

INVEST IN YOUNG LIVES

Building philanthropic support for disabled children
and young people

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CAF **Charities Aid
Foundation**

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About this report

NPC and CAF identified disability in young people as an area that is not getting the attention it deserves among philanthropists. There is a rich body of evidence showing what can make a difference to disabled children and their families, but interest in this cause is lower than might be expected. Here, we make the case that more philanthropic support should be channelled towards organisations supporting disabled children and young people.

This report seeks to bridge the gap between the evidence base and philanthropic support—highlighting why the cause is important and identifying opportunities for philanthropists to drive lasting change for children and their families. It is based on interviews and a roundtable with experts in the disabled children and young people’s sector. In addition, we present insights from previous research in this area.

About NPC and CAF

New Philanthropy Capital (NPC) is a charity consultancy and think tank that works to make the charity sector more effective. We work with funders and charities to ensure that they are maximising their impact, and conduct research to explore issues that are affecting the sector as a whole.

Charities Aid Foundation (CAF) is one of Europe’s largest charitable foundations. It helps people and companies support the causes they care about and provides financial and other services designed for charities. CAF works with more than 50,000 charities and manages donations on behalf of wealthy philanthropists, 2,500 businesses and more than 250,000 people.

Foreword from the Charities Aid Foundation (CAF)

Philanthropy plays a hugely important role in supporting disabled young people and children, but how well is it understood? There are so many committed volunteers and charities providing invaluable support, but do the general public really understand the issues and challenges they face? And how do the motivations and attitudes of people who donate to disability charities differ from people who give money to other causes?



At CAF, we understand the importance of helping donors to make informed decisions in their philanthropy. We've teamed up with New Philanthropy Capital (NPC) to shed more light on the relationship between charity and disability through joint research, highlighting an area where philanthropy could have an even bigger impact.

CAF works with a large number of major donors. Our donor survey ranked disability seventh as a cause donors choose to support. The results suggest that disability causes are largely supported by donors with personal experience of the challenges involved. Through this report, we would like to highlight the key issues for people who are less directly involved.

This research is very timely after the Brexit vote, which has created a degree of uncertainty over public funding, making it even more important for UK charities to be able to access private funding. The more evidence we have about the challenges faced by disability charities across the country, the more we can help donors and other funders to make informed decisions about how to help address these challenges.

There are many questions left unanswered but I hope this paper encourages further discussion. We welcome your feedback.

David Stead, Executive Director, Philanthropy, CAF

Foreword from New Philanthropy Capital (NPC)

One of NPC's core aims is to help guide philanthropic activity so that the good it can do is maximised. We do this in a variety of ways, but one key approach is to analyse what the needs are within a specific area and identify how resources can be used most effectively to meet these needs.



Issues facing disabled children and their families in the UK is one area that we have long highlighted. This focus goes back as far as our *Ordinary lives* report a decade ago.¹ Subsequent reports have focused on children with life-limiting conditions,² the transition from childhood to adulthood,³ autism⁴ and issues affecting autism charities.⁵

Philanthropic support has undoubtedly made a difference to children's lives. However, it is clear that disabled children and their families still face many difficult issues, amplified by recent cuts to services and rising numbers of disabled children.

This report therefore not only updates our earlier research to take account of new evidence and understanding of the issues; it also goes beyond just guiding philanthropists towards the right one-off grants to make. We believe that philanthropists who want their support to drive lasting social change for disabled children and their families need to look harder at how the system is working and how we can improve that. Opportunities for this kind of philanthropic support are expanding, with options for social investment and non-financial support complementing traditional giving.

We further argue that, for the most ambitious philanthropists, a collective 'cause fund' dedicated to tackling the root causes of the issues facing disabled children is one of the best ways of achieving lasting social impact.

We invite you to join us in exploring ways to transform the lives of disabled children.

Dan Corry, Chief Executive, NPC

WHY IS MORE SUPPORT NEEDED FOR DISABLED CHILDREN AND YOUNG PEOPLE?

The issue is growing

There are 800,000 disabled children in the UK.⁸ Improved diagnosis, better survival rates for pre-term infants and reduced stigma mean that this figure is set to rise. By 2029, there could be more than 1.25 million disabled children and young people in the UK.⁹

While the term 'disability' covers a huge variety of conditions—ranging from learning disabilities to physical conditions such as cerebral palsy—there are common needs that exist across the board. Many of these needs are immediate and directly related to the disability, including equipment, medical treatment, housing adaptations, educational support and understanding of the condition.

On top of this, many families with a disabled child will develop needs that extend beyond those directly related to the disability. For example, disabled children and their families are at greater risk of living in poverty.^{10,11} Parents and carers face emotional, practical and financial pressures—more than three in four report that they are stressed or depressed.¹²

'People are disabled by society, not by their impairments.'

The environment is changing

Recently, the disability sector has experienced the most significant policy reform it has seen in many years. The *Children and Families Act 2014* and the complementary *SEND [Special Educational Needs and Disability] code of practice 2015* focus on putting disabled people and their families at the centre of services across health, education and social care.^{13,14} Funding is increasingly being channelled through personal budgets and direct payments to users of services. While many welcome the underpinning philosophy of the changes, they have caused instability as children, families and service providers adapt to new systems.

In parallel with policy reform, there have been significant cuts in funding. Families are losing out with changes to the benefits and tax system. Under Universal Credit, for example, extra payments for a disabled child are to be cut by more than 50% for the majority of disabled children.¹⁵ Charities working with children have faced widespread cuts, including the removal of ring-fenced funding for short breaks. There is likely to be further strain on the limited resources in the sector in light of the rising prevalence of disability. For example, the number of children diagnosed with autism, attention deficit hyperactivity disorder (ADHD) or learning disabilities who are receiving the Disability Living Allowance increased from around 50,000 in 1995 to around 210,000 in 2012.¹⁶

What is disability?

The **Equality Act 2010** defines disability as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.⁶

Many charities and disabled people's organisations believe in the **social model of disability**. The social model of disability says that people are disabled by society, not by their impairments.⁷

New technology brings opportunities for impact

The sector has great potential to benefit from technological improvements. Specialised equipment is central to the lives of many children and young people with disabilities, creating unique opportunities for technological innovation and social design. Charities and social enterprises can benefit from digital solutions that help them to improve their service delivery, internal management systems and ability to collaborate for the benefit of users.¹⁷ An improved understanding of data would also mean that the sector could collect information more strategically about disabled children's needs, services and impact, in order to better target limited resources.

Plenty of charities work in this area

The umbrella body for the disabled children's sector, the Council for Disabled Children (CDC), has a membership of over 200 voluntary and community organisations.¹⁸ The CDC shares knowledge and best practices across the sector, coordinates collective action and represents the sector to policymakers.

