

MORE TO LIFE

Ensuring we meet the needs of people
with physical impairment across Essex



REVEALING REALITY

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A Revealing Reality Report

Acknowledgements

About the report

This research was commissioned by Essex County Council on behalf of the people of Essex. It was designed and delivered by the Revealing Reality research team in collaboration with the Research and Citizen Insight team at Essex County Council, with support from a wide range of people across the council and the county more widely.

The project would not have been possible without generosity and openness of a large number of people with physical impairments living across Essex. These individuals shared their time and stories for the benefit of others – and we would like to thank them for their warmth and candour.

Who is this report for?

This report comprises a summary of the research findings. It will provide an evidence base of people's experiences with PI from which Essex County Council, their partners and providers, and communities across Essex can make decisions and plan strategy for improving lives.

Structure of this report

- Background and introduction to the project – including a foreword by Essex County Council
- An introduction to the individuals who participated in the research, illustrating the diversity of the population with physical impairment across Essex
- Four thematic chapters which describe the key issues experienced by those who participated in the research: sidelined from society; fragile support networks; diminished aspirations and confronting the future
- Each thematic chapter includes starting challenges and opportunities for system-wide change for people with physical impairment

Foreword by Essex County Council

Essex County Council works closely with a range of services to ensure people can lead healthy and fulfilling lives and live as independently as possible. Every day we come into contact with individuals who are among the 90,000 adults of working age across the county with a physical impairment. Many of these are supported by friends, family and colleagues to live to their fullest potential. Yet, for some, there is a need for additional support.

Through our contact with them, we see the range of difficulties they experience, whether it be getting up in the morning, socialising and accessing transport, or finding and sustaining work. Moreover, they are often exposed to false assumptions that people make about their capability. Some report feeling as if the richness of life is lacking. They were not living, but merely existing.

We believe that to provide the quality of support needed for people with physical impairments to live well, greater attention needs to be paid to the complex interplay of experiences—physical, emotional and cognitive—that colour the lives of people of a variety of ages, locations and conditions. This report explores the challenges they face and the support they receive from public services and family or friends; it pinpoints bright points in their lives and opportunities that we can learn from. And we wanted to hear not just from the individuals themselves, but also from the family members who cared for them.

By speaking to people with physical impairments at length and in their own environment, we learned that they often feel side-lined from society, and as such can experience loneliness, isolation and a range of mental health problems for which they receive inadequate support. These not only affect them in the present; but can have a major impact on their aspirations for the future. So too can their support networks grow more fragile, with the number of people on whom they increasingly rely shrinking bit by bit.

The research also found that our respondents commonly lacked confidence in their own abilities. The sense of disconnection from social life and work did little to alleviate this. People often felt peripheral to society, whether they lived in a care home or spent most of their days inside their houses.

Many people are already contributing in this space, and Essex is proud to boast a range of dedicated social workers, nurses, doctors, care providers, housing providers, volunteers and more. But a more robust and collaborative approach to improving the lives of those with physical impairments is needed. Forces across the public sector—from social care, housing and environment to leisure, skills, health and wellbeing, and more - can join hands.

We also see a clear need to invest more in early intervention over late response. For people with physical impairments, whether they begin at birth or are acquired later in life, decisions made at the start of their journey cause a lasting impact for many years to come. A good decision would enable them to live independent and fruitful lives; a bad decision could rob them of the opportunities that most of us take for granted.

Anyone of us could be affected by a physical impairment. With a deeper understanding of the lived experiences of those with one, we can realise better outcomes not just for Essex, but for people beyond its borders.

Lisa Wilson

Head of Strategic Commissioning and Policy, February 2020

Introduction

Project objectives

Living with a disability provides an extra layer of complexity when it comes to achieving everyday goals and ambitions. While many people living with a physical impairment (PI) have the same ambitions as those without a PI, the additional challenges faced by the latter can make these goals harder to achieve.

Ultimately, this project aimed to identify the unmet needs of people with physical impairments living across Essex. Research was conducted with individuals with PI to explore their goals and aspirations, investigating the barriers to achieving these, and the opportunity areas that would better support them to meet their ambitions.

These findings are intended to inform a new approach to supporting people with PI, both across Essex and beyond. By focusing on 'needs' rather than service evaluation, the research kept people with PI at the centre of the enquiry, ensuring that their experiences were at the heart of analysis throughout.

Specific research objectives were to:

- Understand the breadth and extent of PI in Essex.
- Identify and review the current service provision and processes in place to support people with PI.
- Understand the experiences, needs and aspirations of people with PI.
- Identify any opportunities for improvements or innovation to better support people with PI.

Research approach

In-depth and holistic understanding

The project was qualitative, including place-based research and in-home interviews.

- Twelve site visits were conducted to different services for people with PI across Essex: four in Brentwood, four in Braintree, two in Colchester and two in Witham.
- Thirty in-home interviews were conducted with people living with a range of PI conditions across Essex, exploring a range of topics, including social life, employment, education, relationships, wellbeing, and family.

Sample: Capturing a range of experiences

No two lives are the same

The population of Essex living with PI comprises a wide range of experiences. These can vary depending on age, severity of condition, strength of support network, location and individual motivations. One factor can compound another, meaning that the needs of someone with PI are often far greater than the physical condition alone indicates. Some people can remain at home with little to no extra-familial support, while others will be institutionalised and require help to meet most of their basic needs.

To consider the whole picture, this report took a deliberately broad sample from within the community of people in Essex living with a PI. Care was taken to select people who had widely differing experiences. As such, we included:

- People who had acquired or congenital physical impairments
- Those who had both learning disabilities as well as physical disabilities
- People who were coping well and people who weren't
- Individuals that had mental health issues and those that didn't

In order to demonstrate key themes and findings of this research, only a select number of the respondents will be covered in detail within the body of this report. All the people that were spoken to are however mapped across the next two pages, thereby demonstrating the breadth of experience for people living with PI in Essex.

Meet the people with physical impairment who took part in the research...



Agnes (50) *Cerebral palsy*

Agnes works three days a week for a stroke support charity as the increased severity of the symptoms of her conditions meant that she has to resign from her full-time management position.



Faruq (32) *Shattered heel bones and nerve damage*

Faruq communicates with friends over video chat regularly. However, since moving to the UK, he has felt neglected by financial and support services.



Maria (83) *Osteoarthritis and rheumatoid arthritis*

Maria is well supported in the religious commune where she lives, yet feels her electric wheelchair is not as good at adjusting to different terrains as it should be.



Peter (34) *Amputee*

Peter works for a charity that supports limbless army veterans. As Peter values his independence he feels uncomfortable asking for help to pay for a wet room, despite the fall risk his current shower presents.



Sarah (27) *Ehlers-Danlos Syndrome and Lupus*

Sarah runs a small business promoting exercise for people with chronic illness. If she didn't have her business, she would be very isolated and bored.



