kidz to ADULTZ
MAGAZINE
ISSUE 2 / MARCH 2019

IN THIS ISSUE...

- CAMPAIGNING AGAINST CUTS
- MY AUTISM JOURNEY
- LOW COST CLOTHING ADAPTATIONS
- SELF-CARE FOR PARENT-CARERS
- A PARENT'S GUIDE TO MOVING & HANDLING

Win!

A pair of your own special *spokeguards!*


ATOM

Welcome!

WELCOME TO THE SECOND ISSUE OF OUR BRAND NEW MAGAZINE…

The launch issue of our new Kidz to Adultz magazine was distributed at our Kidz to Adultz North event in November and we have been delighted with the response. It seems that you enjoyed the content and the styling and so we are looking forward to your comments about the second issue.

In the last issue we ran a competition to win a Cerebra Sledge and we had over 80 entries! You can see the winner of the competition in this issue.

This time you have the chance to win a very special personalised pair of spokeguards, so why not send us your entry today.

As in the launch issue, we have a wide mix of articles and advice so settle back and have a read.

We hope you find it useful and remember, please let us know what you think. If you do have a story that you would like to tell us all about for the next issue, which will appear in May, then please do get in touch by contacting us at magazine@disabledliving.co.uk.

Carmel Hourigan
Editor & Manager Kidz to Adultz Exhibitions

CONTENTS…

FANCY BEING IN THE NEXT ISSUE?

If you would like to talk to us about promoting your company or organisation in the next issue of Kidz to Adultz magazine, call us on **0161 607 8200** or email us at **magazine@disabledliving.co.uk**

Pepsi the Labrador PROVIDES PAWSITIVE SUPPORT FOR IZZY

A MOTHER HAS TRAINED HER SPRINGER CROSS LABRADOR PEPSI TO HELP HER DAUGHTER IZZY, WHO WAS BORN 16 WEEKS PREMATURE WEIGHING JUST 500G. IZZY IS NOW TWO YEARS OLD AND HAS COMPLEX NEEDS

As a dog trainer by trade, mum Heather Pyne was inspired to use her skills and knowledge with dogs to support her daughter and other young people with any disability.

Heather told us: “Izzy suffered a severe brain bleed when she was very young. This means that she now cannot do a lot of things for herself such as sit up, move around or talk.”

Heather says “Pepsi had been my assistance dog before I brought Izzy home from hospital so I had planned to train my other dog to support Izzy and keep Pepsi focused on me however it quickly became clear that Pepsi would be the perfect support for Izzy so we decided to share her. From the day we came home Pepsi kept looking into Izzy’s cot and the first time Izzy had breathing difficulties Pepsi, without any training to do so, alerted us. This could have saved Izzy’s life.”

Heather trained Pepsi to do a variety of tasks to support Izzy. Some tasks focus on Izzy’s development. For example, Pepsi lies across Izzy’s lap which grounds her pelvis into the floor and which allows Izzy to sit up.

Heather has also been teaching Izzy to ask Pepsi to do physical assistance tasks for her such as taking off her blanket and clothes and fetching toys when Izzy drops them using subtle movements and vocalisations.

Heather explained: “There is an art to training Pepsi to do these things. I had to work out what Izzy was capable of doing and understanding and then getting Pepsi to understand what the very subtle movements and sounds mean but already Pepsi is becoming very confident responding to Izzy’s requests and it’s lovely seeing Izzy starting to communicate. It’s really helping Izzy get some independence and stopping her from feeling frustrated by our lack of understanding.”

Heather has also trained Pepsi to provide a medical alert for Izzy, meaning she lets Heather know if Izzy is going to have a seizure before they happen and when Izzy is experiencing any breathing difficulties. This has made Izzy’s life a lot safer and family life more relaxed knowing they have Pepsi as an alert system.

After realising how far she could go training dogs to support young people with complex needs Heather founded Pawsitive Squad CIC in July 2018 to provide assistance and support dog training, canine assisted activities classes and canine assisted activities and therapy within organisations. Pawsitive Squad provides services for young people with any type of disability or who are recovering from trauma and is based in Nottinghamshire but provide therapy and activity visits across the East Midlands and specialist training holidays across the country.

Pawsitive Squad CIC is a type of not for profit company called a community interest company. For customers under 25 with disabilities or recovering from trauma it means they can access services at a low cost and without long waiting lists.

You can find out more about Pawsitive at www.pawsitivesquad.co.uk

CELEBRATING 10 fantastic years OF KIDZ TO ADULTZ MIDDLE!

THURSDAY 21ST MARCH 2019 MARKS THE 10 YEAR ANNIVERSARY OF OUR KIDZ TO ADULTZ MIDDLE EVENT AT THE VERY PRESTIGIOUS RICOH ARENA, COVENTRY. A MOMENTOUS ACHIEVEMENT AND ONE OF WHICH THE TEAM AT DISABLED LIVING (ORGANISERS OF THE KIDZ TO ADULTZ EVENTS) ARE EXTREMELY PROUD OF

Collectively the Kidz to Adultz events are the largest, free, UK exhibitions totally dedicated to children and young adults up to 25 years with disabilities and additional needs, their families, carers and all the professionals who support them.

This event was established and added to our events portfolio in 2009 following on from feedback from our visitors to make our Kidz to Adultz events more accessible to those in the Midlands area (Warwickshire, Worcestershire, Leicestershire, Northamptonshire and further afield). The event proved to be an immediate success and to accommodate demand for expansion, the exhibition has grown from the original 2,000sqm to 4,000sqm plus additional seminar rooms - a remarkable team effort from the dedicated staff at Disabled Living.

Since 2009 we have welcomed 22,476 visitors through the doors at the Ricoh Arena. Our visitors have been able to access the most up to date information and advice on equipment, products and services for children and young adults with disabilities and additional needs. 6,567 visitors were also able to boost their CPD and update their knowledge on a number of really hot topics by attending one or more of the 100 free seminars delivered.

2015 saw the name of the event change to Kidz to Adultz Middle (originally named Kidz in the Middle). The name change was in-line with changes to the Care Act 2014 and to support children and young adults up to the age of 25 years. In-line with these changes we expanded our remit to include information on transition, education (colleges, university process and support) training, career information, holidays, travel, financial matters and much more. We continue to develop this area to meet our growing visitors' needs, particularly as a large number of our children are now entering their teenage years and looking for more independence. We would love to hear back from you on what you would like to see at future events, or indeed if you are a provider of transitional services or equipment, so please do get in touch.

Free

Prize Draw worth over £900!

This year, with the support of the Ricoh Arena, all visitors attending will be entered into a fabulous free prize draw worth over £900! All our visitors will have a chance to win a table of four at the Saracens match at the Ricoh Arena Premier Hospitality Lounge. The prize draw includes:-

- Three course choice menu
- Champagne reception on arrival
- Complimentary selected wines, beers and soft drinks until the final whistle
- Pre-Match commentary from a Wasp first team player
- A complimentary official match day programme
- Complimentary tea & coffee
- Direct access to the corporate balcony
- On-site match day parking
- Includes hotel accommodation – 1 night (twin or double room with breakfast).

Watch out for some highlights of our past ten years and information on our other Kidz to Adultz events on our social media channels and within our Disabled Living newsletters!

Disabled Living
0161 607 8200
info@disabledliving.co.uk
www.kidzexhibitions.co.uk

My Autism JOURNEY

BY JOELY WILLIAMS

In our quest for Autism Acceptance, what is the first word that you think of, when you hear the word, Autism? As an Autistic, young woman, I first think of the word 'Beauty'. I always have, and probably always will, and here is the reason why.

You see, Autism, is a beautiful disability that impacts every second of my life, in a multitude of complicated, hard, frustrating and invisible ways.

However, I have learnt that this is ok, because, I wouldn't change my disability for the world. I love my AspergerWorld, after all; thanks to the beautiful and positive attributes and unique perspective, that my ability gifts me with, on a daily basis.

My name is Joely Williams, and I am a passionate Autism Activist, Motivational Speaker, and Author of "AspergerWorld: My Fairy Jam Jar" book.

I was diagnosed as Autistic when I was 2 years old, and after years of battling depression, PTSD- Post Traumatic Stress Disorder, and not understanding my disability, a disability which has finally become a gift which I adore; a gift that may have countless hidden hardships, but also embraces me with the quirks I love most about myself.

Learning to understand my disability changed my life for the better. Through volunteering as a teenager, with disability youth action charities, councils and the government, I began to understand myself, and I finally became happy again. I volunteered a lot, and I loved it, focusing on making concrete changes within our communities to make society more disability and autism friendly.

> "I began to understand myself, and I finally became happy again"

There is simply nothing more important than trying to make a positive change in people's lives; because everyone has a unique spark of beauty within them that can be empowered to shine, by an understanding environment that enables us, as autistic people to be the best we can be.