The collection of organisations that makes up the disabled children's sector is diverse. A few very large charities (with an income of over £100m) work across different disabilities and have national reach, such as Scope, Mencap and Leonard Cheshire. Existing alongside these are large condition-specific charities such as the National Autistic Society or the Royal National Institute of Blind People (RNIB).

On top of this, there is a wide network of local, small-scale disability charities and social enterprises. As disability among children is so prevalent, many families have been personally affected by the disability either of their own child, or of someone they know. As a result, many parents have formed charities that work towards different goals, depending on the unique experiences of their family.

These various categories of charities are vastly different in terms of size and mission, and each will have unique funding and support needs.

There are many ways to make a difference

Many philanthropists feel strongly about making a difference to the lives of disadvantaged children and young people. Disabled children and young people and their families face acute challenges and should be a priority for philanthropists who are looking to make a difference in this area.

Plenty of philanthropists already support disabled children and young people through funding organisations that work directly in the disability sector. Others address this need indirectly through health, education or employment organisations that have disability streams in their work. Many experts and philanthropists are of the view that disability is not a separate cause, and that the needs of disabled people should be integral to efforts to improve health, education or employment. In reality, disabled children and young people have additional specialist needs that are not being addressed by current provision—so may need special focus by philanthropists.

Given the complexity of need, and of the sector as a whole, however, it can sometimes be difficult for philanthropists who are interested in this area to know where to begin. While NPC conducted its research, CAF surveyed a sample of their donors to understand how they view the cause (see Box 1).

Box 1: Insights from the CAF donor survey

CAF sent an online survey to a sample of 295 high net worth clients who have given to disability charities.

The purpose of the survey was:

- to assess their motivations and concerns about the sector; and
- to gauge their interest in supporting organisations via different forms of philanthropic support (including social investment and traditional grants).

CAF received 55 replies, and a few key findings emerged:

- Donors were asked to rank their preferred issue areas for a social investment fund, and disability came in seventh out of 12. This could be because disability also falls into other areas like education, health and children and young people, which all ranked higher.
- Donors are currently most likely to support charitable activities in the form of grants (86%). Only 4% were most likely to support disability through social investment.

Opportunities to address the problems faced by disabled children and young people are expanding. Different options for supporting charities and social enterprises working in this field include:

- **Grants:** Conditional or unconditional gift(s) of money with no expectation of a financial return.
- **Social investment:** The use of money to achieve both a social and a financial return—for example, a loan to support an organisation to grow their services.
- **Non-financial support:** For example, in-kind support, pro bono work or capacity building.

When selecting a method of support, philanthropists should consider the purpose of the support and the organisation's track record and capabilities.¹⁹ For example, social investment can be a powerful way of scaling services where there is a reliable income stream to repay the investment. Organisations at different stages of development will be more or less suited to repaying a social investment.

Grants may be more appropriate for supporting innovation or piloting approaches that do not have a guaranteed income stream. Grants can also support research to understand how the system is working for disabled children and their families, as well as campaigning to improve it.

Case study: Social investment and KIDS

What is the approach?

KIDS—a charity working with disabled children and young people from early years to transition—found itself needing to adapt to a changing funding landscape for the work it does. KIDS used social investment as a vehicle to fund the delivery and expansion of its charitable activities in a number of ways, from improved facilities at one of its centres to a new online booking system for short breaks.²⁰

What can this achieve?

KIDS' services are more effective and efficient as a result of the improvements funded by social investment. The new online booking system for short breaks increased the organisation's capacity by using the time of its care workers more efficiently. Families are now better able to connect to short breaks that meet their needs.

KIDS has used the social investment to improve its services and generate unrestricted revenue to repay loans within the terms and conditions agreed with social investors. For social investors, this approach to funding charities means they are able to recoup their funding—often with a return—and reinvest it in other causes.

WHERE SHOULD PHILANTHROPIC SUPPORT BE TARGETED?

Disabled children and their families face many issues. Philanthropists can make the most difference by targeting their support at several points in a child's journey. We explored what a typical journey for a disabled child and their family looks like and how philanthropic support can make a difference in their lives.

We undertook desk research and interviewed experts in the disability sector to understand the issues facing disabled children and young people, and the organisations that support them. We also held a roundtable with individuals from the disability sector, funders and social investors in order to understand the opportunities for philanthropists to make a difference. (See Acknowledgements for a full list of people who participated in the research.)

Four priority areas for support

While there are many different areas that could benefit from philanthropic support, our research pinpointed four areas where support could lead to particularly positive outcomes for disabled young people and their families:



Education was also recognised as important to disabled children and young people. However, we did not include education in our final analysis because there are high barriers for philanthropists looking to make a lasting impact in this area. Education policy for disabled children is in flux and philanthropists face the challenge of understanding how statutory provision interacts with third sector provision. For philanthropists looking to get involved in this area, we recommend starting with existing research about the school system and recent reforms.^{21,22}

