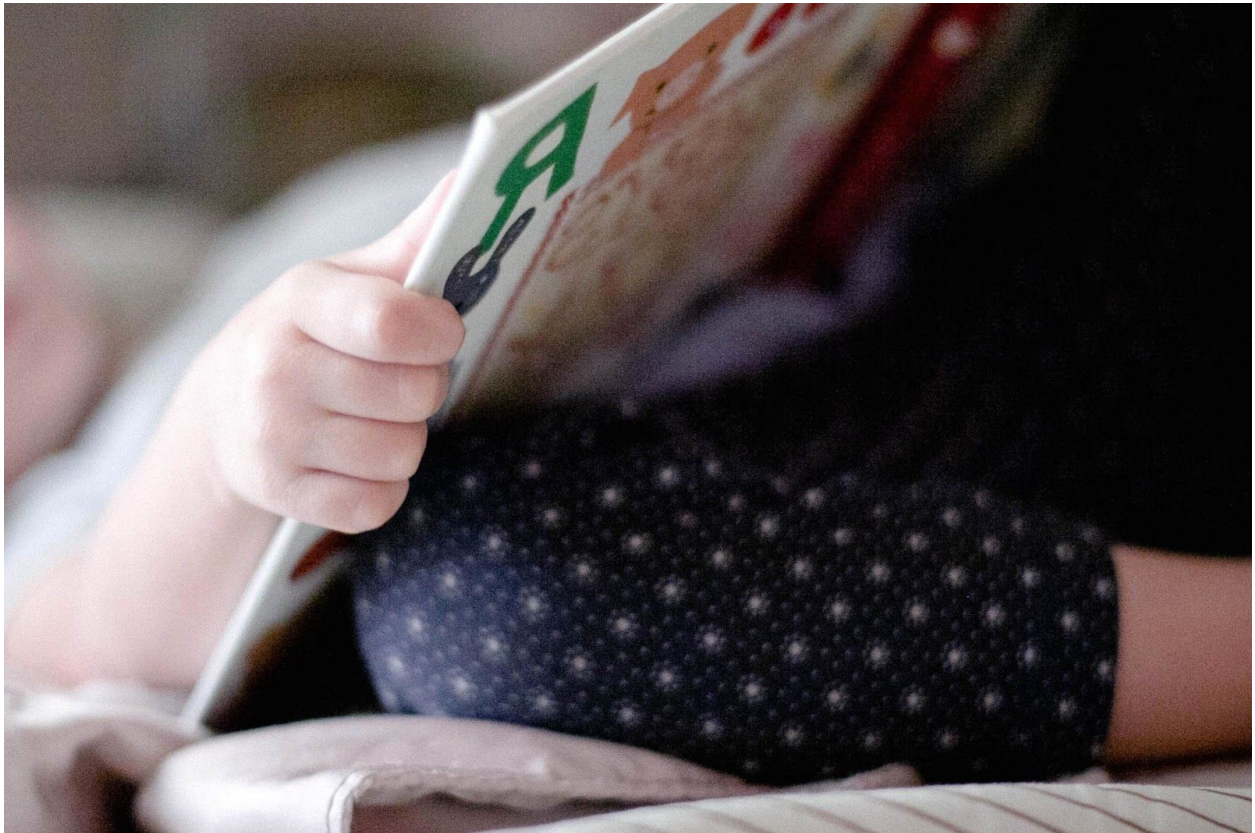


Seminar Report

# Invisible Children

Serious illness, prolonged school absence and long-term impact

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## Foreword

The experience of being off school for many months because of illness can be immensely challenging for a child or young person. Not only can they be seriously ill and undergoing gruelling treatment, tests or operations, but during this time they may lose contact with familiar friends and classmates.

Educational support will vary according to where they live. As a consequence of treatment, their appearance may change, bringing a new self-consciousness and a feeling of being different. Isolated from their peers and the wider school community, their attainment and confidence often suffers.

There were an estimated 49,000 children and young people with life-limiting and life-threatening conditions in the UK in 2009-10. This figure is expected to have increased significantly when new analysis is published next year because of advances in medical technology and treatment. While only a minority will be absent from school at any given time, some will be unable to attend for weeks, months or even years, because of their condition. In addition, we understand that there are children with mental health problems (sometimes because their own sibling is seriously ill) or sporadic unpredictable illnesses (such as asthma or diabetes) who are also not in school for sustained periods of time. These children are invisible, in that the numbers of them are not fully known, and their needs demand our attention if they are to live as full a life as possible.