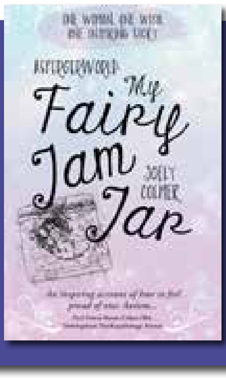
So, the question is, what is the best way to enable autistic people? Quite simply, by challenging our misconceptions, to encourage Autism Acceptance, and learn to understand the hows and whys of what Autism is, and appreciate the unique depths, hardships and quirks of the Autistic Spectrum.

I published my educational resource book, 'AspergerWorld: My Fairy Jam Jar', and my journey to help others, sky rocketed from there.

My disability has many fascinating depths that are hidden and often shrouded in mystery and in the book I help uncover those mysteries, and enable a positive understanding, inspiring hope with a 'can do' attitude to our autistic community.

The book follows my life's journey through the countless trials and tribulations of my difficult childhood; communicating with Hieroglyphics, the 'whys' of Behavioural Issues and Meltdowns, through to the chaos of being a teenager, Mental Health Issues, Independence Training and Learning Environments at School, right up to Life Skills and Shutdowns as an adult, and adult life volunteering.

Joely is presenting at Kidz to Adultz Middle on Thursday March 21st at 2pm. Her book is endorsed by Professor Simon Baren-Cohen, a world leader in Autism research and Lorraine Petersen OBE, an educational consultant and trustee of Ambitious about Autism. **For more information, visit www.aspergerworld.co.uk**



WIN A SIGNED COPY OF JOELY'S BOOK!

You can win a signed copy of Joely's book. Just email magazine@disabledliving.co.uk with your contact details and use 'Joelys Book' as the subject line. Entries close on Monday July 1st 2019.

Med Page

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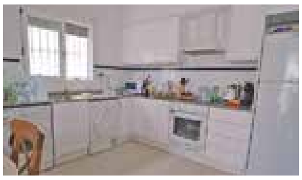
Equally important, the area surrounding the location of this villa is beautifully flat which any wheelchair user will more than welcome!!!



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BIRTH RELATED neurological and developmental disorders in the newborn

BY KAY TAYLOR, PARTNER, KNIGHTS PLC

The arrival of a baby is a special time in any family but sometimes not everything goes to plan. Complications in pregnancy, a premature birth or other issues at delivery can lead to a baby requiring intensive neonatal support.

HYPOXIC ISCHAEMIC ENCEPHALOPATHY (HIE)

Many of the children we support at Knights plc have birth related neurological and developmental disorders. Some are diagnosed with hypoxic ischaemic encephalopathy otherwise known as "HIE" shortly after birth - a technical term describing brain damage caused by a lack of oxygen (hypoxia) and/or restriction of blood flow (ischaemia) to the baby. It is often associated with full term babies but can occur in premature babies too. It is likely to cause periventricular leukomalacia (PVL) when it occurs before 35 weeks gestation and other forms of brain injury at term. There are 3 categories of HIE: mild, moderate and severe.

Babies in the womb can cope and compensate for a brief period of time when they are not getting enough oxygen. The otherwise healthy baby at term can usually survive a period of around 10 minutes of acute and profound hypoxia before beginning to sustain brain damage. Sometimes the oxygen supply to the baby is not completely cut off - this is known as a chronic partial insult. The longer the period of oxygen starvation (whether acute or partial), the worse the damage can be and the more significant impact this may have upon the child.

THE CAUSE AND SIGNS OF HYPOXIA AT BIRTH

There are a number of events during pregnancy, labour and birth that can contribute to a lack of oxygen supply such as cord compression, abnormal foetal position, a lack of progression in labour, uterine hyper stimulation as well as placental insufficiency or abruption. Signs of hypoxia at birth can include:-

- An abnormal foetal heart rate pattern. This is monitored using a cardiotocography monitor (CTG)
- Meconium stained amniotic fluid
- The baby being born blue or white in colour and floppy in appearance
- The baby suffering seizures shortly after birth
- Difficulty with feeding, unable to latch, suck or swallow
- If resuscitation is required to help with breathing

An assessment of the baby's condition will be recorded at 1, 5 and 10 minutes of age. This is known as an Apgar score and may be a good indication of the baby's condition at birth as well as cord blood gases which provide evidence of the new-born's metabolic condition. Cranial ultrasound scans or an MRI may be performed to assess the nature and extent of any brain damage.

TREATMENT

One of the most effective treatments used to treat HIE is therapeutic hypothermia, also known as active cooling. This involves reducing the core body temperature to slow down the progression of any damage caused by the lack of oxygen. It's important that this treatment is provided swiftly to maximise the potential benefit.

A diagnosis of HIE doesn't always lead to the development of cerebral palsy or other health issues but this can often be the case. A claim for damages can be pursued if it can be shown that the medical team involved should have provided alternative treatment/care that would have led to a different outcome. Although this cannot reverse the damage caused it can make a life-changing difference to the whole family relieving a huge financial and emotional pressure.

Kay Taylor is a Partner at Knights plc and a member of The Law Society Clinical Negligence Accreditation Scheme. Knights' brain injury team specialise in brain injury claims and in particular those involving obstetric and neonatal negligence.

Kay Taylor

AMBITO EDUCATION
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Ingfield Manor – fulfilling potential through Conductive Education

We are a Centre of Excellence for Conductive Education, for children and young people who have neurological motor impairments.

We are a non-maintained day and residential special school for children and young people between the ages of 3 and 19 years.

We aim to provide an exceptional learning environment for children and young people who have neurological motor impairments, such as cerebral palsy. Some of our students also have additional needs like visual impairment and more complex medical needs.

Our curriculum is stimulating and diverse and delivered through Conductive Education, and we are acknowledged as one of the leading centres for this education system in the UK. Our staff work collaboratively using a transdisciplinary team approach. This approach involves professionals sharing roles, with blending of skills, teaching and learning.

Our qualified nursing team are here to enable the children and young people at the school to access all aspects of the curriculum by ensuring that their many health care needs are met throughout the school day

We also run the Ingfield Manor School for Parents, which provides a specialist service for families of children with cerebral palsy and other motor learning difficulties. We support families with babies and children under five years of age. Parents and children learn daily living skills together using the principles of Conductive Education.

01403 782294 • ingfield.manor@ambitoeducation.co.uk
Ingfield Manor School, Ingfield Manor Drive, Five Oaks,
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www.ingfieldmanorschool.co.uk

Ingfield Manor SCHOOL

Craig-y-Parc School – a place to grow

We are a specialist school that offers flexible placements to children and young people aged 3 to 19 years old, with complex support needs, including physical and sensory impairments, and severe or profound and multiple learning difficulties (PMLD).

Through our nurturing environment, and multi-disciplinary approach across education, nursing, residential and therapy, we guide our students to realise their full educational and personal potential. We also have a specialised team of Conductive Educators to aid our students in developing their daily living skills.

Students can access a variety of specialist on-site facilities including a hydrotherapy pool, sensory room and assistive technology hub, as well as outdoor learning areas and a woodland walk set within our 33 acre site.

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www.craigyparc-school.co.uk

Welcome to Ty Cwtch, our Children's Home at the Craig Y Parc School site

At our residential home, we make sure the young people we support get the most from every experience and can find the best ways to improve their physical, cognitive and communication skills. This can be through one to one support or may include the benefit of a team of specialist staff.

Ty Cwtch can accommodate up to 16 students in two-bedded bedrooms (single occupancy is available).

We offer a variety of packages, each tailored to the individual needs of the young person. Whether you require all year accommodation or are here for short breaks, you can enjoy the same level of personalisation, interaction and choice of fun activities.

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Do our children have the right TO PLAY?

BY KATE SHEEHAN, DIRECTOR AND OCCUPATIONAL THERAPIST, THE OT SERVICE

Photo by Markus Spiske on Unsplash

Kate Sheehan

A child's job is to learn, develop and connect, by engaging with their environment and with the people around them. Our job as parents and carers is to provide them with a safe, rich world and to share knowledge to enable them to develop to their full potential

Play is one of the main ways in which children learn and develop, it helps to build self-worth by giving a child a sense of his or her own abilities and to feel good about themselves. Children's right to play is enshrined in the United Nations Convention on the Rights of the child and Article 31[1]:

'Play is recognised as a fundamental human right and children have the right to relax and play'.

As a society we have a duty to support our children to access play that is age appropriate and suitable for their individual needs. Play is very important as it assists in the development of their physical abilities, language skills, emotions, creativity and social skills. Play helps to nurture their imagination and gives a child a sense of adventure and can allow risk taking in safe environments. Through this, they can learn essential skills such as problem solving, working with others, sharing and much more.

Children learn during play through all their senses, taste, touch, vision, hearing, smell and proprioception (awareness of the position in space, and of the relation to the rest of the body). They will watch those around them and copy language and behaviour. It's important that learning through play is fun at any age and it needs to be about doing things with them that they like.

So how do we support learning through play when our child has more complex needs? We need to look at the three key areas that impact learning.

