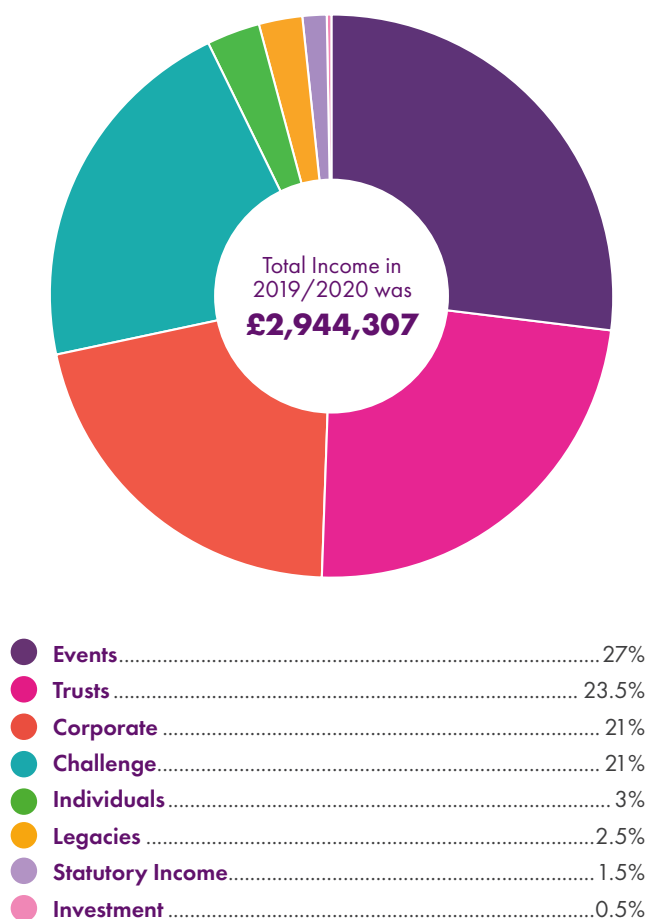
In addition, the flexibility of some existing WellChild funders in allowing the charity to re-direct funds to key areas to help with that Service, and also towards securing the organisation's future, was especially important.

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.

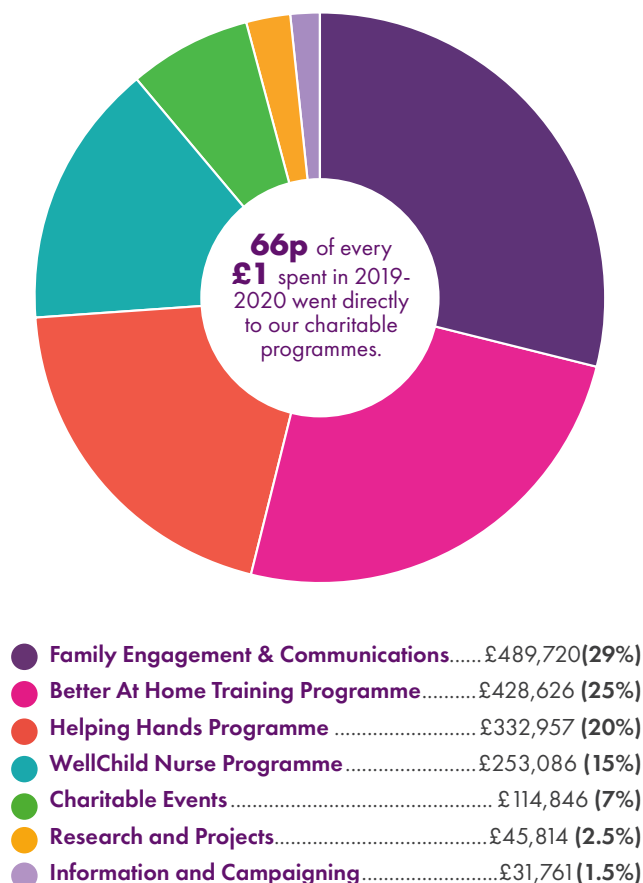
However, fundraising remains a huge challenge and will do so for many months or years to come – and WellChild will need support more than ever to help us continue to invest in the services which are now so vital to so many families.

In 2020, COVID-19 resulted in a loss of 60% of forecasted income through cancelled and postponed fundraising events and partnerships.

INCOME SOURCES



CHARITABLE EXPENDITURE





A huge thank you to all our supporters for getting us through one of the most uncertain and challenging years in the charity's history. You have made all of this possible – from our 150 virtual London Marathon runners, to our long standing corporate partners who have pulled out the stops to help us through this difficult time. Special mention must also go to the many organisations and individuals who donated PPE to our direct response service. Thank you!

Whilst we celebrate the great impact we've had in an uncertain year, our families and our organisation faces an equally challenging year ahead. We must be ready to respond again, but with the strength of our fantastic supporters behind us, we know we can meet whatever the next year brings.

To find out how you, or your organisation can get involved in our work, visit [wellchild.org.uk/get-involved](https://www.wellchild.org.uk/get-involved)

CORPORATE PARTNERS

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Masonic Charitable Foundation
Medicash Foundation
Michael Cornish Charitable Trust
Milton-Lloyd Charitable Trust
Moondance Foundation
Multithon Trust
National Lottery Community Fund
People's Postcode Trust
QBE Charity of Choice Awards

R and J Bleach Trust
RIND Foundation
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Scottish Wellbeing Fund
Sir John Fisher Foundation
Sir Jules Thorn Charitable Trust
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Summerfield Charitable Trust
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Thousandth Man - Richard Burns Charitable Trust
True Colours Trust
Waterloo Foundation
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Wooden Spoon (Rugby Tots)
WPH Charitable Trust

WELLCHILD COVID-19 RESPONSE TEAM DONATIONS

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Care Home Stroud
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Med supply
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PAI Skincare

Rachel Riley Children's Face Masks
Rhodar
Scrub Hub
Selection Corporate Clothing
Tickletots
Top Gear Consumables
True Colours Trust/Johnson & Johnson
Virustatic Shield
Waterless



Patron: The Duke of Sussex



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