Kitty (17) *Cerebral Palsy*

Kitty is proactive in searching for social clubs to join but there is a limited number of social clubs that cater to her needs.



George (64) *Osteoarthritis and had a triple bypass following a heart attack.*

George is part of the options for independent living (OIL) group and lobbied for accessible services locally. Despite this, he is unaware of support groups for people with Arthritis.



Bruce (40) *Cerebral palsy*

Bruce has built a 19-year career at a reputable finance firm. Bruce has little complaints about his life apart from being concerned that his mother currently helps him with his physiotherapy.



Mark (52) *Friedrich's Ataxia*

Mark attends social evenings held by the MS. society, he feels he can attend without being judged. However, he would like someone to help him around the house.



Amelia (30) *Multiple sclerosis (MS)*

Amelia is planning on starting a family with her husband. However, she is reliant on her parents during the week when her husband is at work.



Stephen (25) *Cerebral palsy*

Stephen regularly attends swimming club and physiotherapy sessions but health care professionals do not always acknowledge his medical history.



Luisa (50) *Cerebral palsy and arthritis*

Luisa is supported living arrangement seems to suit her needs as she has a meal a day and friends there. Although she enjoys living where she is, Luisa doesn't get to visit her friends in Southend-on-Sea as much as she'd like to.



Hannah (59) *Brain injury and diabetes*

Hannah attends a day centre once a week where she can interact with people similar to herself. Whilst she enjoys this activity, she has lived in the same care home for 23 years and questions what else she could be doing with her life.



Amy (49) *Spondylolysis*

Amy received a grant for a wet room but her true aspiration is to be employed but she doesn't know how to achieve this.



Mabel (6) Cerebral palsy
Mabel is excelling in mainstream primary school but her parents are unsure what publicly funded services are open to Mabel.



Linda (63) Acquired long-term injuries in a car accident and has osteoarthritis
Linda currently tutors young people with learning difficulties. Even though she struggles to navigate her home, she feels that she doesn't deserve support yet and is waiting until her PI worsens.



Maddison (75) Hypercholesterolemia and has had a shunt fitted
Maddison enjoys attending her local day centre around 3 times a week. Although, she would like to see her daughters more regularly.



Arlo (16) Muscular dystrophy
Arlo uses technology to communicate with friends e.g. facetime. His parents are concerned about the limited availability of respite care.



Sally (57) Psoriatic Arthritis, glaucoma and Crohn's disease
Sally is part of a strong Church community that offers her immense support as her PI worsens and she struggles to do the hobbies she once enjoyed.



Annabel (50) Paralysed from the waist down
Annabel transformed her life by becoming a Paralympic cyclist and she believes that there should be more support groups designed with just physical impairment in mind.



Obie (60) Cerebral palsy
Obie as plans to set up a heritage site in Nigeria when he retires in a few years. As of now, he is unsure of pain management options and how his condition will affect him as he grows older.



Brian (61) Brain injury
Brian was involved in the creation of a centre that supports people with brain injuries. However, he hasn't talked to anyone about what support he might require in the future.



Cody (26) Arthritis and Crohn's disease, for which he has a stoma bag
Cody has built a strong support network online. Yet, this has not helped him process who will care for him once his parents are unable to.



Mandy (65) Paraplegia
Mandy has retained a high level of independence by acquiring a part-time job and purchasing her own home. However, Mandy is frustrated about not being able to go out and attend activities spontaneously.



Gerard (67) Acquired severe injury to shoulder and has rheumatoid Arthritis
Even though Gerard is proud of establishing his own photography business, he feels isolated from social activities and events.



Janine (60) Slipped disc, Diabetes, terminal lung cancer
Janine explains that her electric wheelchair gives her the independence to leave her home on a daily basis. As she is able to get out and about, Janine is eager to volunteer but doesn't know what opportunities would be open to her.



Fleur (57) Muscular dystrophy, arthritis and osteoporosis
Fleur is passionate about her garden and is able to keep it immaculate. As well as maintaining this hobby, she would like to return to work but is reluctant to as she fears being discriminated against.



Nicholas (60) Multiple sclerosis (MS) and type 1 diabetes.
Nicholas enjoys living at his current care home as the care for a wider age range. He would, however, like to go out on trips without carers.



Jake (3) - Myotonic Dystrophy and Cerebral Palsy
Jake enjoys and is doing well at mainstream nursery. His parents are concerned about how long he will be able to stay in mainstream education.



Laurie (25) Cerebral palsy
Laurie values responding to emails on behalf of his local church but he would like to interact with people who are of similar cognitively to himself on a more regular basis, as the other residents he lives with have learning disabilities.

Chapter I:

Sidelined from society

Summary

- People with PI had to work a lot harder in order to stay involved with mainstream activities.
- Feeling excluded could impact the aspirations of people with PI, which could in turn lead them to further losing confidence or limiting their engagement with wider society.
- Whilst specialised activities were often well-intended and welcome, in some cases, attending specialised services could exacerbate people's feelings of isolation, as these services served to segregate people further from more mainstream activities.

I. Sidelined from society

Struggling to engage in mainstream activities

Kitty lives with her parents in a village in East Essex, close to the town of Maldon. Born with cerebral palsy, the 17-year-old spends her days surrounded by her parents and the healthcare professionals who visit regularly to help her wash, dress, cook and complete the various tasks she struggles with.

Reliant on a wheelchair from an early age, Kitty speaks of an uncomfortable irony: her condition means she interacts with people from the moment she wakes until bedtime, yet she feels alone. She wants to escape the confines of her house to be around people of her age and develop a sense of independence, but so far, this has not been possible.

Like others with physical impairments, Kitty has struggled to participate in the kinds of activities she sees her peers engage in. The physical, practical and emotional constraints of her condition leave her feeling isolated. “I feel like I spend half my life indoors”, Kitty explains.

She is not alone. There are over 11 million people in the UK that live with conditions—long term illness, impairment or disability—that limit their movement and their ability to interact with others¹. Some of these are present from birth, while others are acquired later in life. They take a range of forms, whether it be muscular dystrophy, multiple sclerosis (MS) or arthritis, or injuries to the brain, spine or joints brought on via accidents. In Essex, figures show that the total number of working age people with physical impairments are 90,000². Around 9000 people over the age of 18 receive support from Essex County Council funded Adult Social Care services in Essex listing ‘physical support’ as a primary support reason. Of these around 2000 are between the ages of 18 and 64.

These people inhabit a world that is primarily designed for people without physical impairments. The difficulties they face in navigating it can compound their sense of isolation and of feeling side-lined from public life. Someone with MS may tire more easily, and therefore be unable to attend evening social groups. Alternatively, someone reliant on a wheelchair may, unless assisted, struggle to catch the bus into town at the weekend.