OUR CHILD

It is vital that we know what a child can achieve and what impacts a child's ability to engage in play, for example, limited vision, reduced hand dexterity, reduced communication, poor skin integrity, cognitive abilities or behavioural challenges.

A full assessment of their abilities is essential to know how to modify or adapt play or provide essential equipment to support fun and purposeful activities and promote full engagement in learning through play.

THE PLAY ACTIVITY (often referred to in occupational therapy as the occupation)

We need to understand how we can break down the play activity into smaller parts to allow children to access the activity, to reward and praise achievements however small.

Most importantly we need to have the toys that promote learning.

THE ENVIRONMENT

We need to have an environment that allows children to play with parents/carers but also their siblings and other children.

> "As a society we have a duty to support our children to access play that is age appropriate and suitable for their individual needs"

The environment is often the easiest element of the three key areas above that can be adapted to meet a child's needs and there are non-means tested grants available via the Disabled Facilities Grant (DFG)[2] to support environmental changes, which can fund works up to £30,000 (England) and £36,000 (Wales).

The DFG has 13 specific areas that you can seek financial support to adapt your home, for example one area states grant funding is available for:

'Facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a bath, shower (or both), or facilitating the use of the disabled occupant of such a facility'.

Bathing is a key area in the home where children can play, it allows a child to potentially play with their siblings, it can be part of playtime with dad and can also be used to wash a child through fun play activities.

By refusing funding for a suitable bath, a child with complex needs maybe missing out on an essential environment that promotes learning through play and therefore would not meet the requirements of The Children's Act 1989, which clearly states:

'Requires that Local Authorities provide services to minimise the effect on disabled children of their disabilities and give such children the opportunity to lead lives which are as normal as possible'.

Another example is access to the garden. An outdoor space is also a key environment for learning through play and the legislation states:

'Facilitating access to and from a garden, or making a garden safe'.

If your property has a garden, then all endeavours must be made to make part of it accessible for a child with additional needs.

So my challenge to you as parents, carers and occupational therapists, let's use the legislation, as a tool to advocate for our children's development and not accept policies that restrict our children from achieving their potential.

The right to play is fundamental to our children's future health and wellbeing.

If you want to hear more on the 'Right to Play' Kate Sheehan is delivering a free seminar at the Kidz to Adultz shows and she would be willing to answer any questions or queries you may have.

www.theotservice.co.uk

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[1] www.unicef.org.uk/what-we-do/un-convention-child-rights

[2] www.gov.uk/disabled-facilities-grants

Low cost CLOTHING ADAPTATIONS MAKE A DIFFERENCE

DRESSABILITY IS A SMALL CHARITY BASED IN SWINDON OFFERING A LOW-COST CLOTHING ADAPTATION AND ALTERATION SERVICE TO BOTH CHILDREN AND ADULTS WITH DISABILITIES

Manager Sharon Tombs explains about the service: "Our aim is to make dressing and undressing quicker and easier. This could mean replacing buttons with Velcro and magnets, or adding new or alternative fastenings to work around a wheelchair. Our team of highly skilled dressmakers can provide advice and information on alterations and adaptations to suit individual requirements."

She added: "We provide free home visits within a 25 mile radius of Swindon together with a postal service for those further afield."

Harry is one of the children who has been helped by the charity. Harry is 10 and has a diagnosis of Asperger's Syndrome with anxiety. Part of Harry's condition is a severe sensitivity to wearing clothing that fits snugly around his waist, making school uniform requirements a challenge. When forced to wear trousers, Harry's anxiety causes him difficulties concentrating or being able to settle and inevitably he was experiencing difficulties and becoming very unhappy in school, with impact on his learning and that of his peers.

Denim dungarees, in which Harry felt relaxed and comfortable, represented a solution at home and Harry's parents approached Dressability to ask whether dungarees could be made to comply with school uniform requirements.

The answer was yes and Harry is now able to wear the uniform in a format that allows him to feel relaxed and happy. Feedback from the school indicates a huge improvement.

"I cannot thank Dressability enough" Harry's mum says. "Although Harry's Asperger's and Anxiety are still challenging, the sensory issues with his clothing have been solved by the hard work of the Dressability team." In fact, Harry loves his dungarees so much that he now wears them all the time - even when he is not at School."

Another success story is Rachel, who was born in 2004 with high muscle tone Cerebral Palsy and has a global learning delay. Rachel is unable to talk or operate a normal or electric wheelchair - meaning her only means of independent mobility is crawling on her knees - which she loves to do – never missing an opportunity to venture out into the garden. However, Rachel's jeans were unable to withstand the impact of her crawling for very long meaning regular replacement was required - and she was experiencing problems with very sore knees.

Rachel's mum approached Dressability for advice, who suggested adding padding and hard wearing knee patches to her jeans. Specialist materials were identified to provide an ideal solution.

Rachel's mum summed up the adaptations made by the Charity as "small things that make a massive difference" which encapsulates Dressability's simple aim, which is to make people's lives better by making their clothes work for them.

You can contact Dressability on 01793 512878 or 07754105297. www.dressability.org.uk

Action video game

USED IN AUTISM RESEARCH

RESEARCHERS AT CHILDREN'S HOSPITAL OF PHILADELPHIA (CHOP) HAVE EVALUATED A DIGITAL MEDICINE TOOL DESIGNED AS AN INVESTIGATIONAL TREATMENT FOR CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) AND CO-OCCURRING ATTENTION/DEFICIT-HYPERACTIVITY DISORDER (ADHD)

The Project: EVO delivers sensory and motor stimuli through an action video game experience. Both parents and children reported that the treatment had value for improving a child's ability to pay attention.

The results of the study, published in the Journal of Autism and Developmental Disorders, confirmed the acceptability, feasibility and safety of Project: EVO, which delivers sensory and motor stimuli through an action video game experience, designed by Akili Interactive, a prescription digital medicine company.

As many as 50 percent of children with ASD have some ADHD symptoms, with roughly 30 percent receiving a secondary diagnosis of ADHD. However, since ADHD medications are less effective in children with both disorders than in those with only ADHD, researchers are exploring alternative treatments.

Children with ASD and ADHD symptoms are also at high risk for impaired "cognitive function," including the brain's ability to maintain attention and focus on goals while ignoring distractions. As children reach school age and beyond, these cognitive impairments make it more difficult for them to set and achieve goals, as well as successfully navigate the demands of day-to-day life in the community.

Both parents and children reported that the treatment had value for improving a child's ability to pay attention and served as a worthwhile approach for treatment. The study also found that after using Project: EVO, children showed a trend toward improved attention on the TOVA API score, and they showed general ADHD symptom improvement based on parent reports.

Image courtesy of Akili Interactive Labs

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THE WORLD IS WONDERFUL WITH A Wizzybug

SIENNA, TWO, WAS BORN VERY PREMATURELY. SIENNA WAS DIAGNOSED WITH QUADRIPLEGIC CEREBRAL PALSY WHICH WAS PREVENTING HER FROM MOVING AROUND INDEPENDENTLY. SHE WOULD WATCH HER TWIN SISTER, LYRA, MOVING AROUND A ROOM WITH EASE BUT WAS UNABLE TO DO THE SAME

The charity Designability gave Sienna a free Wizzybug through their loan scheme when she was just 18 months old.

She took to her new companion well and named it 'Winnie'. It took a little bit of time to get to grips with how to use Wizzybug, but now she's learning some great skills, as her dad said: "To begin with she was limited to going around and around in circles in the back garden churning up the lawn, which she thought was hilarious."

"During the last 7 months Sienna has become extremely proficient and skillful in her Wizzybug. Something has just 'clicked' with her – she can go virtually anywhere in it, from going over cobblestone paths to driving through narrow doorways."

Designability designed Wizzybugs with children in mind. They wanted them to look fun and desirable and nothing like a clinical wheelchair. It needed to be something that children would be happy and proud to use.

Sienna's dad added: "Sienna gets a huge amount of attention when she is out and about in Winnie. It has enabled her to explore her surroundings, interact with other children and develop her spatial awareness."

Designability is a national assistive technology charity that changes the lives of disabled people. Their team of designers and engineers create products which make a difference, including the Wizzybug powered wheelchair for under 5s.

If you would like to find out more about how to get a free Wizzybug through the loan scheme, please visit https://designability.org.uk/meet-wizzybug/ call 01225 824103 or email wizzybug@designability.org.uk

You will find Designability and their Wizzybugs at Kidz to Adultz South on Thursday 16th May 2019 and Kidz to Adultz North on Thursday 14th November 2019.

Think Wheelchairs Think SMART

At SMART Wheelchairs we are able to meet and accommodate the needs of some of the most complex disabilities. Our aims and objectives are to provide as much independent access for all of our customers by using the latest technology and equipment available.

Here at SMART we believe we're best equipped to deal with your needs. From electric and manual wheelchairs, specialist seating systems that deal with a wide range of conditions to control systems that allow the user to control anything from a light switch to a PC or even a Sky TV Box.

We realise that everybody is an individual and that is why all our chairs are tailored to you, the individual. Our aim is to provide each client with maximum comfort and functionality.