How this support can make a difference

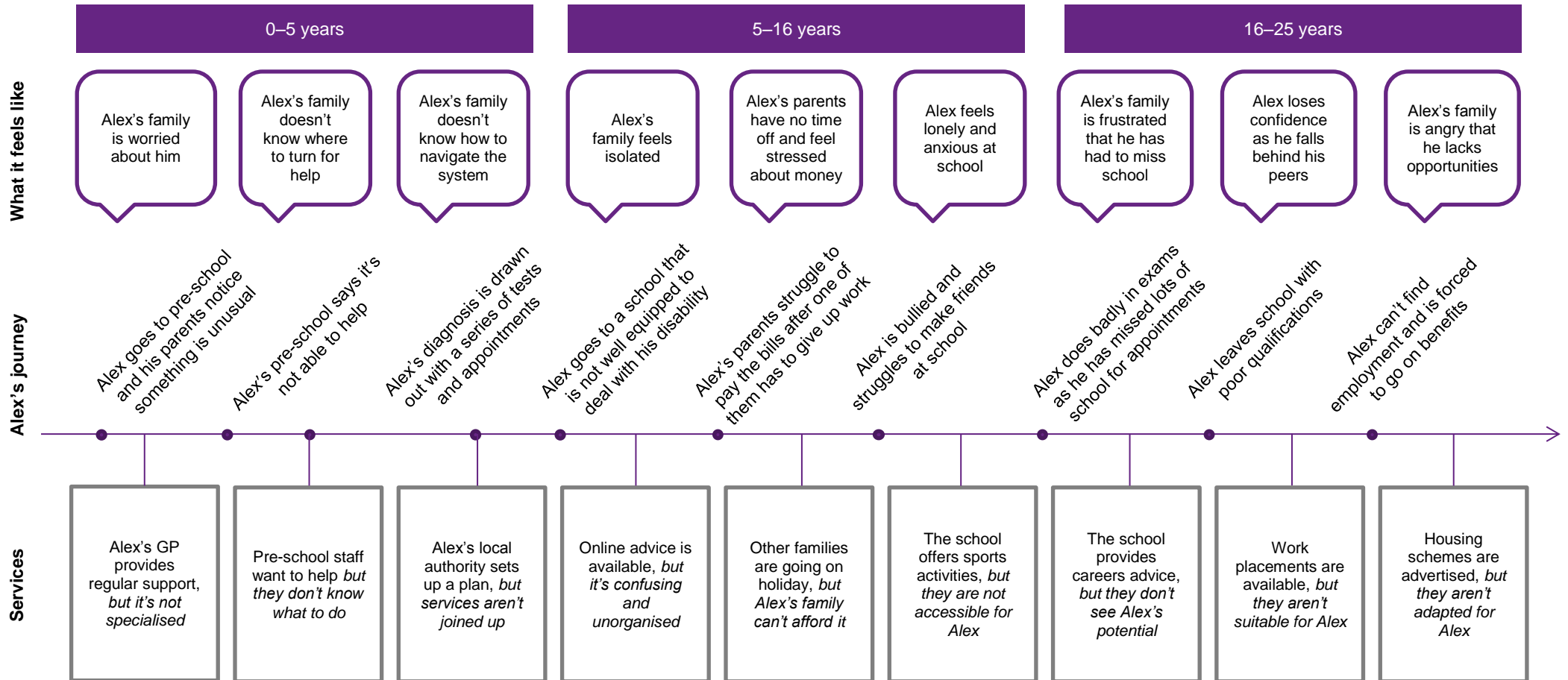
We created 'user journeys' to show a hypothetical pathway for disabled children and their families and where philanthropic support can make a difference. Every child's experience of disability is unique, and the user journey is not representative of all children with disabilities. However, the user journey allows us to map user interactions with services and consider opportunities for filling gaps along the way. It builds on what experts told us about the experiences of disabled children and families, as well as user research that has been conducted by others.^{23,24}

The user journey spans from the birth of the child up until the age of 25, which is the age by which children should have fully transitioned into adult services. We have produced two user journeys showing:

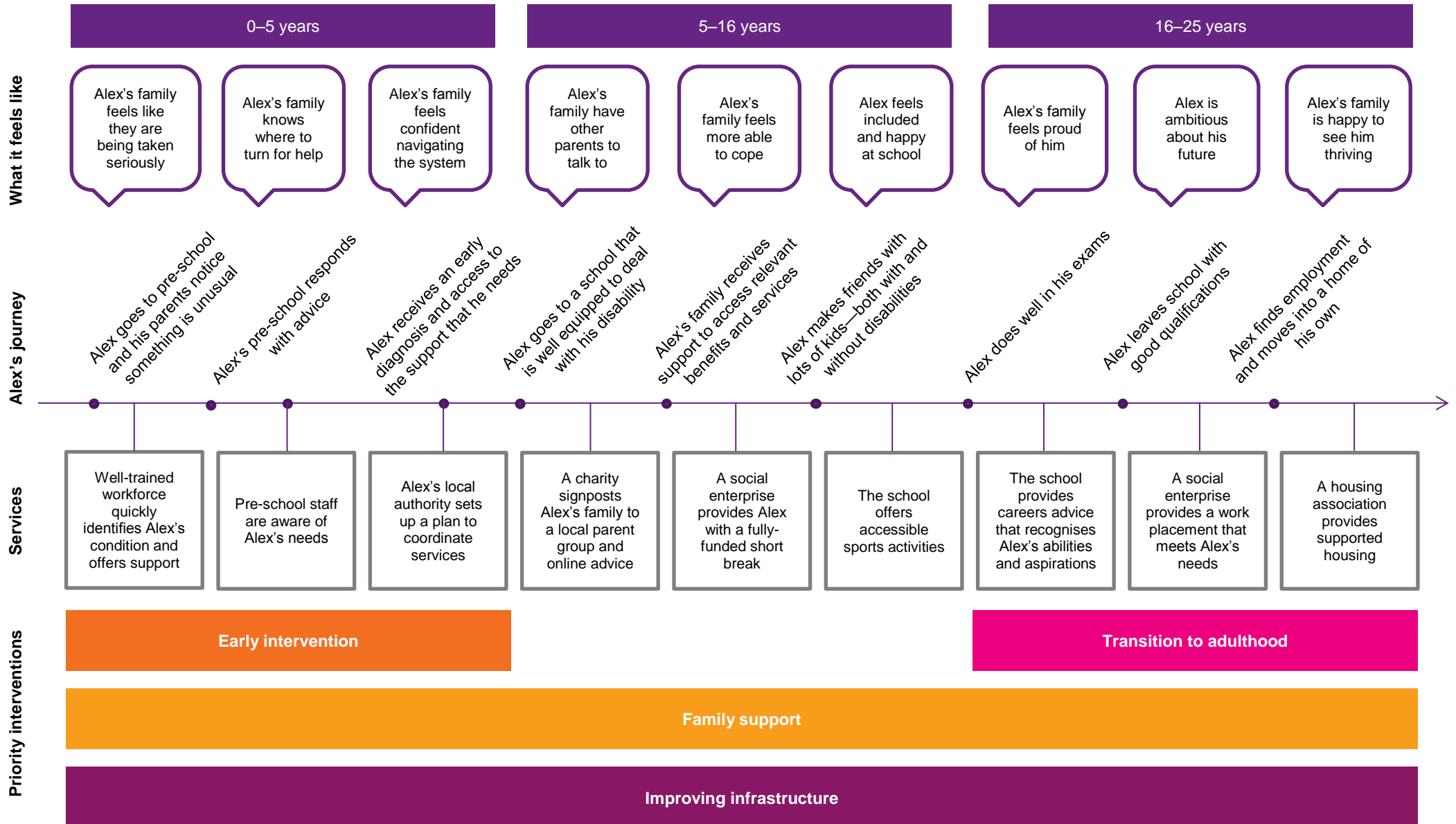
1. A hypothetical pathway for Alex and his family as he interacts with **existing** services and organisations.
2. A hypothetical pathway for Alex and his family after **additional funding and support** has changed the four priority areas mentioned above.

This user perspective helps to illustrate the social, emotional and financial benefits that could result from informed and strategic funding in these areas.

USER JOURNEY: ALEX'S JOURNEY THROUGH EXISTING SERVICES



USER JOURNEY: ALEX'S JOURNEY WITH PRIORITY SUPPORT



WHAT ARE THE PRIORITY AREAS FOR SUPPORT?