Some people living with PI can feel ostracised from public spaces if these are not made accessible - steps instead of a sloping entrance, for example, or lack of adapted toilets. All told, these factors tap into a general feeling of being unwelcome in wider public life. They feel forgotten and pushed out of view: out of sight, out of mind.

But while practical barriers can be gradually overcome by improving accessibility, this alone is not enough to ensure people with physical impairments feel well integrated into public life. Given the range of issues people with PI face, it is unlikely that physical measures that aid inclusion will be all-encompassing or wholly perfect. Therefore, people become an essential ingredient in making individuals with PI feel included. This is where Essex could develop strategies to be more resourceful. Even if no formal adaptations are in place, the people of Essex should adopt a problem-solving mentality to accommodate people with PIs and make them feel welcome.

Forty-nine percent of the 13.9 million disabled people in the UK report feeling excluded in their day-to-day lives³. The perpetual sense of being side-lined can trigger feelings of loneliness, which can in turn feed anxiety and depression. This is something that Kitty,

¹ <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#fn:1>

² Figures come from the 2017 PANSI data-set <https://www.pansi.org.uk/>

³ <https://www.scope.org.uk/media/disability-facts-figures/>

who feels cut-off from her teenage peers, experiences: “It’s...really hard to find friends; to find people that are common to you”.

Teenagers are not the only ones to face this issue. People in Essex report similar knock-on effects well into their middle and older years. Janine, 60, is more than four decades Kitty’s senior. Living with terminal lung cancer, chronic obstructive pulmonary disease (COPD) and a slipped disc, she has spent the past two years in a purpose-built tower block in Chelmsford that provides assisted living. But the limits on her movement—Janine is reliant on a wheelchair—means that she spends much of her time in the tower block, a place she likens to a “jail”. Her son lives nearby, but only comes to visit monthly, leaving her bored and lonely for much of the time. She knows a handful of people she can chat with, but is otherwise surrounded by residents who all have their own conditions, and who avoid or lack encouragement to join social activities: “Too many people stay in their flats here. I would say I wouldn’t know three quarters of the people in here because I’ve never seen them.”

Losing confidence

Some people lacked confidence as a result of their impairments, and tended to stay at home. Cody, for example, rarely leaves the house, burdened by the pain caused by his arthritis and the inconvenience that can arise from dealing with a stoma bag in public. Currently living with his parents in Ockendon, the 26-year-old would like to go out more often in order to meet people who face similar challenges, as well as people who are around the same age.

While he is limited by the practical barriers of pain and inconvenience, it is a lack of confidence that Cody feels truly prevents him seeking out possibilities or joining groups to meet new people. Cody voiced his concerns about how uncomfortable he feels in his local community, “I do get a lot of looks”, he says, and “some people in my local community, when I first moved here...constantly questioned, ‘Are you actually disabled?’ ‘Are you trying conning, trying to get extra money?’”

Seeking friends, Cody attended a support group for people with stoma bags but felt excluded from existing members. It seemed as if everyone knew each other already. “Everyone had their own specific tables [so] they just go to their group”. Cody said they were “all friendly enough to...ask after you but then they just walk away and go to their group.” He didn’t feel comfortable accompanying people back to their circle of friends.

This had a knock-on effect on his already low confidence, and he is now worried he will struggle to fit in to any public environment. Cody is not being actively excluded from society, but his diminished confidence has left him fearful of being treated badly in public or rejected.

‘One-size-fits-all’ support

As Cody’s experience also shows, attending a specialised support group may not necessarily solve the issue of loneliness or isolation if the group is not right for the attendee. People with PI have a range of needs and levels of dependency. However, some find themselves attending specialised services with a one-size-fits-all approach that group people in with varying levels of need together. This can be demoralising for people both at the more severe and less severe end of the spectrum and means that some spend a lot of their time surrounded by people with more complex needs than themselves.

Kitty had an experience like this when she went to a youth club to meet people her own age. She was placed in a group designed for people with a range of conditions where the majority of the attendees had learning disabilities. Kitty, who does not have a learning disability herself, found it difficult to approach and make lasting connections with people here. She would have preferred the opportunity to engage with a wider mix of people and may have chosen to attend a mainstream group if she could have been supported to do so.

The promotion of specialised support could leave people feeling further segregated from mainstream activities, particularly if they believe these are the only spaces suitable for them. It is therefore important to strike a balance between providing specialised services that create spaces for those with PI to meet people similar to themselves and helping to instil those with PI with the confidence to join mainstream spaces and be an active member of their community.

Some would have valued being able to take part in more mainstream activities but did not know how to find opportunities that were right for them. For example, while Janine is desperate to undertake a voluntary role that will help her regain some purpose in life, she doesn't know what options for volunteering are open to her, or what charitable organisations she could contact in her local area to help her find a suitable opportunity. "I just want to help but I don't know what I could do", she says.

She is proactive and relatively independent, using her wheelchair to get into town on a daily basis to visit shops. However, she is worried that her PI would prevent her from being able to do the majority of the volunteering duties on offer. She is concerned that tasks such as serving tea or coffee at a charity run café would not be possible for her, given that she would find it tricky to weave through tables.

Janine is warmer to the idea of selling poppies around town but doesn't know whether this is a possibility in her area. This suggests that the community services on offer in Essex are struggling to sufficiently advertise themselves to people like Janine, who would like to get involved but who are unsure if their condition can be accommodated.

There is a clear drive on the part of people with PI to get more involved in public life, although they recognise that they may need the right support to do so. Aspiring to be a famous actress on the West End, Kitty is eager to join a reputable theatre company. She knows it has an inclusive ethos and would cater to the needs of people with physical impairments, learning disabilities and those who have neither. Kitty sees this as an opportunity to learn in an environment where she can build relationships with similar people, while at the same time acquiring the skills to build a career. For Kitty, this opens up the possibility of moving away from the periphery of public life towards its centre.

Sideline from society

Summary of the challenges and opportunities to help people feel more included within Essex Life

MORE TO LIFE



AT HOME AND WITHIN
THE BUILT ENVIRONMENT

Trapped at home

Problem: People with PI can feel 'trapped at home'.
Opportunity: Enable people to easily leave their homes and interact with others.

Access to transport

Problem: Public transport is difficult to navigate with a PI.
Opportunity: Make public transport accessible to all.

Unknown spaces

Problem: Unfamiliar places can be difficult for people with PI.
Opportunity: Provide helpful resources and signposting of facilities in all places.

PI ghettos

Problem: People with PI risk being confined to ghettos, away from public life.
Opportunity: Integrate people with PI into public life.



SKILLS AND PERSONAL
DEVELOPMENT

Social contact

Problem: Usual opportunities for meeting people are limited for those with PI.
Opportunity: Ensure people with PI are encouraged to join social activities.

Re-entering work

Problem: People with PI often lack awareness of what support there is to help them re-enter work.
Opportunity: Assist people with PI to continue with, or find alternative, work.