You can rest assured that SMART will only recommend the right wheelchair or equipment that is best suited for our customer's needs.

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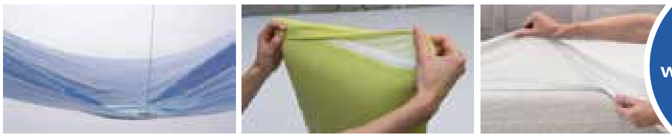

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SEN TRANSPORT through the ages...

WHAT YOU NEED TO KNOW ABOUT POST-16 AND POST-19 TRANSPORT ARRANGEMENTS, BY STEVEN BAYLIS, SOLICITOR, PUBLIC LAW AND HUMAN RIGHTS, IRWIN MITCHELL LLP

Transport provision for young people with special educational needs ('SEN') has become an increasingly contentious area recently. Many councils are altering or proposing to alter their transport arrangements for one or both of these age groups, leading to concern from many parents about how their child will continue to participate in education.

POST-16

Since the government introduced the 'Raised Participation Age' young people are required to remain in education or training until they are 18 years of age. For many young people with SEN the practical effect of this is that they continue to attend the same school at the end of Year 11 as they then attend in Year 12. However, whilst they were entitled to, and receiving, free transport as a child of compulsory school age when in Year 11, there is not an automatic entitlement to the same transport provision when starting Year 12. This is having a significant effect, both in the type of provision available and the cost of transport.

The law requires councils to prepare a transport statement for each academic year specifying "the provision of transport or otherwise that the authority consider it necessary to make". The Department for Education published updated statutory guidance 'Post-16 transport to education and training' in January 2019. This sets out the matters to which councils must have regard to when assessing what transport or financial assistance is required.

The wording of the statutory guidance has led some councils to alter their transport offer to young people in post-16 education. Whilst the current legislation allows councils discretion as to the specific arrangements that they will make, be it actual transport provision or financial assistance, it will be important for each council to consider whether its policy may potentially discriminate against young people on the basis of age and/or a disability. For young people who require specialist transport provision, for example a wheelchair accessible vehicle, the provision of a Personal Transport Budget (a financial arrangement) instead of a wheelchair accessible bus (a transport arrangement), could be unsuitable.

It is not unusual for councils to charge young people and their families for transport, whether or not the council is directly arranging the transport or providing financial assistance. Although the statutory guidance permits councils to seek a contribution towards the cost of transport, charging for transport is a discretion, not a requirement for councils. Councils must exercise their discretion if seeking a contribution and ensure that, where a contribution is sought, it is affordable and that families who are considered to be of 'low income' are supported. Councils must also ensure that their policy does not adversely impact on particular groups, including for example, young people with SEN and/or disabilities.

If councils implement policies and/or individual decisions which are unlawful these can be susceptible to a legal challenge. Even if councils consider that they are following the statutory guidance this may not be sufficient as such policies and decisions may be discriminatory or otherwise reached unlawfully, for example, failing to consider the relevant evidence and reach a rational decision. For parents and young people applying for transport it will be important that they provide their council with all relevant information about the young person's SEN and/or disability, and information about why any specific transport arrangements they are seeking are required, taking into account not only the young person's needs but also any wider implications on the family if such provision is not arranged.

> "If councils implement policies and/or individual decisions which are unlawful these can be susceptible to a legal challenge"

POST-19

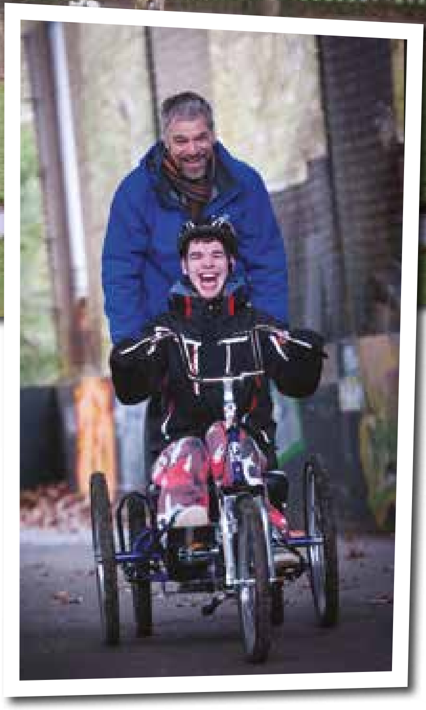
Transport provision for adults who are in post-19 education will be determined by whether a council considers that it is necessary to make transport arrangements. Where a council determines that provision of transport, or otherwise, is necessary for a young person this must be provided free of charge.

Whether transport is 'necessary' is not subject to a statutory definition. Therefore, where an adult seeks transport provision to enable them to attend the education or training provider the relevant council will need to decide whether such transport is necessary by consideration of factors which the council will need to determine. Some factors are identified in statute, including the adult's age and the nature of the route or alternative routes which the adult could reasonably be expected to take. Councils would also be expected to take into consideration whether the adult has SEN and/or disabilities. As with decisions in relation to post-16 provision, any decision made by the council which is unlawful can be subject to legal challenge.

Any person concerned about the lawfulness of their council's transport policy or individual decision should seek legal advice from specialist solicitors at the earliest possible opportunity to consider the options available to them. Legal aid may be available for such advice.

You can contact the company at www.irwinmitchell.com

Tom's trike
TRANSFORMED



LIKE MANY TEENAGERS, TOM HAS A REAL 'NEED FOR SPEED' AND RECENTLY GOT A THERAPLAY TRACER TRIKE WHICH GIVES HIM A LOT OF FUN AND MUCH NEEDED REHABILITATION AFTER MAJOR LEG SURGERY

Tom's learning difficulty makes it hard for him to perceive danger so it's not safe for him to cycle independently in most situations. Tom's parents turned to Remap for help – could the charity modify his trike to make it safer?

Mum Sharon says: "We have previously had carer control trikes but Tom is too strong and too fast for us and we can't keep up. So we asked Remap if they could build a hop on buggy-board type arrangement that would allow us to keep him safe and to tackle more exciting terrain, by helping him on the tough bits".

Remap West Midlands discussed the family's requirements and built them a special trike trailer. Handlebars and brakes are provided for the passenger who stands behind Tom and is able to assist or brake if needed. The trailer can be quickly detached when not being used and for transport purposes.

Remap is a UK charity that helps disabled people of all ages to live more independent lives by designing and making customised equipment free of charge. For examples of Remap's work, visit the case studies section of their website. To find out more, simply contact the national office or find your local group through the website.

Call 01732 760209, email data@remap.org.uk or visit www.remap.org.uk

Motability
The leading car scheme for disabled people

Making life easier
for disabled people

> "Our Motability Scheme car helps us get to and from hospital with ease."
>
> Marcelle, Samuel's mum

The Motability Scheme enables disabled people to lease a new **car, scooter** or **powered wheelchair** without the worry of owning and running one. Parents and carers can drive on behalf of the customer. The vehicle should be used by, or for the benefit of, the disabled person.

Who can join the Motability Scheme?

You may be eligible to join the Scheme if you receive one of the following:

- Higher Rate Mobility Component of Disability Living Allowance (DLA).
- Enhanced Rate of the Mobility Component of Personal Independence Payment (PIP).
- War Pensioners' Mobility Supplement (WPMS).
- Armed Forces Independence Payment (AFIP).

What's included on the Motability Scheme?

- ✓ Insurance
- ✓ Breakdown assistance
- ✓ Servicing and repairs
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Charitable Grants

Motability may be able to provide a charitable grant towards the cost of a Scheme vehicle, adaptations for a Scheme vehicle or driving lessons.

For more information, visit **motability.org.uk/charitable-grants**

Sign up today for your FREE information pack

motability.org.uk/kidz or call **0300 123 3367** (quote Kidz)

Motability is a Registered Charity in England and Wales (No.299745) and is authorised and regulated by the Financial Conduct Authority (Reference No. 736309). The Motability Scheme is operated by Motability Operations Limited under contract to Motability. Motability Operations Limited is authorised and regulated by the Financial Conduct Authority (Reference No.735390).

A PARENT'S GUIDE TO

moving

& handling

AFTER A SIGNIFICANT ILLNESS OR INJURY AN INDIVIDUAL'S ABILITY TO MOVE INDEPENDENTLY AND FREELY WITHIN THEIR ENVIRONMENT CAN BE COMPROMISED

They may require assistance either from a person or from equipment to facilitate this. It is this movement with support that is often referred to by professionals as 'moving and handling'. The movements that an individual may need or wish to do are called 'transfers' and examples of these include moving around the bed, moving from the bed into a wheelchair or shower chair, getting on and off the toilet or in and out of the car. These are all movements that can require extra support and therefore have moving and handling considerations.

This article aims to demystify some of the language that you may hear around the moving and handling of your child and provide some insight into the process that you may go through to ensure that your child's transfers are carried out as safely as possible.

WHAT IS A MOVING AND HANDLING ASSESSMENT?