For this reason, Rainbow Trust Children's Charity was pleased to contribute to this important discussion of the impact of prolonged absence from school on a child or young person's outcomes. We welcome the start of this important conversation, and we urge policy-makers to take up the mantle for this often forgotten group.

**Zillah Bingley**

*Chief Executive, Rainbow Trust Children's Charity*

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## Introduction

On 11th of June 2019 twenty-six people came together at the Royal Society of Arts for a roundtable discussion on **children and young people who experience serious or prolonged absence from school due to illness and the long-term impact on their educational and wider outcomes**. This report is a themed write-up of that discussion.

As a country we do not treat the wider group of young people who miss out on schooling as a result of suffering prolonged or serious illness as a distinct cohort. The purpose of coming together was to exchange perspectives and build up a picture on what is known about the status quo, and to discuss ways in which it might be possible to help this cohort of young people and their families more effectively given the enormous challenges they face. Participants in the discussion included young people and parents directly impacted, data analysts, school leaders from hospital and mainstream schools, charities and service providers, people involved in frontline delivery, Whitehall officials and members of parliament (see full list at Annex). The goals of the event were three-fold:

- to discuss what is known about the scale of the problem and what data sets are available to help us make a judgement about that;
- to get a sense of the adequacy and gaps in current service provision, and explore some innovative work taking place to help fill the gaps;
- to discuss what the priorities now are in terms of improving our understanding of the challenge and the way in which we address it to the benefit of the children, young people and families affected.

The event was hosted by a new network of public policy professionals, Tomorrow Today, and supported by the Norwegian start-up No Isolation which has developed a telepresence avatar to support sick children to access schooling remotely.

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## Key themes and messages

### 1. No comprehensive data on children with serious illness

There is no comprehensive or systematically collated dataset which allows the tracking of children missing significant periods of education due to chronic or serious illness. Whilst islands of data exist, participants agreed that policy makers remain largely in the dark about both the scale and nature of the issue.

#### Missing and mis-categorised children

The Department for Education (DfE) collates some relevant data through the Alternative Provision Census, the General Hospital School Census and the National School Census. According to their data, of the 783,400 children recorded as persistently absent in 2017/18 (i.e. with an overall absence rate of 10%+), 41.6% missed school due to illness and 4.7% due to medical appointments.

Seminar participants reflected that a number of children are likely to fall between the cracks and are at risk of not being picked up in any DfE surveys. It was reported that large scale analysis by the Education Policy Institute shows that of pupils completing GCSEs in 2017 who meet the persistent absentee threshold for illness or medical appointment absences in secondary, 15.5% experienced at least one 'unexplained exit' (i.e. have been removed from a school roll for reasons not explained by a house move, a migrant background, parents in military service, or another reason evident from data). This is compared to 8.1% of the overall pupil population. A number of these children may be missing from the education system entirely.

In addition, several factors may be muddying the water in the collation and categorisation of pupil absence data within schools. Seminar participants observed that the range of incentives on schools mean there are significant differences in how headteachers categorise/code absences, and also in the way parents communicate and report them.

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In some cases, young people are 'dual registered' at their mainstream school as well as their AP school. And when a child is illegally 'off-rolled', a local authority is not always made aware of this, so cannot track them in their own data sets.

The newly formed National Association of Hospital Schools has recently tried to pin down numbers of sick children entitled to education outside mainstream schools. This has similarly presented challenges. There are twelve hospital schools and 352 Pupil Referral Units (PRUs), but of the latter only some are for those with medical needs and it is unclear how many. The number of sick children being educated in home schools is also unknown.

### **Islands of education and health data**

The DfE's full academic year absence publication includes overall break-downs by region, district, local authority and school level and segments by pupil characteristics creating some potential for tracking the behaviours, progress and outcomes of this group of children, notwithstanding the possible miscategorisation issues highlighted above.<sup>1</sup> However, no breakdown of background for the subgroup who are persistently absent due to illness is included within their publications. And participants noted that no detailed information on the nature or impact of health conditions is collated within any of their surveys, limiting the extent and relevance of analysis that is possible.