Self-development

Problem: PI can affect one's ability to access learning and self-development opportunities.
Opportunity: Encourage people with PI to try new forms of self-development and integrate them into mainstream skills-building activities.



PHYSICAL HEALTH AND
WELLBEING

Public services

Problem: PI can have a negative effect on one's confidence in dealing with public services.
Opportunity: Ensure people with PI feel confident dealing with public services.

Holistic support

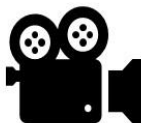
Problem: Support for people with PI often focuses on physical health, not social.
Opportunity: Ensure people can access more holistic support.

Mental health stigma

Problem: People with PI often experience mental health problems, but struggle to discuss these.
Opportunity: Open up channels through which these can be supported.

Social spaces

Problem: Social activities and clubs are not always accessible to people with PI.
Opportunity: Support clubs and activities to be accessible to everyone.



LEISURE AND FUN

False assumptions

Problem: Assumptions that people with PI don't have the same leisure and fun-related needs as others can make them feel more isolated.
Opportunity: Review what activities are available for people with PI and encourage them to take part.

Insufficient information

Problem: There is insufficient information around what leisure activities there are for people with PI to pursue.
Opportunity: Ensure people with PI are aware of available opportunities and feel empowered to ask questions of particular services.



RESIDENTS AND LOCAL
COMMUNITIES

Negative stereotyping

Problem: People with PI are sometimes stereotyped as being cognitively impaired.
Opportunity: Inform the wider public that a PI does not automatically result in cognitive impairment.

Public Support

Problem: The wider public lacks confidence in supporting people with PI and worries about doing the wrong thing.
Opportunity: Build confidence around 'best practice' in interacting in a caring way with someone.

Chapter 2:

Fragile support networks

Summary

- People with PI had to work a lot harder in order to stay involved with mainstream activities.
- Feeling excluded could impact the aspirations of people with PI, which could in turn lead them to further losing confidence or limiting their engagement with wider society.
- Whilst specialised activities were often well-intended and welcome, in some cases, attending specialised services could exacerbate people's feelings of isolation, as these services served to segregate people further from more mainstream activities.

2. Fragile support networks

Losing friends

While working at a steel factory three decades ago, a 1000-kilogram weight fell onto Gerard's shoulder. Only 36 at the time, he had been responsible for managing large-scale steel shipments brought to Essex, but in an instant, his life was changed. For some time after the accident he was unable to walk, and although he has slowly regained mobility over the last 30 years, today he lives with chronic pain and osteoarthritis.

Now 67, Gerard recounts how his social network gradually dissipated following the injury. In his twenties and thirties, he says, he had enjoyed “a good social life, the wife and I”, but as the years passed the invitations slowed, eventually grinding to a halt. “I don't really get invited out to the social occasions because they believe wrongly, I think, that we can't take part in their social life.”

At his home in Colchester, Gerard now spends much of his day editing photographs—family portraits, landscapes—that have been commissioned by customers. This is now his job, one that he finds great purpose in. He treasures the interactions he has with those who commission him, but they can only achieve so much. He explains that his social network has been in gradual decline since his injury as the pain and immobility has worsened. He has been unable to maintain old friendships, while the nature of his work—at home, and dealing with people only on an intermittent basis—means that he struggles to forge new relationships. His physical impairment leaves him feeling isolated, both emotionally and physically, and he is largely reliant on his wife and a few close family members for support.

Gerard's story will be familiar to many people, both in Essex and beyond, who have a physical impairment, especially those who acquired it later in life. The limitations on mobility can worsen over time, and as a result people find themselves increasingly restricted to their house or care home as their pain or discomfort worsens. Fruitful social networks become trickier to build and sustain and new avenues of support are harder to come by. With people becoming less able to participate in the activities they once did, and as leaving the house or care home becomes more of a hassle than a pleasure, connections with old friends weaken and new opportunities for social engagement are reduced.

This has been the story of Faruq, who relocated from Afghanistan to Colchester four years ago. While working as a mediator and interpreter on behalf of the British Armed Forces in Afghanistan, Faruq's vehicle hit an improvised explosive device (IED). The explosion left him with shattered heel bones and permanent nerve damage in his hips and back, which give him chronic pain. The event also resulted in him developing PTSD, which has diminished his confidence to go out in public. Rarely leaving the small, two-bedroom council flat that he shares with his wife and three young children, Faruq doesn't feel like engaging socially with anyone: “I don't really know a lot of people. I hate going out”.

Growing dependencies

Physical impairments affect an entire network of people, not just the individual who has them. Faruq, like Gerard, is now somewhat dependent on his wife for support. This raises key questions about what might happen should things change for either man or their wife. Without the care and support provided by their immediate family, both men would find themselves in a position of far greater vulnerability, and needing to source alternative means of support. The predicament of these Essex residents is reflected in the prevalence of unpaid care across the UK—that which is provided by a family member, partner or

friend. Statistics show that there are 5.7 million unpaid carers in the UK⁴. The development of a dependency on close family members or friends can exert significant strain upon, and complicate, the web of relations that often tightens following a life-changing event. In a worst-case scenario, valuable bonds can sever, thereby dismantling an individual's existing support system.

Mandy knows this only too well. After a spinal fistula left her paralysed from the waist down six years ago, the 65-year-old struggled to maintain her relationship with her husband, and they eventually separated. Adapting to life as a wheelchair user prevented her from doing the things she and her husband once enjoyed—most importantly, travelling. “[We] used to travel a lot...in Europe, South Africa, Australia, and there were lots of other places we wanted to visit.” Now, she says, “[it’s] not really possible”.

“Having a physical relationship when you’re in a wheelchair is difficult”, she continues. She can’t do the kinds of things that previously made up a big part of her character.

Yet fortunately, Mandy, who now lives in Colchester, adjusted quickly to life with a physical impairment. Retaining her independence was crucial to her, and this drive helped her to achieve the ambitions she set herself—to get a car and a house, and to get back to work. Despite the breakdown of her relationship and the disruption of her close support system that followed, she sought out the support of others, namely her children and professional carers. Establishing a new career in turn provided opportunities to meet new people.

Pressure on carers

Family members that do undertake the responsibility of care are themselves subject to enormous pressures arising from such an entangled relationship. The ability to retain or construct a life outside their role of caregiver can help to combat these difficulties, and this is where support services—not just for the person with the PI, but also for their carer—can make a real difference.

Arlo, a 16-year-old from Southminster who has muscular dystrophy, would require full-time professional care if it wasn’t for the ongoing support of his parents, particularly his mother. However, she must also juggle raising Arlo’s three siblings with studying part-time for an occupational therapist qualification. “It would be good for us [herself and Arlo’s father] to have some time off,” she says. The many competing priorities and demands on her time are a cause of stress. but she does not feel supported enough to take a break.