You may well hear the words 'moving and handling assessment' used by your case manager or other health care professionals involved with your child's care. A moving and handling assessment is a process where a professional who is knowledgeable and skilled in moving and handling practices will visit your home and look at the movement or 'transfers' that you and your child wish to complete to find the safest and easiest way of doing them for all involved.

The assessment should be carried out by a registered health care professional such as an occupational therapist. During their visit they will be looking at the home environment to look at the space available for safe movement, they will be considering the medical needs of your child, and observing you if you are completing any of the transfers. They will also ask questions about the care package that your child may have and their daily routine.

Moving and handling does not just take place within the home, and during the assessment the assessor will discuss your child's transfer needs in environments such as school or college, leisure activities and within the general community.

After the assessment you or your case manager will receive a report with all of the transfers discussed and any potential risks highlighted. From here any solutions to mitigate these risks will be provided.

Potential solutions may include the use of some equipment such as height adjustable beds, shower chairs or hoists. It might also include recommendations for possible changes to the home environment such as level access shower rooms, home lifts or even extensions to create additional space. Recommendations are also likely to include changes in physical techniques used.

If anything new is to be implemented, there should also be a recommendation of training for yourself or other carers to ensure that you receive the support required to implement the recommended changes safely.

The use of the recommended equipment and techniques will be summarised in a moving and handling plan. This document is personalised for your child, home and the transfers bespoke for their routine. The aim of a moving and handling plan is to ensure that your child receives consistent and safe movement and handling.

HOW DO I INITIATE A MOVING AND HANDLING ASSESSMENT FOR MY CHILD?

Initially these assessments can be requested by a member of your care team or yourself if you are finding some of the transfers with your child challenging. The assessments are available through your local social care team or privately.

Once a moving and handling plan is established it will need to be reviewed in the following circumstances:

- Should you or your child's needs change in any way.
- There are any changes to your environment such as moving house.
- Routinely every 6-12 months during the time that your child is growing, as equipment such as slings may need to be reordered in a larger size.

ABOUT THE OT PRACTICE

The OT Practice provide children's occupational therapists nationally to work with children and their families in their own homes and community settings. We are proud to have the largest network of paediatric OT's in the UK covering all specialisms including moving and handling, housing, seating and sensory development.

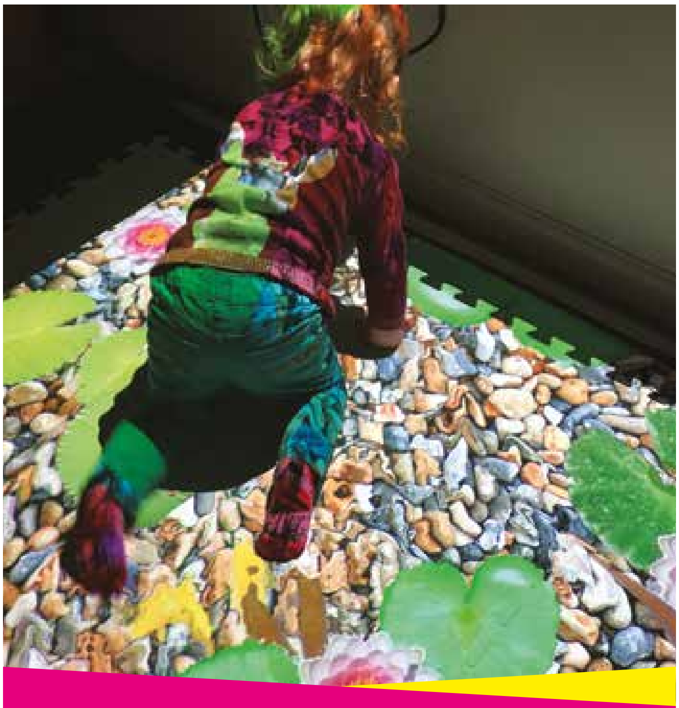
The website is at www.theotpractice.co.uk

DON'T MISS OUT ON FUTURE ISSUES OF OUR BRAND NEW MAGAZINE

If you can't get to the shows, then you can still get all the news by reading the Kidz to Adultz magazine online

The next issue will appear in May

Just go to **www.kidzexhibitions.co.uk** to have a read!



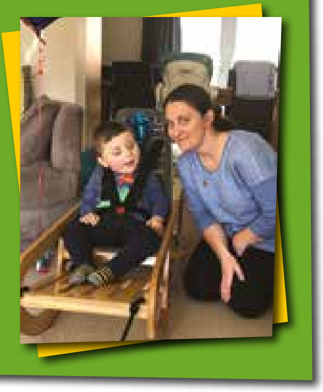
And the winner is...

We had a fantastic response to the competition we ran in the launch issue of the magazine to win a stylish Cerebra Sledge. The winner was 2 year old Efan Williams.

Efan was diagnosed with Quadriplegic Cerebral Palsy at 7 months old. Having this condition comes with many others for Efan such as Global Development Delay, Dysphagia and being non-verbal. But this doesn't stop him being a happy little boy and an adrenaline junkie!

Speaking to his mum Sarah at their home in Denbighshire, she said that Efan loves to be outside and has special riding lessons which helps with his therapy and building core muscles.

Sarah is over the moon with the sledge, there is nothing else on the market like this and she feels that this will now give Efan the chance to participate with others in the snow as the sledge supports him very well, and will allow the family to enjoy the experience with him and will give the family years of joy.



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Win!

Jazz up YOUR WHEELCHAIR!

WIN A PAIR OF YOUR OWN SPECIAL SPOKEGUARDS!

If you fancy personalising a wheelchair with a pair of jazzy and individual spokeguards, then here's an opportunity to do it for free.

We have a pair of your own designed spokeguards to give away, courtesy of Frank and Hilary Rodgers who started the Spokeguards company a few years ago after the idea to brighten up wheelchairs came to them after a visit to a fashion show featuring disabled models.

Frank told us: "The models' clothes were colourful, the make-up magnificent and the hair styling superb. However, in contrast, the wheelchairs were predominately black or grey, hence the idea to produce something special for wheelchair users."

By far the most popular design sold to date is the option where clients send in their own design to print and truly personalise their own wheelchair and that's what we are offering one lucky reader who can design their own spokeguards.

All you have to do to be in with a chance of having a pair of your own designed spokeguards worth over £100.00, is to email magazine@disabledliving.co.uk with your name and contact details by Tuesday April 30th 2019.

One lucky reader will be selected and in just a few weeks' time will have some very special spokeguards for their wheelchair.

For more information about the company and to see some of the designs that have already been produced for customers, go to www.spokeguards.co.uk

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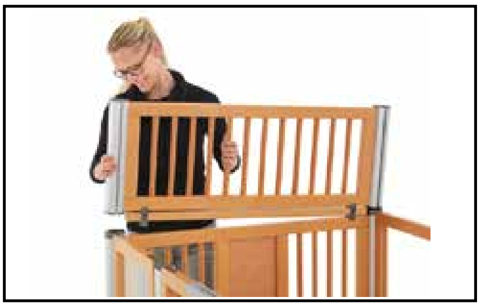

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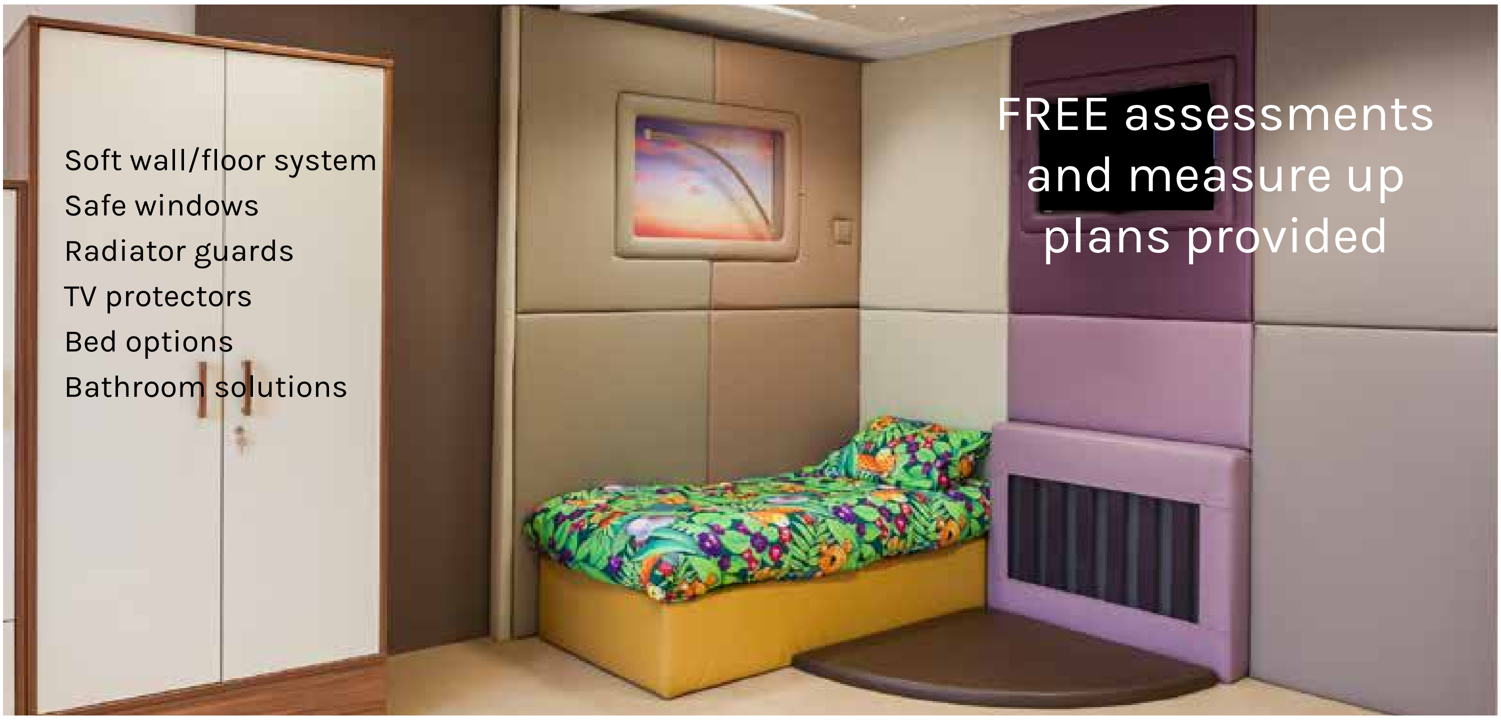