Early intervention

The benefits of rapid intervention in a child's early life are widely recognised. Skilled intervention—such as speech and language therapy or physiotherapy—can have lasting impacts on a disabled person's life, often helping to improve quality of life, prevent disabilities from becoming severe and even avoid death.²⁵

'Early identification and skilled intervention at the earliest opportunity for babies and children with movement disorders is crucial for maximising their potential for greater independence in later life. It makes good financial sense to invest in intensive specialist intervention at a time in a very young child's development when the brain is at its optimum state for learning due to its high level of plasticity.'

Amanda Richardson, Chief Executive of PACE, Interview with NPC

The Early Years Foundation Stage Framework (2014) from the Department for Education recognises the potential value to be gained from intervening at the earliest possible point, and provides guidance for early years providers along these lines.²⁶ Building on this, *SEND code of practice 2015* extended its remit to 0–25 year olds, rather than just 2–19 year olds.²⁷

What is the problem?

As it currently stands, early intervention rarely happens. Diagnosis is often a drawn out process, which can involve a stream of appointments with many different healthcare professionals. In the case of some children, the process is prolonged even further by an inaccurate initial diagnosis. Once a family has a diagnosis, they often struggle to access specialist therapies or appropriate support due to a shortage of available services.

One of the key challenges is a shortage of qualified staff trained to identify and manage disabilities at an early age. This ranges from staff involved in the initial diagnosis, to nursery staff who work closely with young children throughout their early childhood. Despite the recent policy emphasis on the importance of early intervention, workforce development has not kept pace. There is an extensive evidence base of which interventions work and for whom, but this knowledge is not reaching frontline staff.

How can we change this?

- **Training nursery and healthcare staff:** Charities and social enterprises are working on training for public sector staff to identify disabilities at an early age and signpost families to appropriate services. Investment in this area bridges the gap between the policy focus on early years and the current reality for families.
- **Pooling data across sectors:** Demonstrating the impact of early intervention requires pooling data across multiple sectors, including health and education. For example, early access to specialist therapies can mean children spend less time in hospital when they are older and achieve better grades at school. Demonstrating these

long-term benefits—and the future cost savings to the state—can encourage funders and commissioners to invest in early intervention.

What would this achieve for Alex and his family?

Early intervention would achieve a prompt diagnosis of Alex's disability, an efficient assessment of his needs and the provision of appropriate therapy and support for him and his family. Ultimately, this changes the course of Alex's future as he is better equipped to deal with his disability from a young age. An added benefit is that his family feel more in control and able to help Alex in his development. He is better placed to get as much as possible out of his education, which in turn will open up employment opportunities to him and stand him in good stead for his transition into adulthood.

Case study: PACE Centre

What problems does it address?

Diagnosing cerebral palsy takes time. In severe cases, the child may be diagnosed soon after birth, but for milder symptoms a diagnosis may not be reached until the brain is fully developed at three to five years of age.²⁸ These early years can be a difficult time for parents, who are often the first to notice delays in their child's development. It is important that charities can support parents to access the most relevant advice and support to navigate this difficult time and get a prompt diagnosis.

The PACE Centre's Infant and Parent Service (PIPS)²⁹ is an early years intervention service that provides a range of services for infants aged 0–4 with developmental needs and disabilities. As well as supporting children to achieve their full potential, PIPs equips parents with the skills and knowledge they need to support a child in their early years. PACE has also developed training modules on cerebral palsy for practitioners such as teachers, special educational needs (SEN) leads, early years professionals, therapists, portage and respite workers and also for parents and carers. This training complements existing mainstream provision and helps to support non-specialist professionals identify the specialist needs of a child with cerebral palsy.

What can this achieve?

Further investment in early intervention services such as PIPS will help to improve the skills and knowledge of the mainstream workforce that supports children and their families at this critical time. Advice and support services will become more consistent and connected, simple to access and tailored to the needs of children and their families. These services result in more timely diagnosis so children and their families can get the support they need when they need it.

Family support

Family support helps families to understand how to meet the unique needs of their child and to deal with the practical, emotional, and financial pressures of caring for a disabled child.

Tailored support—such as help with caring responsibilities—enables families to more easily leave the house and engage in other activities, including employment. Sending children on trips with other disabled children offers the child an enjoyable holiday away from home and a chance to make friends, while giving the family valuable time to focus on each other. Families also benefit greatly from speaking to or hearing about others in similar situations, learning from their experiences and understanding their rights.

What is the problem?

The period following diagnosis can be a very difficult time for families with disabled children. They sometimes feel isolated and overwhelmed, struggling to come to terms with their new reality. It is difficult to know how to adjust to the changes in their lives as seamlessly as possible, and many families struggle over the course of their child's life to know who to speak to as issues arise. A respondent to a survey administered by Scope commented:

'Having to find out about things that you don't even know exist is hard. No one is there to tell you what to look for. Sometimes if you don't find out by mistake services pass you by eg, sports, short breaks, funding, aids, health and education...'

Survey respondent quoted in Pyer and Bush (2009) *Disabled families in flux*³⁰

Caring for a child or young person with a disability is a full-time commitment for many families. Up to 99% of disabled children live at home.³¹ Over time, this puts great logistical, emotional and financial pressures on families to the extent that:

- 84% of mothers of disabled children do not work, compared with 39% of mothers of non-disabled children.³²
- 76% of parent carers are stressed or depressed and 72% have trouble sleeping.³³
- 33% of families with disabled children are going without heating, and 31% are going without food.³⁴

The majority of local authorities have cut funding for family support and short breaks in recent years. Only 9% of parent carers in a 2015 survey agreed with the statement that 'Families with disabled children can access the short breaks they need'.³⁵ Families are increasingly receiving personal budgets to buy their own services but they are often unable to find out information about what is available. In some parts of the country, parent carer groups are providing services such as childcare, but these are on a small scale and cannot reach all the families that would benefit.

How can we change this?

- **Improved signposting and marketing of services available:** For example, KIDS Direct Short Breaks³⁶ is a web-based service that allows families to create a personal profile and book short breaks tailored to their needs. Families can pay for short breaks themselves or use their direct payments or individualised budgets to fund the break.
- **Stronger networks of local support groups to meet families' needs:** There are multiple parent-led charities and support groups already providing small-scale ad hoc services to families with disabled children. These organisations add value at the local level and additional funding and support to scale up would enable them to

expand their reach and impact. As well as providing direct services, they can support families with advice on their legal rights, benefits and how to navigate the healthcare system.

What would this achieve for Alex and his family?

