



# Co-Occurring Physical Health Challenges in Neurodivergent Children and Young People: A Topical Review and Recommendation

Bethany Donaghy, David Moore & Jane Green

To cite this article: Bethany Donaghy, David Moore & Jane Green (2023): Co-Occurring Physical Health Challenges in Neurodivergent Children and Young People: A Topical Review and Recommendation, Child Care in Practice, DOI: [10.1080/13575279.2022.2149471](https://doi.org/10.1080/13575279.2022.2149471)

To link to this article: <https://doi.org/10.1080/13575279.2022.2149471>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 17 Jan 2023.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)

# Co-Occurring Physical Health Challenges in Neurodivergent Children and Young People: A Topical Review and Recommendation

Bethany Donaghy <sup>a</sup>, David Moore<sup>a</sup> and Jane Green <sup>b</sup>

<sup>a</sup>Department of Psychology, Liverpool John Moores University, Liverpool, England; <sup>b</sup>SEDSConnective Charity (Symptomatic Hypermobility, Ehlers-Danlos, NeuroDivergence Syndrome Sussex), Sussex, England

## ABSTRACT

**Background:** Neurodivergence has been established as associated with a significant number of co-occurring physical conditions, particularly for autistic individuals who are at risk for increased pain, hypermobility (including Ehlers-Danlos Syndrome) and gastrointestinal problems. However, data, so far, has been focused on adults and generally limited to discussions of condition prevalence alone.

**Methods:** The following article will present a topical review of the literature considering evidence for increased physical health concerns within neurodivergent populations, particularly autistic individuals, with a focus on the impact that these physical health concerns may have in an educational setting.

**Results and discussion:** The impact of physical health concerns within neurodivergent populations in an educational setting may be concerning. Such populations may face a range of challenges in obtaining appropriate support for physical conditions. We discuss a number of said challenges including; communication challenges, misattributing physical health symptoms as a part of neurodivergence, and a history of not being believed, which limits symptomatic reporting. We further consider the potential impact these physical health concerns may have on scholastic and social development, such as impacts for attainment and attendance. Furthermore, we provide recommendations for teachers, parents/carers and other allied professionals in young people's lives, on supporting young neurodivergent people with physical health concerns.

## KEYWORDS

Neurodivergent; physical health; children and young people; hypermobility; pain; gastrointestinal; autism; ADHD; DCD

## Introduction to neurodivergence

The neurodivergent population are defined as having or related to a type of brain that is often considered different from what is usual (Cambridge Dictionary, 2021); usual referring to those who are not neurodivergent having a neurotypical brain. The neurodivergent population includes, but is not limited to, individuals with diagnoses of autism

**CONTACT** David Moore  D.J.Moore@ljmu.ac.uk  Department of Psychology, Tom Reilly Building, Liverpool John Moores University, Liverpool, L3 3AF.

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

spectrum condition (ASC), attention-deficit hyperactivity disorder (ADHD) and/or developmental coordination disorder (DCD), also known as dyspraxia (McGee, 2012). However, not all neurodivergent people have a formal diagnosis, consistent with the current medical model (Young et al., 2020); a portion may not have a diagnosis or even be seeking one, but still perceive and experience the world differently to those considered neurotypical. Whilst this article will focus primarily on autistic, ADHD and DCD children and young people (CYP), more research is needed to understand physical health conditions experienced by the wider population, including Tourette's syndrome (Csecs et al., 2022).

Whilst research explores at length psychiatric co-occurring conditions of neurodivergent populations with an estimated 56.6% of autistic adults experiencing a psychiatric condition (for example, anxiety and depression (Buck et al., 2014)), often overlooked are co-occurring physical health challenges. It is clear from current evidence there is a co-occurring physical health disparity in neurodivergent adults. For example, neurodivergent adults display a higher expression of joint hypermobility and pain compared to neurotypical adults (Csecs et al., 2020). Furthermore, autistic women with generalised joint hypermobility (GJH) experience higher immune- and endocrine-conditions than autistic women without GJH (Casanova et al., 2018). However, it is vital to understand physical health in neurodivergent CYP (aged up to 25 years (National Institute for Health and Care Excellence (NICE), 2020)). Neurodivergent CYP experience worsened physical health conditions than neurotypical CYP (McLeod et al., 2019).