A mirror issue was reported by a participant in relation to health data. Data on children suffering a number of serious illnesses, such as cancer, is collated within the health system. But the information gathered is limited to medical outcomes and does not connect to educational performance or wider wellbeing or socioeconomic outcomes.

### **Loneliness a major issue but poorly understood**

The group were in agreement that long term and chronic conditions which lead to significant absences from school are highly likely to have a serious emotional and mental impact on the child concerned, and to lead to children experiencing loneliness. Conflating the problem, research shows that there is a need to tackle the stigma of being lonely as a child. One parent described the dramatically isolating impact that three years of exclusion

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<sup>1</sup> Source:  
<https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2017-to-2018>

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due to a Leukemia had had on her son. Once a socially confident child, he now suffers from anxiety and OCD. He has lost his confidence in relating to other children to the point that he has panic attacks in their presence. Another participant described the range of factors that could lead to a loss of social and academic confidence for a child. These included being subject to extended periods of isolation, the stigma of looking different, pressure of trying to make progress/catch-up at school and a sense of slipping away. It was noted that isolation is used as a punishment for criminals, and that it is not fair to isolate our young unwell children. Having a child with a serious illness in the family can also have a range of psychological impacts on parents and siblings.

Yet again, there is a lack of data in this area and these issues are poorly understood or considered in policy making. Emotional/mental wellbeing data is not collated as part of key education and health surveys. And while 'loneliness' is known to affect one third of young people, and to disproportionately impact disadvantaged groups and those with disabilities, no data could be identified that looks specifically at on loneliness amongst sick children.

### **Long-term impacts on children's lives not recognised**

One young participant shared her and her peers' experiences of the long-term practical and economic impacts of having experienced a serious illness as a child or young person. It was clear that the consequences could be far reaching across all aspects of life, well after recovery. Issues included long-term disadvantages finding work due to 'unexplained' CV gaps such as missing GCSEs, limits to fields of employment where exposure to germs poses a continuing risk, difficulties getting a mortgage or being prioritised for private rental or social housing, lifetime issues with obtaining travel insurance, problems with fertility and adoption.

Much of the support that is available ceases when a young person is still in need of help. For example, a local authority's statutory responsibility in relation to education ends at the end of Year 11. In case of cancer, support from charities generally stops after 5 years but challenges for young people continue well beyond that.

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## **2. Some excellent provision but no consistent offer to children**

A very complex and mixed picture of provision emerged from the discussion with some excellent practice in place but also huge gaps and challenges.

### **Limited progress in policy recognition**

Participants noted that over the last two decades there had been some progress in policy and recognition terms, with the first statutory guidance on Education for children with health needs who cannot attend school published in 2001, and a revised and strengthened version published in 2013. The 2013 version requires local authorities to “Arrange suitable full-time education (or as much education as the child’s health condition allows) for children of compulsory school age who, because of illness, would otherwise not receive suitable education”, stating that this should kick in after 15 days of absence, whether consecutive or cumulative.<sup>2</sup> This is significantly more ambitious than the requirement for five hours per week stipulated in the previous guidance.

However, overall it was not felt that this guidance amounted to clear political leadership or real ambition on the issue. It was noted that the wording of the requirement was open to interpretation, leaving local authorities able to continue to offer a five hour maximum without being challenged. Furthermore, the ‘off-rolling’ of ill children is still effectively allowed in the current guidance.

More broadly participants noted the lack of political recognition or drive. They could not recall the subject being discussed by a Select Committee, or debated on the floor of the House of Commons. The lack of data discussed above was also perceived as a driver and a consequence of weak political leadership in this area.

### **Examples of excellence and innovation on the ground**

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<sup>2</sup>

<https://www.gov.uk/government/publications/education-for-children-with-health-needs-who-cannot-attend-school>



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The group noted numerous individual examples of excellent practice, professionalism and innovation in supporting children with serious illnesses. These were evident at the local authority level, school and hospital setting level and professional level. They included:

- Expert and dedicated school hospital staff working closely in partnership with health professionals and mainstream schools and transforming children's experience and educational outlook,
- A mainstream school with a stand alone specialist learning mentor unit on-site, using a stepped approach to sensitively support and re-integrate children,
- A local authority committed to offering a minimum 15-hour weekly home tuition to children who can't be in school, and working innovatively to achieve this on tight resources,
- Extensive outreach work in the community by professional hospital playworkers engaging children who are isolated at home and playing a crucial role in supporting their mental health and re-integration,
- The successful deployment of No Isolation's AV1 robot in mainstream and hospital schools, acting as children's eyes, ears and voice in the classroom, allowing children to re-connect with learning and peers and participate actively yet remotely in school life as well as out of school life.