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FREE assessments and measure up plans provided

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Tel: 01609 785360 info@carebase.net

Sophie has benefitted from support from Rett UK

OUR AAC JOURNEY AND AN AMAZING future

BY JULIE MASON

My daughter, Sophie, is 17 years old and started her AAC journey two years ago when a local charity came into school to assess Sophie's suitability for using eye tracking technology.

It could not have gone better as Sophie understood immediately she was in control as she flung custard pies at the faces that appeared on the screen. The school secured a large 32" screen static device for Sophie. The future was amazing, and our hopes were high. At the end of each term I would dismantle the device and bring it home for the holidays.

At first Sophie was thrilled with playing games to practice using the eye tracking. Each holiday I would watch Sophie become less engaged and bored playing games on the device. There was no progression to more challenging programmes or communication and I was at a loss who to turn to. Sophie was the first and only child with this technology in the school and staff had no previous experience to help. It was at this point an email from Rett UK arrived…

My husband and I signed up for the October Getting Started with AAC course. I didn't allow myself to get too excited considering our previous experience. That completely changed as the first day unfolded. Callie and Emily are wonderful tutors, starting with the basics and explaining everything so clearly with the help of slides, videos and hand-outs. I never felt out of my depth at any point. I did however feel a tumult of emotions, shame – why didn't I know this already? Guilt – why wasn't I doing this with Sophie? Foolish – why did I put my trust in the 'experts'? Euphoria – the future is amazing (even though I'd been there before!). We rushed home to put our learning into practice.

We started at the beginning with the 'best yes'. Sophie has a confusing array of ‘no’s’. A firm ‘no’ for no. A cheeky ‘no’ for maybe and a weak ‘no’ for yes. We videoed our conversations with Sophie, which was an awkward hurdle to get over at first.

We have recorded and watched so many conversations with Sophie I’m now completely comfortable watching myself and listening to my Liverpool accent. Scouse AAC! Watching the videos over and over we spotted a blink before Sophie answers with her exaggerated no’s. We tried asking Sophie questions and saying ‘you blinked was that a yes?’ as soon as she blinked and before she started to shake her head.

Literally overnight we had secured a ‘best yes’ and Sophie was so relieved. Our only problem now was Sophie had dropped all her exaggerated movements and her yes and no was so subtle we have to look very closely.

We were given a communication record sheet to complete during the term of the loan device. This could have been a chore to be quite honest but reading it back it’s hilarious. I’m clearly over excitable about using the device and was repeatedly put in my place by Sophie. I have dreamed of conversations with my daughter but they hadn’t included the phrases ‘please stop talking’ and ‘I need a break’. Neither was I prepared for the pain of brutal honesty from Sophie when she said she was mad with Dad for not taking part in a conversation and how bored she was of school work (I will expand on this).

We were encouraged to use low tech aids and were given laminated sheets of words and symbols along with a booklet. I was less interested in these low-tech aides initially, but they proved their weight in gold. On arriving at her grandparents’ house Sophie became upset so we tried the booklet which we had hung on a string to her wheelchair. Selecting the help page using partner assisted scanning (I can use this term smugly as I learnt what it meant on the course), Sophie told us she was thirsty. It took less than a minute to securely understand what Sophie needed than go through a protracted process of elimination and maybe not get the right answer. The low-tech aides have become my preferred option when Sophie is upset as they are so quick to use.

The day we returned the device was bitter sweet. Worried how we are going to secure a high-tech device for Sophie without giving everyone IOU’s for Christmas weighs heavy on our minds. We took Sophie with us to visit Callie at Rett UK, to give her an opportunity to thank her and show off her new skills.

> “I had worried in the past if I was treating Sophie like a baby for referring to myself as Mummy, but I am proud to say Mummy is my title”

Whilst at the meeting we chatted about literacy and how I suspected Sophie could read but I had no idea how to confirm this. To my shame I had previously suggested to Sophie she wasn’t able to read and she had become very upset. Callie simply asked Sophie ‘do you read some words as well as looking at the picture? Sophie replied with a clear ‘yes’.

Callie produced an alphabet booklet and asked Sophie would she like to spell. ‘Yes’ came the next reply. I held my breath whilst Callie showed Sophie the pages of letters. M. U. M. blinked Sophie, and Callie wrote the letters. I thought my chest would explode with pride. My daughter’s first written word was Mum. Callie asked if Sophie wanted to continue, an E was added to make 'mume’. A phonetic ‘Mummy’! I had worried in the past if I was treating Sophie like a baby for referring to myself as Mummy, but I am proud to say Mummy is my title.

Sophie was exhausted but wanted to continue. Sophie’s second word was ‘daad’ (Dad). My daughter can read and spell. Clearly when Sophie told us school work bored her, she was not being cheeky but honest. She is capable of so much more and is not being challenged. Looking back on the Class Dojo communication App we use with school it is painful to see Sophie looking bored in so many photographs.

Part of me feels that I should hang my head in shame for not knowing my daughters’ capabilities, but I am elated and looking forward to our amazing future. That future starts with the urgently arranged meeting with school where Sophie’s Education and Health Care Plan will be torn up, especially the bit about twenty minutes of eye gaze per day.

For more information, visit www.rettuk.org or call 01582 798910.

MORE ABOUT RETT UK

Rett UK is a small, Luton based charity supporting anyone affected by Rett syndrome, wherever they live in the UK.
Rett syndrome is a rare, neurological disorder that mainly affects females. After a period of near normal development, children regress around the age of 12-18 months, losing key skills including the ability to walk, talk and feed themselves. Many other health problems then emerge; epilepsy, scoliosis, breathing problems to name just a few. People with Rett syndrome need 24/7 care for the rest of their lives.
Rett UK’s vision is that everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

Campaigning against cuts

RESEARCH HIGHLIGHTS THE IMPACT OF UNIVERSAL CREDIT CHANGES

Contact, the charity for families with disabled children has been campaigning against cuts to financial support under Universal Credit affecting the families they support.

The government's own analysis of the impact of Universal Credit estimates that 100,000 families with disabled children will be worse off by more than £1,750 per year as a result of the 50% cut to the child disability payment under Universal Credit. That's £175 million less going towards helping disabled children with their extra care costs.

Una Summerson, Head of Campaigns at Contact, said: "It costs more to raise a disabled child and families often can't work as much as they would like, due to their caring responsibilities. Families with disabled children who'll be affected by reduced financial support under Universal Credit are already struggling to afford basics. A cut of more than £1,750 a year is likely to result in increased debt, stress and ill health."

"Following a legal challenge in 2018, the Secretary of State for Work and Pensions announced disabled adults who are facing cuts in payments when moving onto Universal Credit will be protected. We are campaigning for the same protections for disabled children because that is only fair."

Together with affected families and supporters, Contact's Universal Credit campaign has:

- Launched research – Counting the Costs 2018 – highlighting the impact of Universal Credit cuts to families with disabled children.
- Secured the support of MP Caroline Lucas. She has tabled an Early Day Motion to draw the government's attention to these Universal Credit cuts, which has secured the backing of 95 MPs.
- Delivered a 5,000 strong petition calling for a reversal of the cuts to Downing Street.