Respite care would give Arlo’s mother the opportunity to recuperate, as well as enable Arlo to have time independent from his family. Arlo and his family are entitled to six respite nights a year, but, as Arlo explains, “due to funding, the hours have come down”, and only three of these are now guaranteed.

Gerard’s wife has taken up Tai Chi in an effort to relieve the worry and pressure she experiences around her husband’s health. She is looking for a way to help Gerard cope with his condition, and key element of this is the support she gives herself.

Gerard, Faruq, Mandy and Arlo all rely on either close friends, family or professional carers to help them navigate life with a PI. Without these sources of support, it would be harder for them to maintain any independence, and isolation may creep as a result. While it is imperative for individuals with a PI to construct a strong support network, it is equally important to understand that the effects of a PI do not fall only on the person with the condition. Close family members and friends who act as carers also face pressures, and it is equally important that they find support to relieve the stresses that accompany their role.

4 <https://www.carersuk.org/news-and-campaigns/news-rss/6004-strain-on-unpaid-carers-putting-adult-social-care-at-increased-risk-of-collapse>

Fragile support networks

Summary of the challenges and opportunities to enable those with PI to develop and maintain meaningful relationships, whilst also supporting carers

MORE TO LIFE



AT HOME AND WITHIN
THE BUILT ENVIRONMENT

Discomfort in public

Problem: Lack of confidence in dealing with PI issues in public spaces stopped people from going out and socialising.
Opportunity: Provide support and facilities for those facing an inconvenience in public.

Restricted mobility

Problem: Some with PI felt housebound or dependent on immediate carers to provide transport.
Opportunity: Support people with PI to navigate public transport and move about as independently as possible.



SKILLS AND PERSONAL
DEVELOPMENT

Over-reliance

Problem: People with PI are often reliant on friends and family for professional, emotional and practical support.
Opportunity: Counteract an over-reliance by enhancing support given by public services.

Meeting 'like-minded' people

Problem: People with PI often lacked ideas for how to interact more with 'like-minded' people.
Opportunity: Ensure that skills-based activities are promoted equally to those with PI so they can take advantage of opportunities that align with their interests.



PHYSICAL HEALTH AND
WELLBEING

Wellbeing of carers

Problem: Carers were sometimes stressed and exhausted, with little access to respite care.
Opportunity: Ensure that carers and family members are supported to protect their emotional and physical wellbeing, and their relationship with their dependent.

family and friends.

Opportunity: Ensure clear signposting to mental health support, and prompt conversations to ensure relationships are sustained.

Strained relationships

Problem: Mental health issues linked to PI can impact on relationships with

Isolation and rejection

Problem: Isolation through lack of support can lead to feelings of anger and rejection.
Opportunity: Encourage and support people with fragile support networks to build these up, and for authorities to listen to concerns of marginalised people.



LEISURE AND FUN

Social activities

Problem: People with PI may find it hard to continue to do the activities that previously brought them together with others.
Opportunity: Ensure people with PI are able to maintain socially-important activities and encourage them to take on new activities.

Limiting beliefs

Problem: People with PI sometimes experience a drop in invitations to interact with old friends who make assumptions about what they can do or enjoy.
Opportunity: Promote positive messaging to those living alongside people with PI so that they avoid imposing limiting beliefs.



RESIDENTS AND LOCAL
COMMUNITIES

Support for carers

Problem: Carers often found that their responsibilities towards the person with PI impacted negatively on their own relationships and priorities.
Opportunity: Ensure carers are given opportunities for socialising and respite, and to build or maintain relationships beyond the person they care for.

Burden of preparation

Problem: People with PI feel that they can't be spontaneous with social engagements, given the additional planning needed.
Opportunity: Consider how services can quickly communicate accessibility features or limitations, and how this could be streamlined to minimise the burden of preparation for people with PI.

Support for parents

Problem: Parents felt they had to provide round-the-clock care for their children.
Opportunity: Consider how parents in particular can be given support and opportunities for rest and relaxation.

Chapter 3:

Diminished aspirations

Summary

- People with PI felt that employment, education or volunteering opportunities were limited and uncertain.
- Social activities were lacking, leading to some people living monotonous routines and feeling bored for most of their day.
- People found it harder to take up new hobbies or maintain ones they had enjoyed earlier in life and felt there should be more to life than the present.

3. Diminished aspirations

Giving up work

Amy had been working in an optician four years ago when, reaching for a pair of glasses, she felt something “like a machete” going through her back. She assumed it was just a bad back, but after a month of rest and no signs of improvement, she went to get an assessment. Following several referrals and X-rays, the 49-year-old was diagnosed with spondylolysis (spinal osteoarthritis), a degenerative condition affecting the spine.

Not long before the diagnosis, Amy had begun to experience mild symptoms of obsessive-compulsive disorder (OCD). The sudden realisation that she now had a physical disability to contend with exacerbated the OCD. There was, she felt, one more area of her life over which she had little control.

A life-altering event, such as that experienced by Amy, impacts far beyond the physical changes that take place. The chronic pain stemming from spondylolysis limited Amy’s mobility. She started to use a wheelchair, and, suddenly having to give up work, was increasingly confined to the house she shares with her second husband and 11-year-old daughter.

Amy is among 318,000 disabled people who currently face unemployment in the UK⁵. Around 20,960 others in Essex, claim disability benefits relating to physical impairments. This figure represents approximately 53% of the total 39,815 disability benefits claimants in the county⁶.

Giving up her job was one of the most frustrating changes she experienced after her diagnosis. She misses the fulfilment that an occupation brings, and says she wants to feel like she could provide for her family. Yet simple tasks, such as shopping, eating and drinking, have become harder as time passes. Over time, she has become increasingly depressed.

Many people with PI experience mental health issues, such as depression or anxiety, which can have a knock-on effect on their aspirations for the future. Data shows that 30 percent of people who are living with a long-term physical impairment in the UK also have a mental health condition⁷. People who feel like they are struggling to cope day-to-day are less likely to aim big, and more likely to see their hopes and aspirations narrow as their world grows smaller.

Amy’s son, who lives nearby and owns his own opticians, suggested Amy pick up some administrative work at his company as a temporary measure until she found something more permanent. However, this ended up altering Amy’s circumstances in a way that made her feel trapped. She wanted to be more proactive about looking for paid work or volunteering and didn’t like the idea of relying on her son, and so, at a loose end, she went to the Job Centre. They suggested she register as self-employed in order to formalise the work she was doing for her son. But on a subsequent visit to find a more substantial long-term job, she was told that because she was self-employed, they couldn’t help her.

Amy’s condition is progressive, and will become harder to manage over time. Despite a caring support network and a well-meaning family, she has no clear plans for how to cope as her condition worsens, and no idea how she can continue to develop skills, contribute to society and support her family financially. She feels trapped, knowing neither what next steps she can now take, nor what she could reasonably expect from a career at this stage.

⁵ House of Commons Briefing Paper, People with disabilities in employment, October 2019.