CYP are at a critical point in their social and communication development, whereby, they may face difficulties in understanding their internal experiences, and the diagnostic pathways for physical health conditions. Some CYP may not receive a correct diagnosis due to interoceptive differences, whereby, a CYP does not understand what they are feeling or may struggle to label these feelings. Furthermore, differences in communication styles may also not be understood, in particular, by neurotypical professionals, especially those without appropriate neurodivergent training. For example, a neurodivergent CYP may be non-verbal, or have reduced/altered communication and, therefore, struggle to verbally communicate symptoms in a manner that medical professionals expect. Consequentially, neurodivergent CYP's physical health needs are overlooked causing a worsening in symptoms, exacerbation of prior psychiatric conditions, and underlying trauma from not being believed, particularly for those with no diagnosis (Sala et al., 2020). Further implications can extend externally with effects for neurodivergent CYP's education. For example, lower attendance due to illness-related absence causing reductions in peer socialisation; something that can have complications for neurodivergent CYP who may already socialise less frequently (Jackson et al., 2018).

However, due to limited research, guidelines for supporting neurodivergent CYP with physical health conditions are sparse; particularly within the education field, where CYP spend most of their time and the implications of physical health conditions are clearer.

This article will discuss co-occurring physical health conditions faced by autistic, ADHD and DCD children and young people including; joint hypermobility syndrome (JHS), symptomatic hypermobility, Ehlers-Danlos syndromes (EDS), pain, and gastrointestinal (GI) problems. Educational impacts of these conditions will be reviewed, and inclusive recommendations presented.

It should be noted that the physical health conditions discussed here are only examples and not exhaustive of those co-occurring in populations; similarly, these conditions are not limited to autistic, ADHD, and DCD populations.

## Physical health conditions

### *Ehlers-Danlos syndromes (EDS)*

Ehlers-Danlos syndromes (EDS) are a group of complex heritable multi-systematic connective tissue disorders. Whilst people with these conditions can present differently, from being asymptomatic to severely affected, all have defective connective tissues (Green, 2020).

EDS is classified into 13 named subtypes (Malfait et al., 2017): the most common being hypermobile EDS (hEDS) or as previously known, Type 3 (Gazit et al., 2016). Hypermobility is seen in most types of EDS and is a key feature of both joint hypermobility syndrome and symptomatic hypermobility in CYP (The School Toolkit for EDS and JHS, 2021d). Both EDS and JHS can be difficult to diagnose due to their complexity and co-occurring conditions and symptoms, although both should be managed in the same way (Engelbert et al., 2017). Exemplar hEDS symptoms and co-occurring conditions include, but are not limited to; soft or velvety skin, chronic and/or musculoskeletal pain, palpitations, anxiety, fatigue, GI problems, neurological conditions such as headaches, epilepsy, increased frequency of falls, and autonomic nervous system effects such as dizziness (Eccles et al., 2014; Gazit et al., 2016; Gensemer et al., 2021; Palser et al., 2018).

Research suggests a co-occurrence of EDS and neurodivergence in CYP (Baeza-Velasco et al., 2018; Sharp et al., 2021). For example, Cederlöf et al. (2016) found higher prevalence of ASC in a group with EDS (2.9%) than in a group without EDS (0.4%). Similarly a higher prevalence of ADHD was found in a group with EDS (4.3%) than in a group without EDS (0.8%) (Cederlöf et al., 2016). These larger between-group differences for ADHD prevalence than ASC, were replicated by Kindgren et al. (2021) who found a higher prevalence of ADHD (16%) compared to ASC (6.5%) in a broad EDS/hypermobile group. Similar patterns were found for DCD, with a high amount of children with EDS meeting DCD diagnostic criteria (55%) (Sharp et al., 2021).

### *Joint hypermobility syndrome (JHS)*

JHS is a connective tissue disorder presumably caused by weaker collagen structures which increase joint extension (such as knees and elbows) beyond the typical range (Kumar & Lenert, 2017). JHS characterisation involves symptomatic hypermobility (soft tissue injury, frequent dislocations and musculoskeletal pain due to joint hyperextensibility) and similar symptoms to EDS (Kumar & Lenert, 2017; Ross & Grahame, 2011).