### **Perception of significant and growing unmet need**

Despite examples of positive practice, there was a wide perception amongst participants that public service support is not keeping up with the needs of seriously ill children, and that families in these circumstances face increasing challenges in securing the necessary help. It is not possible to give an exact scale of this but one charity that supports families of seriously ill children nationally reported experiencing significantly growing demand across their services, including a notable 10% rise in referrals in the last year. They considered this growth to be a reflection of widening gaps in local public provision.

Given the long-term global trend which has seen the number of children with serious long-term/chronic illnesses increase as survival rates improve, some rise in unmet need could potentially be seen as inevitable. Reduced mortality at birth, improving diagnosis and



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ever developing medication have extended the life chances of even those with the most serious conditions. Whilst positive, this puts more pressure on services.

### **Stretched and fragmented context for key services**

Participants cited various examples of how the harsh public funding environment could be placing an impediment to meeting the needs of seriously ill children. A parent spoke about the lack of availability of Child and Adolescent Mental Health and Special Educational Needs Support services early on in the area where they lived. Another participant argued that ideally diagnosis of serious illness should trigger immediate supportive action from professionals working in these areas, and that this would have significant potential to off-set issues further down the line. Yet currently these services are struggling and over-stretched at a national level, and broadly failing to act preventatively in relation to any single group of children.

In parallel, it was felt that despite the commitment of staff the current legal and accountability frameworks in the school system can put mainstream schools in a conflicted position. With a large proportion of schools now academised, persistently absent sick children can find themselves passed between the care of the independently governed school/multi-academy trust and the local authority. Where relations are not good, children and their education can get lost in the mix of responsibility. And while the revised Ofsted framework will shift emphasis from a narrow set of results to wider wellbeing indicators, current incentives mean that some schools choose quickly not to retain affected pupils on their rolls, or to de-prioritise them for support. A parent whose son had been retained on the school roll after a long period of absence, spoke of how he had not received any in-person teaching support for two years, until the term prior to his Year 6 SATs.

### **Postcode lottery**

A key message from the discussion was that the extent of support and provision received was to a large extent determined by the postcode in which a child lives. Examples were given of families living in different locations being offered wildly different levels of support.

Hours of home tuition offered was a key area of difference across areas, with many local authorities still only offering four-six hours per week of home tuition, closer to the

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requirement in the original 2001 statutory guidance. It was also noted that some local authorities make very rigid requirements on medical proof before they provide anything at all. A local authority that provided a proactive and generous offer noted that this was challenging to do and plan for, given the financial climate and lack of historical data. It seemed the strength of their offer was the result of personal commitment amongst key staff rather than any systemic support.

Proximity to a Children's Hospital or Hospital school could be another factor that might determine levels of provision in the community, for example outreach playworkers.

### **Parents need more support to make demands**

The support and education given to a child can also be determined by a family's strength to fight for it. Overall it was felt that parents need more proactive support in this respect.

When a child is seriously sick, education is rarely a parent's immediate priority. When it does become an issue of concern, parents frequently do not know what their child is entitled to and lack the emotional energy to demand services and support. Typically parents will also have little idea of what they should expect, for example in relation to home tuition, access to a Special Education Needs Coordinator (SENCo), an Education Welfare Assessment or an Education Healthcare Plan. More disadvantaged/less educated parents are least likely to be confident in making requests and navigating the system. One parent told the group they had not known that they could apply for an Education Health Care Plan until her son had already had cancer for three years. She had received much valued help from charity sector specialist support workers, but they knew little on the education side. Having access to a support worker who was sufficiently informed to act as an advocate for her with the school and local authority would have made a big difference.

### **3. Strong momentum for action**

There was a strong sense of the need to build on the momentum created by this exchange with further collective action to improve the long term outcomes of this group of children.