> "A cut of more than £1,750 a year is likely to result in increased debt, stress and ill health"

Lisa Keyte from Eastbourne, mum to eight-year-old Finley who has autism and bowel problems, said: "Because of a change in circumstances I was transferred onto Universal Credit and it's had a massive impact. Initially I had to wait 6 weeks for my claim to be processed and now the amounts I receive vary wildly each month. It makes it difficult to budget and ensure Finley gets what he needs to keep him healthy. I used to be able to pay for respite care for Finley to give him independence. And I used to buy sensory toys to help Finley's development and reduce his anxiety. I can't afford them now. I'm trying to do my best for my son, but moving onto Universal Credit has hit us really hard."


Left to right: Louis and Marie Collins, Zoe and Kathleen Max-Lino handing in Contact's Universal Credit petition to Downing Street

The government has announced delaying the roll out of Universal Credit to some people. However it is still likely that many tens of thousands of families will have to claim during 2019.

Natural migration - when a family has a change of circumstances, such as moving house, separating from a partner or losing a job - will continue as normal. Managed migration – for all other people in receipt of means tested benefits and tax credits - has been delayed, except for a sample of 10,000 claimants being migrated during 2019. The government says it still expects to have moved all three million existing claimants of means tested benefits and tax credits onto Universal Credit by the end of 2023.

Families with disabled children affected by Universal Credit can call the Contact Freephone helpline for advice: 0808 808 3555 or visit the relevant web page www.contact.org.uk/universal-credit.

You can become a campaign supporter for Contact at www.contact.org.uk/campaigning

LOOKING AFTER you!

SELF-CARE FOR PARENT-CARERS BY JOANNA GRIFFIN

Being a parent is a demanding as well as a rewarding experience. When your child is disabled there can be additional challenges and pressures on your time and emotional resources. Often we, as parent-carers, are at the bottom of the pile when it comes to having our emotional needs met.

It is important to recognise times when you require extra support to avoid everyday stress becoming a longer-term mental health issue. As well as the 'basics' – exercise, eat well and get enough sleep - I outline some further ways you can support your own emotional well-being below:

FIND A SUPPORT NETWORK

Parents of disabled children often report feeling isolated and not part of the 'mainstream'. They may feel like the odd one out at playgroups and coffee mornings, despite other parents often wanting to help but not knowing how. Finding your own community of like-minded families can be a key factor in reducing isolation and realising you are not alone. It is worth contacting organisations such as Contact, Mencap or Scope as well as your nearest Children's Centre to find out if there are groups near you. Research also suggests there are benefits to our self-esteem and wellbeing in supporting others.[1]

Many parents turn to social media such as special needs Facebook groups to connect with others in a similar situation. There may be times, however, when you would benefit from speaking to a trained professional who has experience of supporting parent carers in a similar situation. You can find relevant organisations and practitioners at www.affinityhub.uk.

CHANGE HOW WE RESPOND

There are times when we can't change the situation in which we find ourselves. When this happens all we can do is work on changing our response rather than keep banging our head against a brick wall. Mindfulness and Acceptance and Commitment Therapy are examples of how you can start to become more aware of your automatic, and sometimes unhelpful, responses and see that 'thoughts' are not the same as 'facts'.

> "There are times when no matter what strategies you put in place, you just need a break"

While mindfulness can appear hard work at first and seem alien to how we normally live our busy lives if you practice it can become an easily accessible way to manage your emotional needs in times of stress say, for example, by focusing on our breathing and being more present.

Apps can make it easier to do, such as Be Mindful Online, Headspace or Calm which provide useful reminders to practice.

HAVE A BREAK

There are times when no matter what strategies you put in place, you just need a break. Plan and do something special for you; a night out with friends, or watching a favourite programme uninterrupted. It could be something simple like buying yourself a special mug for a cup of tea, one that makes you feel nurtured and reminds you to take time for yourself. Short Breaks or Carers' Needs Assessments may help you access more formal support.

TIME

One of the most common reasons that people find it hard to stick to self-care activities is because of time restraints. Life is busy, there are constant demands on our time, household chores, appointments to arrange. However, we have to realise that no one else is going to make the time for us, we have to take responsibility for re-connecting with who we are beyond our 'carer' identity. This involves recognising that we deserve some time and space for ourselves.

Joanna Griffin is a Chartered Counselling Psychologist, mum to an 11 year old son who has cerebral palsy and learning disability. She is also the Founder of www.affinityhub.uk which signposts to emotional support for parent carers. Follow here www.facebook.com/affinityhub.uk, www.twitter.com/affinityhub_uk

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[1] Shilling, V., Bailey, S., Logan, S. & Morris, C. (2014) Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study, Peninsula Cerebra Research Unit and NIHR PenCLAHRC, University of Exeter Medical School, Exeter, UK

COLLABORATION AIMS TO HELP PARENTS UNDERSTAND THEIR RIGHTS

The British Healthcare Trades Association (BHTA) has been working with Newlife charity for over a year to look at how they can help the parents of disabled children get the information they need to help their child get essential equipment.

Newlife, the Charity for Disabled Children, commissioned a report by Barristers, In the Matter of Provision for Disabled Children, interpreting what the law says about the rights of disabled children to equipment, and who is responsible for the funding.

The BHTA came up with the idea of producing an easy to read leaflet for families, to help them understand what legal rights their child has to funding for equipment which will help them live life more fully. The result of this project is the ‘Help for Families – Your Legal Rights in Getting Help for Your Disabled Child’ leaflet.

The leaflet explains about rights in plain English and will help parents to understand which laws can help them, who is legally responsible for providing what for their child and who they can go to for help if their child is not receiving what they are legally entitled to.

Clare Dangerfield, Policy Development Manager for Newlife said: “It is clear that disabled children are in crisis; often unable to get the equipment they desperately need. We hope that by working with national and local decision makers, alongside the BHTA, we can implement the four-point-plan to improve equipment services.”

Jill Morony who chairs the Children’s Equipment Section of the BHTA and who has been leading the work on the document said: “Families contact us on a regular basis who are confused about whether they are entitled to funding, and if so which agency is responsible for providing it. Some families are under the impression or have been told wrongly that a learning disability does not qualify as a disability eligible for equipment funding. The Newlife Barrister Report clarifies where the legal responsibility lies.”

You can read the leaflet at http://bhta.com/bhta-campaigns. To request a copy of the leaflet, call 01933 272437

It’s showtime!

kidz to ADULTZ EVENTS

SAVE THE DATES FOR OUR FUTURE EVENTS…

SOUTH

Thursday 16th May 2019
Farnborough International Exhibition & Conference Centre, Farnborough

NORTH

Thursday 14th November 2019
EventCity, Manchester

WALES & WEST

Thursday 4th July 2019
Thornbury Leisure Centre, Bristol

MIDDLE

Thursday 19th March 2020
Ricoh Arena, Coventry

PUSHCHAIR IN THE SPOTLIGHT: Snappi Cloud

TOO OFTEN DESIGN AND DEVELOPMENT ARE OVERLOOKED WHEN A PRODUCT FULFILS A SPECIFIC NEED

If it does what it's supposed to do, why bother improving it? But what if you didn't have to just 'make do'? what if you could combine design-innovation with enhanced usability? Introducing the latest in pushchair-innovation: the Snappi Cloud.

With the Snappi Cloud, gone are all preconceived notions about the appearance of special needs buggies. This is a buggy which mirrors high-street luxury; a buggy to show off; a buggy which embraces both functionality and design. Its pioneering oval frame has been specifically designed and manufactured for the special needs market. Consequently, this ensures you receive a cutting-edge design without having to compromise on features or functionality.

Oval frame has in recent years become synonymous with high-end, high-street pushchairs. It epitomises contemporary, style and sophistication. Whilst aesthetics are undeniably important - after all who would want to encourage a resurgence of the clinical, bulky buggies of the past? It is imperative to remember this is a specialised pushchair and so mustn't lose sight of its primary purpose – to be a supportive seating system. This is where the Snappi Cloud really shines, it manages to successfully combine an abundance of features and postural aids in an attractive, state-of-the-art shell.

This buggy has a whole host of features including tilt in space; back recline; an incredibly high weight capacity; an extensive range of growth (from a teeny tiny five-and-a-half-inch seat depth); and height adjustable push handles to name just a few. What is particularly clever about its tilt and recline functions are these are without fixed positions meaning you can position the occupant at any point within this range as opposed to in a pre-determined slot.

The Snappi Cloud is a buggy designed to adapt to you and not the other way around! As such, it can be fully customised from top to bottom. Examples of such adaptations include pressure relief covers, bespoke headrests, dynamic back / footrest options, front locking castors etc.

To summerise, the Snappi Cloud is an exciting development in the field of specialised pushchairs and seating systems. It successfully navigates the tricky tightrope of fashion and function to become a product which is not only genuinely eye-catching but perfectly practical.

For more information, visit www.tendercareltd.com

‘HURTLING DOWN AN unmarked road’

THE STORY OF ONE MOTHER’S EXPERIENCE

In 2005, Rachel Wright’s son was born with a bump. He didn’t breathe on delivery and was diagnosed ten weeks later with having severe brain damage.

She says that, from then, she and her husband “hurtled down an unmarked road of loving a child with complex disabilities and life-limiting epilepsy.”