⁶ Statistics from May 2018 dataset

⁷ The Shaw Mind Foundation, Mental health of those suffering with physical or learning disabilities, Nov 2019.

The same old routines

Physical impairments can create a cycle of isolation and self-doubt that causes horizons to narrow and confidence to diminish. Many people in Essex with long-term PI had seen their routines grow increasingly monotonous and repetitive over time, and they became stuck in habits that limited their chance for new experiences. This was especially the case for those who needed to enter care homes to manage their physical impairment. There, they often felt walled off from society, with fewer opportunities to engage with the outside world. Even within the home, social interaction for these people could be minimal.

Hannah, 59, is the youngest resident in the Colchester care home she has lived in since a motorbike accident 23 years ago left her with a life-threatening brain injury. She has seen her physical and mental capabilities improve gradually over time—from being wheelchair-bound she is now able to walk and look after herself day-to-day. Yet while the care home has given her necessary support, she also feels trapped. Her surviving family members visit only infrequently, and she rarely gets out. Most of her days follow the same routine: breakfast, watching television, lunch, afternoon nap, dinner, television and bed. Most of the residents there require more intensive support than Hannah, which leaves her feeling like an outlier. She does not have many friends, and she eats her meals alone.

Hannah finds temporary relief in her weekly group trips to shopping centres, museums or tourist attractions organised by a local support organisation. She would like to do more, she says—exercise, perhaps, or go to the pub—but has neither been offered the opportunity nor been pushed to break out of her normal routine.

Sometimes, she says, she feels as if she is “just existing”.

More to life than this

While she aspires to go out and try more things, and, eventually, to move out of the care home, she is unsure how to achieve these. Like many people living with intensive support for a long period of time, she has lost the confidence to put herself out there. She says she would feel “like a burden” if she were to ask support staff at the centre for help in breaking out of her insularity. She has also been following her routine for so long that she now gets easily fatigued and needs extra support to try new things. “I’m well looked after and comfortable,” she states, “but occasionally I think to myself there must be more to life than this.”

Hannah and Amy feel like they could achieve more than they currently do, but neither have a clear vision for how to do so. The physical limitations of their condition compound their lack of confidence, and their reluctance to be pushy means they are unlikely to make any radical changes to their lifestyles, goals or aspirations. Despite being dissatisfied, neither are sure where to look for help. Their goals have consequently diminished, and they are uncertain as to how to re-frame their expectations for the future.

Diminished aspirations

Summary of the challenges and opportunities to enable those with PI to develop and maintain meaningful relationships, whilst also supporting carers

MORE TO LIFE



AT HOME AND WITHIN
THE BUILT ENVIRONMENT

Independent living

Problem: Some people wanted to move to new homes where they could live more independently but were not sure how to go about finding these.

Opportunity: Ensure that people who wish to are supported to live independently where possible, and that there are regular reviews of living situations to avoid people with PI feeling trapped in their homes.



SKILLS AND PERSONAL
DEVELOPMENT

Limited expectations

Problem: People with PI can be grouped with others who have more limited cognitive abilities. This can impact what expectations they have for themselves, and what people expect of them.

Opportunity: Ensure people with PI are surrounded by inspiring, motivating individuals who they can learn from and be challenged by, and that people with PI can set realistic and ambitious goals.

Opportunity: Ensure that lifelong learning and skills development are a core part of the care and support for everyone with PI in Essex.

Catering for additional needs

Problem: People with PI are often unaware of what education, employment and voluntary options there are for them, and how additional needs will be met.

Opportunity: Ensure that opportunities around education, employment and volunteering are promoted to people with PI and support additional needs.

Inclusion of children

Problem: Parents are often not sure what options are open to their children, and whether they will be able to stay in mainstream schools in the future.

Opportunity: Enable parents to establish open dialogues with schools and be informed about options for their children's education..



PHYSICAL HEALTH AND
WELLBEING

Reaching goals

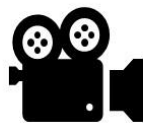
Problem: Many people feel that their PI or mental health is limiting their ability to pursue their ambitions.

Opportunity: Support healthcare professionals and health touchpoints to encourage individuals to make lifestyle changes so that they reach their goals.

Worthy of support

Problem: Some people with PI think they don't deserve the support needed to progress and achieve their ambitions.

Opportunity: Find a way to show people they are worthy of this support and encourage them to take it up where it's available.



LEISURE AND FUN

Everyday activities

Problem: Some people with PI found it difficult to engage in even the simplest activities, such as going to the pub.

Opportunity: Ensure that facilities are welcoming to people with PI and their friends and family, and that they make the most of small and regular leisure activity where possible.

Personal development

Problem: Activities that are tailored to specific PI needs do not always encourage people to achieve greater independence or develop personal skills.

Opportunity: Ensure that appropriate challenges and personal development plans are integrated into activities for people with PI where desired.



RESIDENTS AND LOCAL
COMMUNITIES

False assumptions

Problem: Some people with PI can feel that they are reduced to seeming 'incapable' or not needing to try, and are therefore not encouraged by those around them.

Opportunity: Support people with PI to overcome barriers and achieve their ambitions, and encourage others not to make assumptions about their ambition

Over-protection

Problem: Some people with PI feel over-protected by the support systems and people around them.

Opportunity: Ensure that people's lives are not 'de-risked' to the point where they can't enjoy life and try the new things they'd like to try.

Chapter 4:

Confronting

the future

Summary

- People with PI were seldom planning ahead or thinking about how to manage their condition as they grew older. This meant they weren't thinking as much about progressing in certain areas of their life, or preventing decline
- Many respondents were not aware of what support might be available to them currently or in the future.

4. Confronting the future

Uncertain futures

Physical impairment often has knock-on effects far beyond the physical realm. Limited mobility may be the foundational problem, but it can cause a range of issues that impact on the overall wellbeing of the individual. This is a concern for Esther, whose six-year-old daughter, Mabel, has cerebral palsy. Mabel is a high achiever—"top of the class", her mother explains proudly—and regularly takes part in hippotherapy, swimming, yoga and other activities designed to keep her physically and cognitively engaged.

But while her current routine is more or less assured, Mabel's future is uncertain. Esther and her current partner have not made detailed plans about how to manage their daughter's physical impairment as she grows older and her condition progresses. There are many uncertainties in Mabel's life, such as whether she will be able to continue in mainstream education, or whether she will need aids and adaptations in order to continue to use the household bathroom. As a result, her mum and dad spend a lot of time speculating about what *might* need to be done in response to *possible* problems. She explains, for example, that she and her husband have "kind of talked about when she gets bigger, we'll probably have to re-do the bathroom". They have also considered whether Mabel will be able to remain in mainstream education: "How will she get around? Will she be in a manual wheelchair all the time? Will she be strong enough and have enough energy to use a walker? Will she need an electric wheelchair? How will we fund that?"