### **Collecting better data**

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Participants agreed on the vital need for a much richer collection of data demonstrating the scale of this issue and nature of challenges affecting the long-term progress of these children. A more in-depth discussion could look at specific options, for example around joining up existing national data sets, adding additional questions to the Millenium Cohort Study and building on the data available through the Children’s Commissioner report on childhood vulnerability<sup>3</sup> on prevalence of children with life threatening and life limiting conditions. This could include a model for predicting future number of children in this category.

There was a plea for any future analytical framework to be set in broad terms, measuring participation and wellbeing rather than results only. More than one participant argued that it would be critical for future analysis to follow children through to at least their early twenties, investigating long term impact on employment, happiness and health.

### **Raising the issue up the political agenda**

As an important but discrete issue it was felt there may be an opportunity to galvanise political support and raise this issue up the public agenda. It was felt that politicians could be receptive to the issues discussed and a number of strategies for their wider engagement were suggested. These included: establishing cross-party champions and forming an APPG, investing time in generating powerful analysis on the ‘cost of not acting’ (such an approach was successful in raising early years up the political agenda) and mounting a very specific or targeted campaign such as home tuition hours or the off-rolling of seriously ill children. It might also be feasible to make ‘asks’ around the future direction of the Pupil Premium or Personal Care Budgets or Child Poverty Impact Assessments.

### **A positive narrative**

The importance of using a positive narrative within any future campaigning was highlighted. Significant opportunities to do this were noted. These included pitching the issues as part of now widely acknowledged ‘prevention’ agenda and ensuring schools were seen as part of the solution - not the problem. One parent participant argued that

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<sup>3</sup>

<https://www.childrenscommissioner.gov.uk/publication/childhood-vulnerability-in-england-2019/>

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long-term childhood illness can also present a 'moment of opportunity' for a child to develop, building resilience and additional skills from experiences outside the classroom. This is not widely recognised but could be developed further.

## Annex: attendees

ATTENDEES	
Session Chairs	Other Contributors
Dr. Ian Kearns, TomorrowToday Network	Emma Cookson, Campaigns Officer, More United
Jodie Reed, TomorrowToday Network	Daisy Cooper, Campaigns Director, More United
Speakers	Paul Dale, Essex County Council
Bertalan Gyenes, SEND, AP and attendance Analysis Team, DfE	Karen Dolva, CEO No Isolation
Cath Kitchen, National Association of Hospital and Home Teachers	Harriet Gridley, No Isolation
Vanessa Lefton, Tackling Loneliness Strategy Team (DCMS)	Joe Hallgarten, Principal Consultant, Education Development Trust and Parent
Sophie Dodgeon, Policy and Campaigns Manager, RainbowTrust	David Hoare, Chair of Teenage Cancer Trust/ Chair of Heart Academies Trust
Clare Laxton, Associate Director, Policy & Influencing, CLIC Sargent	Julie Keating, Essex County Council
Young person with experience of cancer	Mark Pearson, School Census Statistics Team, Department for Education
Amy Dixon, parent of Sam who has been out of school for 3.5 years	Tom Richmond, Snr Research Fellow, Policy Exchange and Director, EDSK
David Sheppard, Executive Headteacher, Leathersellers Federation	Daniel Sobel, Founder, Inclusion Expert
Phillipa Moore, Learning Mentor, Prendergast School and parent	Laura Walsh, Head of Play Services, GOSH
Jayne Franklin, The Children's Hospital School, GOSH and UCH	
Sarah Dove, Director, Phoenix Education Consultancy	
Liz Kendall M.P.	

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## **About No Isolation**

No Isolation is a Norwegian startup, founded in October 2015 with a mission is to reduce involuntary loneliness and social isolation by developing communication tools that help those affected. No Isolations AV1 is a telepresence robot which acts as the child's eyes, ears and voice in the classroom, of which there are currently 200 in use in the UK, nearly half of which are funded through the DfE Alternative Provision Innovation Fund.

[www.noisolation.com](http://www.noisolation.com)

## **About Tomorrow Today**

Tomorrow Today is a new network of professionals bringing together experience from the public sector, technology and finance in order to help develop and advance innovative solutions to public and social problems. The network has been established by a group of staff alumni from the progressive UK think tank Institute for Public Policy Research.