Sometimes, an individual with JHS may be referred to as having hypermobility spectrum disorder (HSD) which acts as an umbrella term for an array of connective tissue disorders, however, it is important to note, an individual can have joint hypermobility without an HSD (Atwell et al., 2021). CYP are commonly referred to as having symptomatic hypermobility as opposed to JHS or EDS due to diagnostic difficulties; displays of symptomatic hypermobility characterisations and forementioned associated problems such as widespread pain (The School Toolkit for EDS and JHS, 2021d).

To be diagnosed with JHS at the time of writing, the Revised Beighton criteria require that an individual satisfies major and/or minor symptomatic criteria. Major criteria include hypermobility determined by Beighton score, and pain for >3 months in >4 joints, and minor criteria includes joint dislocations/subluxations, and >3 soft tissue lesions (Beighton et al., 1973; Castori, 2012; Grahame et al., 2000). Additionally, no EDS or Marfan's (a connective tissue disorder caused by mutations of genes coding fibrillin (Pepe et al., 2016)) presence is required to account for hEDS symptomatic and diagnostic overlaps (Ross & Grahame, 2011). Further, co-occurring JHS conditions and symptoms include but are not limited to: GI problems, chronic fatigue, fibromyalgia, dizziness, and psychiatric conditions such as anxiety and depression (Eccles et al., 2012; Kovacic et al., 2014; Smith et al., 2014).

In the same study previously discussed for EDS, 1.6% of a group with JHS were autistic, compared to 1.2% in a group without JHS (Cederlöf et al., 2016). Similarly, a higher prevalence of ADHD was found in a JHS group (3.0%) compared to a group without JHS (0.5%) (Cederlöf et al., 2016). Csecs et al. (2020) highlighted joint hypermobility as 3.52 times more prevalent in autistic and ADHD females, than those with no neurodevelopmental condition, suggesting gender further affects JHS prevalence in the population. Furthermore, a literature review by Ghibellini et al. (2015) suggests as most CYP with DCD are hypermobile by Beighton score, a subgroup of CYP with DCD fit JHS diagnostic criteria. Further, Kirby and Davies (2007) found 37% of a group of young people with DCD experienced 2 or more JHS symptoms, compared to 7.4% in neurotypical group; however, it must be acknowledged symptoms were parent-reported.

## Pain

As defined by Raja et al. (2020), pain is “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”. Pain is considered as both a side-effect of medical health conditions and as a physical health condition itself, with risk of chronicity in both.

Chronic pain currently has seven subcategories, each with their own set of characteristics, however, most relevant here are chronic primary and secondary pain syndromes (Treede et al., 2019). Chronic primary pain syndromes are characterised as pain that recurs for more than 3 months in one, or more anatomical regions and is associated with significant emotional distress or functional disability (Treede et al., 2019). Examples include headaches and musculoskeletal pain (Friedrichsdorf et al., 2016). Chronic secondary pain syndromes are characterised as symptomatic pain to other medical conditions that requires specific care in its own right (Treede et al., 2019). Examples include juvenile rheumatoid arthritis and inflammatory bowel syndrome (Friedrichsdorf et al., 2016). Those whom satisfy chronic pain remits may experience co-occurring psychiatric conditions such as anxiety and sleep disturbances, causing increased fatigue and “brain fog” (Dahan et al., 2014).

Of the neurodivergent CYP population, there are inconsistent findings regarding acute pain sensitivity (Moore, 2015; Vaughan et al., 2020), however, it is evident that chronic pain is of concern, particularly for neurodivergent females (Casale et al., 2021). Lipsker et al. (2018) highlighted concerns finding that of 146 children attending tertiary chronic pain care, 26% had either ASC clinical scores or ADHD

clinical scores, and a further 8% had both ASC and ADHD clinical scores. Whitney and Shapiro (2019) further demonstrated this prevalence, having found from 1158 ASC children, 15.6% experienced pain, increasing to 19.9% for children with at least one additional co-occurring developmental condition. Moreover, significant pain anxiety phenotypes are evident in autistic populations, which may predict greater pain experience for neurodivergent than neurotypical groups (Failla et al., 2020). Unlike ASC and ADHD evidence suggesting chronic pain prevalence, those with DCD are thought to experience overlaps in symptomatology with chronic pain such as poor attention and higher reports of pain, headaches and fatigue, etc (Kempert et al., 2019). There are likely several reasons why neurodivergent CYP might be at greater risk of developing pain-related problems than their neurotypical peers. These include but are not limited to; a co-occurring genetic disposition towards pain conditions, central sensitivity syndromes, motor control difficulties predisposing neurodivergent people to injury, or disparities in healthcare experience which cause medically ignored or mismanaged minor aches developing into pain and disability. At present more research is needed to identify important pain factors and how pain management can best be designed to support these populations.