Today, Rachel uses her memories, experiences and skills to support families like hers and inform the practitioners who care for them. She has also written a book about her experiences.

Here is Rachel’s story....

“I’m afraid it isn’t good news.”

The doctor stood perched with her back against a desk, the glare of an MRI scan casting a shadow on the wall. My eyes flicked between my seemingly perfect 10-week old in a pushchair, across to the MRI and then comforting face of the consultant. Her carefully considered and well-crafted words became white noise as my mind reeled with questions.

How had I let this happen? How had I carried on living with the baby inside me suffering? What kind of mother was I?

Despite our son’s traumatic entrance to the world I was still deeply shocked by the MRI results less than three months later. The news of his severe brain damage

> “It’s a long road to acceptance and I certainly haven’t arrived; adaptation is the best I can do for now”

and resulting complex disabilities changed our lives. The world looked different and nothing felt the same.

I wandered around as a stupefied first-time mum. Not only was I fighting the midnight tide of feeding, vomit and poo, but soon my medical expertise as a nurse came in handy. I needed to arrange appointments, communicate with professionals and undertake various therapies at home. It was a whirlwind of the emotions and multi-tasking.

So many things changed. As well as the perpetual lack of sleep, friendships drifted away and I had to learn the lingo of disability. Then before long I was slowly subjected to more and more pieces of equipment. So many looked big and cumbersome and none fitted with my current soft furnishings.

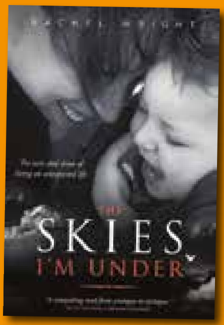
It's a long road to acceptance and I certainly haven't arrived; adaptation is the best I can do for now. Still the grief can wash over, sending me into a hologram world littered with 'what ifs'. The feelings of loss and pain can slip back on like well-worn shoes which fit just right.

Thirteen- years later there is much to be grateful for and the changes in me I hope are for the better. Our family life is unlike most but I have discovered that hard is not the same as bad. In fact some of the most remarkable views only come from walking the most challenging paths.

In 2015 I published my memoir, The skies I'm under. Fellow parents have shared how reading our story has made them feel less alone. Hearing their emotions echoed in my words brings the comfort of solidarity. Many professionals state they have gained a deeper insight into the emotions and complexities of family life with a severely disabled child which has changed their practice. But the most profound impact happened in me. Writing and telling our story has helped me try to live the life I have, not the one I expected.

Today, my work takes me to speaking at conferences and training professionals. As a parent and a healthcare professional, I am deeply passionate about co-production and bridging the gap between families and practitioners with effective communication. I know as a mum, that the little things can make a big difference. A professional using my name, asking my opinion or simply listening, can dramatically change my experience of a consultation. We cannot ignore the gap in priorities and perspectives between professionals and parents but we can bridge it with effective communication.

SAVE 25% OFF RACHEL'S BOOK



For more information about training, the 'Don't call me Mum' initiative or to buy a copy of The Skies I'm Under, go to www.bornattherighttime.co.uk and use the code Kidz2Adultz to get 25% off the RRP.

MORE ABOUT RACHEL

Rachel also started the "Don't call me mum" campaign because she was fed up of professionals who knew her name, weren't her son or daughter, and yet chose to call her 'Mum'.

She says: "Basically, it is an initiative to facilitate practitioners and companies to acknowledge the invaluable contribution parents make. It is the little things that make a big difference, and for parents being called by their chosen name demonstrates the respect and inclusion professionals want to foster. It also gives parents the chance to say (politely) I am a partner in my child's care, please don't call me Mum/Dad."

NEW UK DISTRIBUTOR FOR sensory products

REPOSE FURNITURE HAS BECOME A MAJOR DISTRIBUTOR OF THE PROTAC RANGE OF SENSORY PRODUCTS FOR CHILDREN AND ADULTS ACROSS THE UK

All Protac products are based around the unique Sensory Stimulating Protac balls which, thanks to the deep touch-pressure and constant contact to the body's surface activate the sense of touch, the body's movement and sense of body position in space.

Products available include the SenSit chair, designed to provide a sensory stimulating chair, the GroundMe, a low-level seat providing positive sensory feedback and the Ball Blanket which helps to relieve sleep disorders and cognitive and motor restlessness among children and adults.

Also in the range is the KneedMe, a sensory stimulating weighted knee blanket with integral pocket, which helps people of all ages suffering with cognitive and motor restlessness and the MyFit vest, a weighted jacket which provides significant sensory stimulation and creates a calming effect.

For more information call 0844 7766001 or visit https://www.reposefurniture.co.uk/sensory-stimulation-products/

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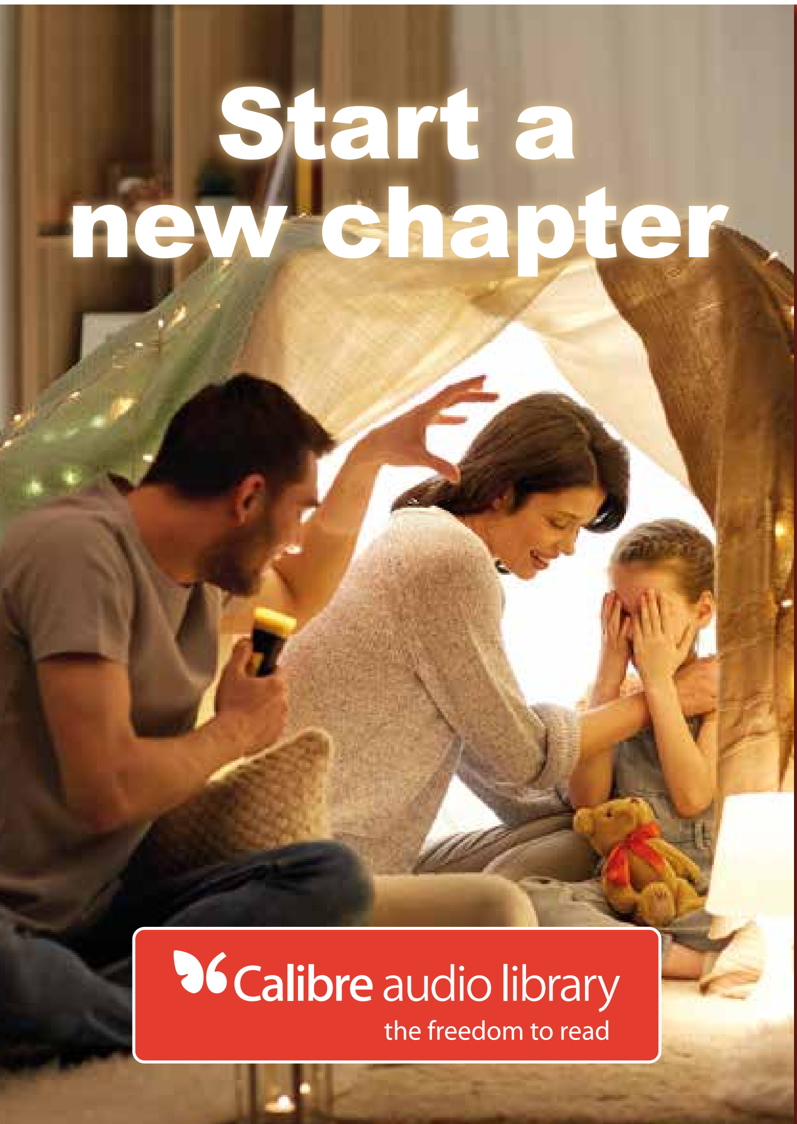

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Calibre audio library
the freedom to read

DESIGN CHARITY seeks new product DEVELOPMENT ASSISTANCE

DESIGNABILITY IS DEVELOPING A NEW WHEELCHAIR BABY CARRIER AND THE CHARITY IS LOOKING FOR PEOPLE WHO COULD HELP THEM TO MAKE IT INTO A USEFUL PRODUCT

They are appealing for mums, dads or grandparents who have experience of using a manual wheelchair and being a parent and are willing to share their experiences.

You could be a new parent / grandparent, or have older children and have gathered lots of knowledge and expertise on what might be suitable.

Designability need to understand lots of practical details about how wheelchairs and buggies work or don't work when used together.

You can either participate by attending a workshop in the Bath/ Bristol area or by filling in short email surveys which will be used to inform and guide the project e.g. your views about practicalities and potential features. You can be involved as much as you choose to be.

If you use a manual wheelchair and are a parent, please email ninaevans@designability.org.uk or call 01225 824107.

To find out more about Designability, please visit www.designability.org.uk

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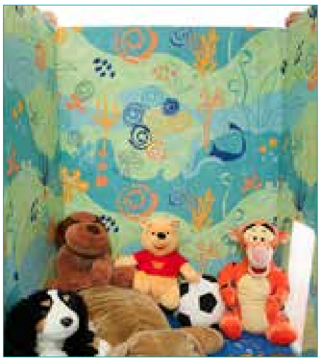

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Timmy

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