The inability to predict in detail how Mabel's condition will affect her as she grows up means that she and her family can only live in the present. They lack confidence in planning for a future that has a multitude of possible eventualities. "You don't know how she's going to develop", Esther says.

For people with the kind of condition that Mabel has, several questions recur: will it get worse, when will it get worse, and how quickly could it worsen? The lack of clarity makes it difficult to prepare for the necessary aids, adaptations, services and finances that would lessen the impact of a physical impairment until a condition progresses and further challenges arise. Future-orientated conversations require individuals to confront the limitations and health complications a PI can cause, but this stark reality stirs feelings of discomfort and conjures up images of losing independence and dignity.

Fleur, who is 57 and has muscular dystrophy (MD) and arthritis, recalls a time when her father was instructed by his carers to go to the toilet in bed because it was easier for them to clean up. Fleur speculates that she too will require a carer in the near future as her mobility decreases, but she has avoided investigating this prospect too deeply: her father's story provides an all-too cautionary tale for how loss of mobility can bring with it a loss of dignity.

Fleur has made limited adaptations to her home in Clacton-on-Sea despite being prone to falls due to her MD, fitting grab-rails in her bath after fearing she may slip and fall when getting in or out. Aside from this, Fleur makes use of the banister and dado rails (moulding fixed to the perimeter of a room) when using the stairs. Fleur is also averse to using a wheelchair. She sees this a downward slope to immobility, attracting the attention of the general public and being judged based on this.

It can be easy to assume that a person who does not voice their desire for change is content with their current circumstances. But it can be difficult for individuals with PIs to articulate what alterations they want to make. Often, the problem is not the result of a lack of aspiration, but rather little knowledge about what services and support is available to help them. The result is that a person with a PI can feel a lack of agency when it comes to planning their future.

Hannah, who we met in the previous section, has lived in the same nursing home in Colchester for 23 years; placed there by her mother, she has never left. Despite not wanting to remain in there for the rest of her life—“I can’t see me spending the next 10 years here doing nothing”, she says—she has not been encouraged to think about whether there are, or will be, alternative places in which to reside.

Hannah’s future appears to be fixed through assumptions held by those who have cared for her over the years. Any alternative care options that could enable her to assume some control over her life have not, she says, been adequately explained to her. After voicing her concerns to staff, Hannah was told that she could “go and ask downstairs” if she needed more help with something, rather than being actively helped by staff to achieve the best future she can.

Feeling uninformed

For Esther, she can only speculate as to what problems Mabel may face in the future. To date, she and her husband have been privately funding the majority of their daughter’s care, including an array of physiotherapy treatments. She encourages Mabel to stay engaged in activities that keep her options broad, thus maintaining a future-orientated outlook, but they will continue to privately fund her care. Asked what free services could be available for Mabel, she replies: “I don’t know what’s out there that we can apply for. I don’t know who else I would talk to.”

The lack of clearly communicated information about what people with PI should expect in the future can be anxiety-inducing. While there can never be absolute certainty over how a condition will develop, there can at least be conversations. But some report that even this is not happening.

Amelia, now 30, was diagnosed with multiple sclerosis (MS) when she was 21. She assumed she would be told by her consultant what support was available to her and how her condition would manifest, but she spent a year after her diagnosis not knowing how to live a life with MS. “[I] didn’t know what MS was. I didn’t hear from anyone for a year; didn’t know what I was doing. Was I meant to do anything? I had no idea.”

Feeling uninformed and lost, Amelia attended an MS talk hosted by an MS doctor close to her home. The doctor was displeased with the lack of advice Amelia had been given, and he took her on to his caseload. Amelia now feels supported and well informed about her physical impairment, so much so that she is planning on starting a family with her husband, stating confidently: “I’ve spoken to my MS doctor about it and he said go for it.”

Yet there is a third dimension to all this. Not only do people with PI often not know what support they are entitled to receive, but some feel they don’t deserve any support because others need it more than they do. This largely stems from people not wanting to feel like a burden or an inconvenience to others. To avoid this feeling, individuals may wait until the severity of their physical impairment passes a certain ‘threshold’ that justifies seeking support. This impacts on how people managed—or did not manage—their condition; whether they would act to prevent deterioration, or instead whether they would wait for their needs to worsen.

Linda, 63, sustained injuries following a car accident in 2011, leaving her with a collapsed ankle and acute pain in her legs and arms. Living in a small mobile bungalow in Braintree with her three cats and one dog, Linda’s home is unkept. As her pain worsens, so does her mobility. She struggles to maintain her living space, and can’t always afford to pay someone to help her with household tasks. The sense of isolation and loneliness she has felt since her accident has gradually intensified, and she rarely ventures outside her bungalow. Yet despite all this, she has not yet reached out for support. She feels other people need it more than her and describes her generation as having a “make-do attitude”, which she often adopts.

Linda gives details of a woman whom she met at a community centre. She was thin and walked with two sticks. Linda could not fathom how this woman’s carer had recently






been “taken away”, asking “how is she supposed to cook?”. While Linda recognises how someone with reduced mobility may be unable to complete simple tasks that give quality to a person’s life, she does not see the similarities between the woman she describes and herself, and continues to regard herself as unworthy of care. Linda explains that “it’s going to be later in life when I start losing my marbles [that I] might need some more help”.

A ‘make-do’ attitude can, however, mean that people with a PI only seek help when their condition has developed to the point at which there’s no choice but to look for support. By that time, the likelihood of being able to function independently is greatly diminished. Mabel’s parents continue to proactively search for further support for their daughter, accessing as many opportunities to increase Mabel’s chances of achieving all the things she wants to during her life and reducing the impact of her physical impairment. This is a distinct contrast to Linda, who is waiting for her physical impairment to worsen until she seeks support. In the meantime, the restrictions and impact caused by her condition continues to grow. However, even when individuals with a PI undertake an active search for support, as Mabel’s parents do for her, they are still left wanting information. That information, it seems, is not proactively presented to individuals with a PI, as exemplified by Amelia. Instead, public bodies and professional services wait until they are approached for information, frequently operating on a ‘build it and they will come’ mentality.

Confronting the future

Summary of the challenges and opportunities to ensure everyone with PI feels hopeful for their future and are making progress towards their goals.