Improved family support would transform the experience of Alex and his family as his childhood progresses. Connections to other families would mean that, instead of feeling isolated, they have a solid support network providing emotional support and peer recommendations about services and interventions. Short breaks and help with day-to-day caring responsibilities would provide Alex's family with an invaluable opportunity to unwind and focus on each other when they are feeling overwhelmed. Ongoing family support would offer them comfort and help them to cope with the challenges they face.

Case study: Parent Carer Forums

What problems does it address?

Many parents of disabled children are isolated and struggle to make their voices heard. Parent Carer Forums bring together more than 77,000 parents and carers across England to connect with each other, share information and participate in local service planning and decision making.³⁷ The National Network of Parent Carer Forums represents the views of local forums to improve outcomes at the national level, working with key stakeholders such as the Department of Health and Department for Education. Some local forums and parent support groups are delivering other important services for the local authority and local health partners, to generate additional income to subsidise and sustain their work.

What can this achieve?

Investing in training and support for local forums helps them to become more professional, effective and able to hold local providers to account for delivering quality local provision. The charity Contact a Family supports local forums with guidance, resources, capacity-building tools and materials. It provides and signposts local forums to training in areas such as advocacy, planning, effective leadership and the practicalities of running a forum. Its Parent Participation team connects local forums to share experiences, knowledge and information with each other.³⁸ Strengthening local forums like this helps families to support each other as well as making a difference to local service provision.

Transition to adulthood

Supporting disabled young people to transition into adulthood will help them to fulfil their potential and participate fully in society. This involves improving their access to further education and employment opportunities, as well as providing suitable housing options that meet their individual needs. A key part of this process is also supporting young people as they make the transition from children's services to adult services.

What is the problem?

Gaining independence and transitioning to adulthood is a momentous phase in a young person's life. Young people like Alex want to be seen first and foremost as individuals with their own views and aspirations, not to be defined by their health condition. They want to lead fulfilling lives in which they are supported to achieve their goals—from meaningful work opportunities to suitable housing.³⁹

However, not everybody has the same opportunities to achieve their goals. Disabled young people often face negative experiences in teaching practices, exams or learning support that lead to them leaving courses or never completing qualifications. As they move from school to college or university, their access to appropriate services, equipment or learning materials can be disrupted. At 18 years of age, 35% of disabled young people do not have a qualification higher than Level 2, compared to only 21% of non-disabled young people.⁴⁰

Disabled young people aged 16–17 and aged 18–24 are far more likely not to be in employment, education or training (42% and 15% respectively) than non-disabled people (19% and 8% respectively).⁴¹ Employers can be hesitant about employing people with disabilities as they feel there may be additional costs involved, or they feel ill equipped to give them what they need as employees. Their decisions may be shaped by negative perceptions of what disabled people are capable of achieving.

'There's a lack of opportunities for people to show what they can do instead of people always making assumptions about what they can't do.'

Young woman quoted in Hamer (2012) *Journey from education to work*⁴²

Disabled young people face further obstacles when it comes to finding a home. A lack of accessible and affordable housing often prevents them from moving out of the family home. This makes it harder for them to gain independence and increases the pressures faced by their families.

'[My] disabled children are approaching transition—this is the most worrying time that we have had in 15 years of disabled life!!! It is like a black hole heading towards us.'

Survey respondent quoted in Pyer and Bush (2009) *Disabled families in flux*⁴³

How can we change this?

- **Employment support:** Employment support programmes enable people with disabilities to make connections, network, do work placements and gain valuable work experience. This is in line with the government's ambition to halve the employment gap between disabled and non-disabled people by 2020.⁴⁴ A grant would provide charities with the resources to offer specialist employment support to young people with disabilities. Philanthropists with leadership positions in businesses can also think about how their own employment practices actively support the inclusion of disabled people.
- **Housing solutions:** Housing options that are tailored to the individual needs of disabled young people support them to live independently in an environment away from home. Given the scale of this issue, small grants may not

be able to achieve much. However, social investment in organisations like Golden Lane Housing—a charity established by Mencap to provide housing solutions for people with learning disabilities—can make a significant difference.⁴⁵

What would this achieve for Alex and his family?

Investment in specialist employment support would give Alex the skills, knowledge, connections and confidence that he needs to enter the workforce. This is in part facilitated by the supportive environment throughout his schooling years, and will in turn allow Alex to get on with what he wants to do. Investment in housing solutions would help Alex to find suitable housing and live independently.

Case study: KIDS Work Tasters

What problems does it address?

As mentioned above, some businesses can be apprehensive about hiring someone with a disability.⁴⁶ KIDS Work Tasters is a volunteering scheme for young disabled people aged 14–25 in Manchester, which provides them with a valuable experience in an organisation based in the leisure services. Placements last for one or two days a week for a minimum of four weeks and help disabled young people gain experience of what it is like to work in and for an organisation. Employers are supported throughout the process by KIDS and benefit from having an additional valuable member of staff in their team.⁴⁷

What can this achieve?

The disabled young people participating in the scheme get to develop existing skills, gain new skills and enjoy a valuable and positive work experience that builds their self-esteem and confidence. This improves the chances of securing employment in future, contributing towards greater independence in their adulthood. Investment in these services will also help to challenge perceptions about employing disabled people, as well as having the support structures in place for businesses to seek advice and guidance where necessary.

Improving infrastructure

Effective infrastructure helps organisations to deliver good services for disabled children and their families. Infrastructure covers many things including a skilled workforce, collaboration between organisations, sharing of best practices, strong digital infrastructure and a positive policy environment. Ideally we want infrastructure that supports joined-up services that are co-designed with users.

What is the problem?

Many of the problems facing disabled children and their families are the result of issues with the systems around them. Services are not joined up and service providers may not be aware of the other services that families are accessing. For example, health workers may not understand the complexities of the welfare system. This makes it hard for disabled children and their families to navigate the services and other help available to them. A report by the charity In Control found that:

‘Overly complex systems are the enemies of effective joined-up working and this is one of the main reasons that today’s system fails families. There is a pressing need to do things in ways that are simpler and less baffling for all concerned.’

Crosby and Tyson (2016) *Me, My Family, My Home, My Friends and My Life*⁴⁸

Many families feel as though they are consistently in the dark, unaware of the many services and interventions they are entitled to. When they do come across websites that outline existing services and relevant information, they are unsure how to determine which support will best meet their needs. This is compounded by the fact that the evidence for what works is inconsistent and often out of date.

How can we change this?

- **Co-designing services:** Disability policy rhetoric emphasises the greater inclusion of disabled people in decision making. Co-designing services with disabled children and their families can convert this rhetoric into reality. Charities like the Council for Disabled Children are working in partnership with children, young people, families and professionals to generate and test new approaches to service delivery.⁴⁹ Embedding this method across the sector can develop more creative person-centred approaches and allow more efficient, flexible and tailored services.⁵⁰
- **Campaigning for better policies:** Charities are supporting disabled young people and their families to campaign for better policies. For example, the National Autistic Society’s campaign toolkit provides guidance on how to build a successful campaign, work with the media and lobby local and national decision makers.⁵¹
- **Workforce development:** Training for frontline staff can transform the experiences of disabled children and their families. However, local authorities and their partners currently lack the skills base to provide the ‘whole life, whole family’ support that is needed.⁵² Charities and social enterprises can step in to support different professionals to identify and respond to children’s needs. For example, Ambitious About Autism offers bespoke training courses to help organisations work appropriately with children with autism in their own settings.⁵³
- **Investing in digital infrastructure:** Digital technologies provide an opportunity to join up services and to fit them around the lives of disabled children and their families. Online portals bring together information from a range of different sources and make it accessible for families. Investment in digital infrastructure can also facilitate improved practice around data collection and analysis. This allows organisations to gain greater insight into the impact of their services and contribute to the wider evidence base about what works.

- **Strengthening charities:** Supporting charities' general operating costs enables them to run more effectively, improve their services and increase their reach. Some of the charities we spoke to mentioned that they needed more support to invest time in collecting data and improving their systems outside individual projects.

What would this achieve for Alex and his family?

Developing infrastructure—including digital infrastructure and local networks—would provide Alex and his family with the resources they need to be well-informed, aware of the support that is available and confident in making decisions between the different services and interventions that exist. They would feel reassured by support that is readily available and accessible, and the stress and isolation that they felt without such infrastructure in place would be one less thing for them to worry about.

Case study: SENDirect

What problem does it address?

In 2013/2014 the SEND consortium⁵⁴ was concerned that the implementation of the Children and Families Act (2014) would have a negative impact on families and service providers, if not handled correctly. Research revealed real barriers for families when it came to accessing key information on products and services suitable for them, in having sufficient choice among those products and services and in transparency of levels of price and service among providers. These barriers prevented families from exercising their true purchasing power, estimated at over £200bn per annum.⁵⁵

What can investment achieve?

SENDirect is a unique website designed to tackle these barriers—part 'Amazon' (a products and service directory); part 'wiki' (built with and informed by families); and part 'TripAdvisor' (families can rate and review services). Investment from the Department for Education and the SEND consortium helped to develop, build and launch the site by January 2015. Designed to achieve scale, accessibility and analytics, SENDirect has helped more than 90,000 unique users to find products and services around special education needs and disability to date. More than 8,000 services have been listed and over 1,000 individuals have registered to use the site's deeper functionality.⁵⁶ Over the next 12 months, Contact a Family, which now owns and manages the service, hopes to expand this significantly by building new functionality to make SENDirect UK-wide (it currently only serves England).

HOW CAN THIS SUPPORT BE ACHIEVED?

Philanthropists looking to maximise their impact should look at ways to make their support more informed, more collaborative and more ambitious. We have identified three levels of support that philanthropists should consider.

Individual support

Philanthropic support goes further when it is underpinned by knowledge about the needs of disabled children, families and organisations that work with them. This report can help philanthropists understand how to make a difference through channelling more funding towards early intervention, family support, transition to adulthood and improving infrastructure. Many philanthropists will want to get additional advice to help them target their funding more effectively.



Case study: Anonymous donor

What is the approach?

A donor wanted to help disabled children and sought advice on which organisations to support and how. NPC supported the donor with an independent impact assessment of charities, guided by the donor's aims and the sector's needs. The assessment tested how far a donation would enable a charity to reach out to more families caring for a disabled child. As a result of this, the anonymous donor gave £290,000 to the charity Contact a Family.

What can this achieve?

The donation has helped Contact a Family to develop a more accessible, complete and seamless service to families with disabled children. The charity was able to develop its brand identity, improve its management systems and forge new delivery partnerships. This helped to generate further income to invest in its services for families with disabled children.

Amanda Batten, Chief Executive of Contact a Family, says *'This grant has been transformational—as a result of this grant we now have stronger management structures, better management information and the leadership to deliver the best we can for families with disabled children.'*

NPC often recommends that donors talk to expert funders in their area of interest to help them target their funding more effectively. For example, True Colours Trust is an expert funder of organisations supporting disabled children and young people.

Case study: True Colours Trust**What is the approach?**

The True Colours Trust⁵⁷ seeks to make a positive difference to the lives of disabled children with complex needs and their families, and to support children and young people with life-limiting and/or life-threatening illnesses. It works closely with organisations that share its ambitions to provide imaginative, practical and often ground-breaking services in addition to delivering programmes that bring about sustained change whether at the level of policy or practice.

What can this achieve?

By investing in a mix of activity, building on an existing evidence base—from funding research to delivery and campaigning to policy development—True Colours Trust is helping to change the way services are developed and delivered in the sector, both now and in future. Initiatives funded by the Trust will help to improve service delivery and the support offered to children and young people with complex needs and their families and siblings. With a focus on funding research, these services can be improved in future and evolve, drawing on a developing evidence base and the increased skills and capacity in the sector.

Giving circles

Philanthropists are stronger when they share expertise and join up their funding. Giving circles are collaborative giving models that not only allow philanthropists to network with their peers, but also help them to make better funding decisions.

Research shows that giving circles encourage members not only to give more, but to give more strategically and to more progressive causes.⁵⁹

**Case study: Dasra Giving Circles****What is the approach?**

Dasra Giving Circles⁵⁸ bring together groups of philanthropists to concentrate giving on the most high-potential social organisations. Dasra provides in-depth knowledge and due diligence to drive funding to priority areas. Each circle involves ten philanthropists, who each commit relatively small but equal amounts of funding over a set term. Their donations provide targeted funding that support organisations over the long term.

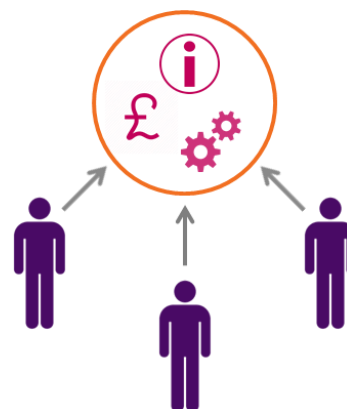
What can this achieve?

The Dasra Giving Circle's sustained support helps organisations to meet their goals and achieve greater impact. The robust research and evidence underpinning the model helps philanthropists to target their funding on areas where it can make the most difference.

Cause funds

Philanthropists looking to achieve impact at scale can consider more ambitious models of support. Dedicated funds can allow philanthropists to achieve lasting social change in a targeted sector. ‘Cause funds’ combine cutting-edge thinking and research with a long-term, patient approach.