MORE TO LIFE

 <p>AT HOME AND WITHIN THE BUILT ENVIRONMENT</p>	<p>Trapped at home Problem: People with PI can feel 'trapped at home'. Opportunity: Enable people to easily leave their homes and interact with others.</p> <p>Access to transport Problem: Public transport is difficult to navigate with a PI. Opportunity: Make public transport accessible to all.</p>	<p>Unknown spaces Problem: Unfamiliar places can be difficult for people with PI. Opportunity: Provide helpful resources and signposting of facilities in all places.</p> <p>PI ghettos Problem: People with PI risk being confined to ghettos, away from public life. Opportunity: Integrate people with PI into public life.</p>
 <p>SKILLS AND PERSONAL DEVELOPMENT</p>	<p>Social contact Problem: Usual opportunities for meeting people are limited for those with PI. Opportunity: Ensure people with PI are encouraged to join social activities.</p> <p>Re-entering work Problem: People with PI often lack awareness of what support there is to help them re-enter work. Opportunity: Assist people with PI to continue with, or find alternative, work.</p>	<p>Self-development Problem: PI can affect one's ability to access learning and self-development opportunities. Opportunity: Encourage people with PI to try new forms of self-development and integrate them into mainstream skills-building activities.</p>
 <p>PHYSICAL HEALTH AND WELLBEING</p>	<p>Public services Problem: PI can have a negative effect on one's confidence in dealing with public services. Opportunity: Ensure people with PI feel confident dealing with public services.</p> <p>Holistic support Problem: Support for people with PI often focuses on physical health, not social. Opportunity: Ensure people can access more holistic support.</p>	<p>Mental health stigma Problem: People with PI often experience mental health problems, but struggle to discuss these. Opportunity: Open up channels through which these can be supported.</p> <p>Social spaces Problem: Social activities and clubs are not always accessible to people with PI. Opportunity: Support clubs and activities to be accessible to everyone.</p>
 <p>LEISURE AND FUN</p>	<p>False assumptions Problem: Assumptions that people with PI don't have the same leisure and fun-related needs as others can make them feel more isolated. Opportunity: Review what activities are available for people with PI and encourage them to take part.</p> <p>Insufficient information Problem: There is insufficient information around what leisure activities there are for people with PI to pursue.</p>	<p>Opportunity: Ensure people with PI are aware of available opportunities and feel empowered to ask questions of particular services.</p>
 <p>RESIDENTS AND LOCAL COMMUNITIES</p>	<p>Negative stereotyping Problem: People with PI are sometimes stereotyped as being cognitively impaired. Opportunity: Inform the wider public that a PI does not automatically result in cognitive impairment.</p> <p>Public Support Problem: The wider public lacks confidence in supporting people with PI and worries about doing the wrong thing.</p>	<p>Opportunity: Build confidence around 'best practice' in interacting in a caring way with someone.</p>

Conclusions and Recommendations

More to life than this?

People living with PI in Essex are subject to a wide range of limiting experiences that relate both directly and indirectly to their condition. No two experiences are the same: some impairments are acquired, while others are inherited; both young and old are affected. The resulting impacts manifest in very different ways from one person to another.

We have seen how physical impairment can affect one's sense of belonging in society, and those with PI have to work a lot harder to stay involved in mainstream activities. This doesn't just mean improving physical accessibility; the way the people of Essex behave is vitally important in ensuring those with PI feel included. Special treatment and segregation aren't helpful; problem solving to ensure 'normal integration' is.

Feelings of exclusion can impact confidence around interacting with others. Many people with PI described how their lives were often oriented around home and revealed specific fears around being in public spaces.

Many people with PI had seen their social networks shrink and their support networks grow fragile. Constricted social groups could leave them more and more reliant on a small number of friends or family members, which can place a strain on these relationships and, in some cases, lead to relationship breakdown. Maintaining meaningful connections with others and preserving the richness of relationships was something that many people with PI keenly wanted.

People with PI often felt their day-to-day activities were monotonous and repetitive, and struggled to find stimulation and variety. Many felt their opportunities were narrower when compared with others who didn't have a disability, and that this became especially apparent around employment, education and volunteering. Having a physical impairment was often accompanied by diminished aspirations and hope for the future.

Overall, a disability adds an extra layer of complexity when it comes to achieving goals and ambitions. Conversations about the future often require confronting difficult realities, including loss of independence and, potentially, dignity, but being uninformed and delaying decisions could achieve exactly the opposite.

Meeting the needs of people with physical impairment across Essex

Across the four chapters of this report there are a number of central challenges that need acting on in order to make progress for people with PI.

- The need to ensure people with PI are fully integrated into Essex—not side-lined or segregated, but generously welcomed into all aspects of day-to-day life.
- The need to ensure that people with PI are able to develop and maintain rich, meaningful relationships, and that carers themselves are valued and treated with respect.
- The need to ensure that everyone with PI feels ambitious and hopeful for their future, and are supported to develop and reach their goals where possible.
- The need to prompt people with PI to think realistically about the future and to make appropriate decisions that will help them to live happily and independently for as long as possible.

Sidelined from society - How can we make sure people with physical impairment are fully integrated into Essex life?

- Enable people to more easily leave their homes by making public transport accessible to all, making signposting of facilities for people with PI clearer, and integrating them further into public life.
- Ensure people with PI are encouraged to join social activities, as well as to continue with, or find alternative, work and new forms of self-development and skill-building that align with their interests.
- Ensure that people with PI feel confident dealing with public services, and that they can access support for conditions other than physical—for instance, mental health or loneliness.
- Review what activities are available for people with PI and empower them to take part in, and ask questions of, public services.
- Develop 'best practice' for how the public should interact with people with PI, and correct any false assumptions about both the cognitive abilities of those with PI, and what their ambitions might be

Fragile support networks - How can we enable those with physical impairment to develop and maintain meaningful relationships?

- Make the most of technologies available to support people with PI, and provide digital training where it can improve quality of life.
- Promote access to wider public services so that people with PI are not over-reliant on friends and family.
- Encourage people with fragile support networks to build these up, while ensuring that carers for people with PI and family networks are themselves supported.
- Ensure that people with PI maintain social activities, and encourage those living alongside people with PI to promote positive life messages.
- Carers and support networks—parents in particular—should be given opportunity for respite, and to build relationships beyond the person they are caring for.

Diminished aspirations - How can we ensure everyone with physical impairment feels ambitious and hopeful for their future?

- Support people to live independently if they wish, and be mindful of the fact they may feel trapped in their present accommodation.
- Ensure education, employment and voluntary opportunities are promoted and made accessible, and that parents of children with PI are able to have open conversations about options for their children's education, and futures more generally.
- Help people with PI to understand they are worthy of support that helps them to meet their life goals.
- Appropriate challenges and personal development plans should be integrated into leisure activities for people with PI where desired.
- Ensure the lives of people with PI are not 'de-risked' so much that they can't try new things.

Confronting the future - How can we ensure that people with physical impairment are prompted to think realistically about the future?

- Empower people to have open discussion around what adaptations they might need to make as their condition progresses, and that they have realistic conversations about planning for the future.
- Encourage people with PI to maintain the hobbies they enjoy, or find alternatives if necessary.
- Regularly review decisions around fluctuating health and wellbeing needs and encourage individuals and key stakeholders to take preventative action where possible.
- People with PI may require more careful long-term planning, and it is important to integrate 'fun' into these plans to give them something to look forward to.
- Encourage carers and support networks themselves to plan ahead so as to mitigate future problems where possible.