Funds can be based around grants, social investment or a mix of the two. For example, CAF Venturesome’s Children and Young People’s Fund provides social investment to charities and social enterprises in this sector. This example shows how social investment can help develop assets or expand capacity.



Case study: CAF Venturesome’s Children and Young People’s Fund

What is the approach?

CAF Venturesome provides capital to build the capacity of high-impact charities and social enterprises. It gives organisations access to the finance they need—not just to survive but to thrive and become stronger. The Children and Young People’s fund is a dedicated vehicle through which philanthropists can support charities and social enterprises in this sector. It provides six-year returnable charitable gifts, from £50,000 upwards. This is used to support organisations several times, in the form of affordable, repayable finance and no management fees are charged.

What can this achieve?

Of the many organisations in this sector supported by CAF Venturesome, one is Tall Ships Youth Trust (TSYT). TSYT is dedicated to the personal development of young people aged 12–25, through the crewing of week-long ocean voyages. Its aim is to increase young people’s life chances and well-being by supporting them to develop life skills. Over 3,000 people sail with TSYT each year with 73% being disadvantaged or disabled. To become sustainable, TSYT decided to sell its largest brig and replace it with a more cost-efficient ship. They knew this could take a few years, which meant the organisation would require some financial support in the interim.

CAF Venturesome provided the charity with a £100,000 unsecured loan, which will be repaid upon the sale of the brig. This support was also valuable in leveraging a further £480,000 of funding from other lenders and trusts.

Other ‘cause funds’ may be set up to tackle the root causes of issues. Once a fund has determined a strategy for addressing a cause, it should choose the product—grant or social investment—best suited to the strategy. Grants may be more suitable than repayable finance when, say, convening partnerships or influencing policy and practice. Social investment may suit scaling or replicating high-impact interventions where there is a sustainable revenue stream, or investing in assets.

There are examples of this approach being taken in other sectors, such as the Royal Foundation’s approach to tackling the causes that matter most to the Duke and Duchess of Cambridge and Prince Harry (see Case study below). However, we are not aware of this approach being taken in the disabled children and young people’s sector. The cause fund model combines the benefits of philanthropists being more informed and more collaborative with an ambition to achieve lasting social change. If done successfully, a cause fund approach to the disability sector could transform the lives of disabled children and their families for generations to come.

Case study: The Royal Foundation of The Duke and Duchess of Cambridge and Prince Harry

What is the approach?

The Royal Foundation could be described as a cause fund.⁶⁰ The Foundation targets causes that matter most to the Duke and Duchess of Cambridge and Prince Harry and approaches them in a systemic way. The Foundation's approach is built around three roles: raising awareness, convening/building partnerships and fundraising seed capital for vital initiatives. The Foundation combines a knowledgeable team with expert advisory boards, and commissions research where necessary, so it can take a sophisticated problem-solving approach to the issues.

What can this achieve?

The Foundation sought to tackle the illegal wildlife poaching problem all along the trafficking chain: from protecting animals on the ground; to preventing transportation of animal parts; and finally reducing demand for wildlife products in Asia. The Foundation brought together the United for Wildlife coalition of non-governmental organisations (NGOs) to develop collaborative solutions, and convened a task force to engage transport companies. Meanwhile the Duke of Cambridge has raised the issue's profile, not only in the US, but also in China, where United for Wildlife partners have developed demand-reduction activities.

The Foundation recently harnessed the public awareness power of all three principals when launching Heads Together,⁶¹ its campaign to end stigma in mental health. This campaign is leveraging the profile of the young royals to reduce the stigma around experiencing mental distress. It has forged a partnership with eight charities to develop practical solutions, helping to signpost people to information and practical support they may need and developing innovative new programmes with expert partners.

NEXT STEPS

There are many opportunities for philanthropists to make a difference to the lives of disabled children and their families. The fast-changing policy context and the potential of technological innovation mean new opportunities are frequently presenting themselves. At the same time, funding cuts and growing numbers of disabled children mean that the need for support is increasing.

Individual philanthropists can maximise their impact by educating themselves about the issues and targeting their support on priority interventions. Beyond this, there is potential for philanthropists in this area to collaborate more closely and pool their resources and expertise. For the most ambitious philanthropists, a cause fund can lead to lasting social impact.

If you have any comments about this report or would be interested in exploring the idea of a cause fund for disabled children and their families, please email NPC's Katie Boswell at Katie.Boswell@thinkNPC.org.

If you would like to discuss your philanthropic giving or social investment with CAF, please email Melissa Cortes at MCortes@cafonline.org or plannedgiving@cafonline.org.

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REFERENCES

- ¹ Langerman, C. (2005) *Ordinary lives*. New Philanthropy Capital.
- ² Joy, I. (2005) *Valuing short lives*. New Philanthropy Capital.
- ³ McGrath, A. and Yeowart, C. (2009) *Rights of passage*. New Philanthropy Capital.
- ⁴ Fradd, A. and Joy, I. (2007) *A life less ordinary*. New Philanthropy Capital.
- ⁵ Fradd, A. and Hedley, S. (2010). *Changing Lives*. New Philanthropy Capital.
- ⁶ Definition of disability under the Equality Act 2010: <https://www.gov.uk/definition-of-disability-under-equality-act-2010>
- ⁷ Scope, The social model of disability: www.scope.org.uk/about-us/our-brand/social-model-of-disability
- ⁸ Department for Work and Pensions (n.d.) *Disability prevalence estimates 2011/12*.
- ⁹ IPPR (2007) *DISABILITY 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020*, report for the Disability Rights Commission.
- ¹⁰ Contact a Family (2012) *The cumulative effect—The impact of welfare reforms on families with disabled children now and for future generations to come*.
- ¹¹ IPPR (2007) *DISABILITY 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020*, report for the Disability Rights Commission.
- ¹² Contact a Family (2003) *No time for us: Relationships between parents who have a disabled child*.
- ¹³ Children and Families Act 2014: www.legislation.gov.uk/ukpga/2014/6/contents/enacted.
- ¹⁴ Department for Education and Department of Health (2014) *SEND code of practice: 0 to 25 years*.
- ¹⁵ Contact a Family, Cuts to benefits: www.cafamily.org.uk/get-involved/campaigns-and-research/cuts-to-benefits/
- ¹⁶ Blackburn, C., Read, J. and Spencer, N. (2012) Chapter 9: Children with neurodevelopmental disabilities, in Annual Report of the Chief Medical Officer (2012), *Our Children Deserve Better: Prevention Pays*.
- ¹⁷ Bull, D., Sabri, F., Bowler, R. and Lumley, T. (2015) *Tech for common good*, New Philanthropy Capital.
- ¹⁸ Council for Disabled Children, About: <http://councilfordisabledchildren.org.uk/about/why-were-cdc>.
- ¹⁹ Rotheroe, A., Joy, I., Lomax, P., and Hedley, S. (2013) *Best to invest? A funders' guide to social investment*, New Philanthropy Capital.
- ²⁰ Kids Direct Short Breaks website: www.directshortbreaks.org.uk
- ²¹ Driver Youth Trust (2015) *Joining the dots: Have recent reforms worked for those with SEND?*
- ²² Kail, A., Wharton, R., and Curvers, S. (2016) *School report: How can charities work best in the school system?* New Philanthropy Capital.
- ²³ Skipp, A. and Hopwood, V. (2016) *Mapping user experiences of the Education, Health and Care process: a qualitative study*, ASK Research.
- ²⁴ Hamer, A.M. (2012) *Journey from education to work*, DWP Insight Team, commissioned by the Office for Disability Issues (ODI).
- ²⁵ Blackburn, C., Read, J. and Spencer, N. (2012) Chapter 9: Children with neurodevelopmental disabilities, in Annual Report of the Chief Medical Officer (2012), *Our Children Deserve Better: Prevention Pays*.
- ²⁶ Department for Education (2014) *Statutory framework for the early years foundation stage*.
- ²⁷ Department for Education and Department of Health (2014) *SEND code of practice: 0 to 25 years*.
- ²⁸ Cerebral Palsy website: www.cerebralpalsy.org.uk/
- ²⁹ PACE Infant and Parents Service (PIPS) website: www.thepacecentre.org/Groups/249824/PIPS.aspx
- ³⁰ Pyer, M. and Bush, M. (2009) *Disabled families in flux: Removing barriers to family life*. Scope.
- ³¹ Contact a Family, Media enquiries: www.cafamily.org.uk/media-enquiries/
- ³² Papworth Trust (2013) *Disability in the United Kingdom 2013: Facts and Figures*.
- ³³ Contact a Family (2003) *No Time for Us: Relationships between parents who have a disabled child*.
- ³⁴ Contact a Family (2014) *Counting the Costs 2014: Research into the finances of more than 3,500 families with disabled children across the UK*.
- ³⁵ Every Disabled Child Matters (2015) *Short breaks in 2015: An uncertain future*.
- ³⁶ Kids Direct Short Breaks website: www.directshortbreaks.org.uk
- ³⁷ National Network of Parent Carer Forums, Who We Are: www.nnpfc.org.uk/who-we-are/
- ³⁸ Contact a Family, How we support forums (England): [www.cafamily.org.uk/get-involved/parent-carer-participation/how-we-support-forums-\(england\)/](http://www.cafamily.org.uk/get-involved/parent-carer-participation/how-we-support-forums-(england)/)
- ³⁹ Together for Short Lives (2015) *Stepping Up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions*.
- ⁴⁰ Papworth Trust (2013) *Disability in the United Kingdom 2013: Facts and figures*.
- ⁴¹ National Development Team for Inclusion (2014) *The use of personal budgets for employment support*.
- ⁴² Hamer, A.M. (2012) *Journey from education to work*, DWP Insight Team, commissioned by the Office for Disability Issues (ODI), p.22.
- ⁴³ Pyer, M. and Bush, M. (2009) *Disabled families in flux: Removing barriers to family life*. Scope.

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- ⁴⁴ Department for Work and Pensions, First Disability Confident city sets out bold employment ambition: www.gov.uk/government/news/first-disability-confident-city-sets-out-bold-employment-ambition
- ⁴⁵ Golden Lane Housing, Who we are: www.glh.org.uk/about/
- ⁴⁶ We Are Purple, Purple Launches To Tackle Inequity in Employment for Disabled People: www.wearepurple.org.uk/news/13/54/Purple-Launches-To-Tackle-Inequity-in-Employment-for-Disabled-People
- ⁴⁷ KIDS Work Tasters, Work tasters: www.kids.org.uk/Event/work-tasters
- ⁴⁸ Crosby, N. and Tyson, A. (2016) *Me, my family, my home, my friends, and my life*.
- ⁴⁹ Council for Disabled Children, Transforming Culture and Practice in Social Care: councilfordisabledchildren.org.uk/our-work/social-care/policy/transforming-culture-and-practice-social-care
- ⁵⁰ Department for Education and Skills (2007) *Aiming high for disabled children: better support for families*.
- ⁵¹ National Autistic Society, Campaigns toolkit: www.autism.org.uk/get-involved/campaign/toolkit.aspx
- ⁵² Crosby, N. and Tyson, A. (2016) *Me, my family, my home, my friends, and my life*.
- ⁵³ Ambitious About Autism, Training and Consultancy: www.ambitiousaboutautism.org.uk/training-and-consultancy.
- ⁵⁴ The SEND Consortium, About Us: www.sendirect.org.uk/information/about-us/the-send-consortium/
- ⁵⁵ The SEND Consortium, State of the Nation 2016: <https://sendirect.org.uk/information/news/research/state-of-the-nation-2016>.
- ⁵⁶ Contact a Family (2016) Unpublished internal monitoring material.
- ⁵⁷ True Colours Trust website: <http://www.truecolourstrust.org.uk>
- ⁵⁸ Dasra, Our approach: www.dasra.org/our-approach#give-strategically.
- ⁵⁹ Lomax, P. and Wharton, R. (2014) *10 innovations in global philanthropy*. New Philanthropy Capital.
- ⁶⁰ The Royal Foundation website: royalfoundation.com
- ⁶¹ Heads Together website: www.headstogether.org.uk

TRANSFORMING THE CHARITY SECTOR

NPC is a charity think tank and consultancy which occupies a unique position at the nexus between charities and funders, helping them achieve the greatest impact. We are driven by the values and mission of the charity sector, to which we bring the rigour, clarity and analysis needed to better achieve the outcomes we all seek. We also share the motivations and passion of funders, to which we bring our expertise, experience and track record of success.

Increasing the impact of charities: NPC exists to make charities and social enterprises more successful in achieving their missions. Through rigorous analysis, practical advice and innovative thinking, we make charities' money and energy go further, and help them to achieve the greatest impact.

Increasing the impact of funders: NPC's role is to make funders more successful too. We share the passion funders have for helping charities and changing people's lives. We understand their motivations and their objectives, and we know that giving is more rewarding if it achieves the greatest impact it can.

Strengthening the partnership between charities and funders: NPC's mission is also to bring the two sides of the funding equation together, improving understanding and enhancing their combined impact. We can help funders and those they fund to connect and transform the way they work together to achieve their vision.

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