### ***Gastro-Intestinal (GI) problems***

The primary role of the GI tract is to digest and absorb nutrients, and excrete digestive waste products (Hornbuckle et al., 2008). However, factors such as gastroparesis, gastro-esophageal reflux disorder (GERD) and psychological distress can alter communication between the GI tract and central nervous system (CNS) resulting in GI problems (Black et al., 2020). Examples of GI problems include constipation, diarrhoea, vomiting, abdominal pain or discomfort, and feeding issues or selectivity (Ibrahim et al., 2009). Additionally, individuals may experience co-occurring psychiatric conditions such as anxiety and depression, and somatic conditions such as food intolerance, back pain, and fibromyalgia (Singh et al., 2012; Vu et al., 2014).

It is evident GI problems are experienced by neurodivergent CYP with research establishing a high prevalence of GI problems in autistic CYP (~9-91%) (Mannion & Leader, 2014). Chakraborty et al. (2021) further highlights this with 93.2% of an autistic CYP population having experienced at least one GI problem, and 88.1% more than one. Similarly, evidence suggests children with ADHD are more likely to experience GI problems such as constipation, than children without ADHD (DiFrancisco-Donoghue et al., 2022; Holingue et al., 2022; McKeown et al., 2013). However, whilst data on GI problems in children with DCD are limited, Price and Butler (2001) highlight higher associations of constipation, suggesting GI problems within the DCD population are present and should be addressed.

### ***Implications of physical health conditions in neurodivergent CYP***

There is limited knowledge and understanding of associated issues of physical health conditions for CYP due to lack of diagnosis, particularly for EDS and JHS. Here, this is discussed in the context of neurodivergent CYP with reference to associated diagnostic and educational implications.

### ***Implications of misdiagnosis and symptom disbelief***

CYP often face misdiagnosis or no diagnosis, due to disbelief or ignorance of condition severity and symptomatology. The latter of which is only exacerbated further by lack of professional understanding and knowledge. For example, whilst at least 10--15% of CYP have hypermobile joints, few enter a JHS or EDS diagnostic pathway.

Further obstacles to diagnosis arise when symptoms are not believed, or incorrectly associated with being a CYP such as musculoskeletal pain, growing pains and greater range of motion (Adib et al., 2005; Cattalini et al., 2015; Murray, 2006). This may further exacerbate in neurodivergent CYP due to overlapping symptoms (e.g. anxiety associated to ADHD as opposed to pain) and differences in pain experience and communication (Happé et al., 2016; Rutherford et al., 2016; Saqr et al., 2018).

The implications of misdiagnosis can worsen throughout a CYP's life due to lack of effective healthcare management in earlier years. For example, of an adult sample with childhood or adolescent chronic pain onset, 80% indicated childhood pain persistence, highlighting longitudinal effects of physical health conditions (Friedrichsdorf et al., 2016). This is of particular concern within the autistic and ADHD community where pain is overrepresented (Lipsker et al., 2018), and if not appropriately treated early may follow the trajectory outlined by Friedrichsdorf et al. (2016).

Furthermore, disbelief of symptomatology experienced by a CYP can cause life-long trauma (Langhinrichsen-Rohling et al., 2021). For example, symptoms of pain are common in neurodivergent CYP compared to neurotypical peers (Csecs et al., 2022), particularly within the autistic population where pain experiences are often overlooked (Baeza-Velasco et al., 2018). When physical health symptomatology is undermined early in life, it makes it increasingly difficult for an individual to acknowledge and express those symptoms later in life. Therefore, the individual is left suffering without relevant treatment and risks further co-occurring psychiatric conditions arising (Newton et al., 2013).

### ***Educational implications***

Educational settings such as schools serve a societal purpose for CYP of education, work preparation and social development (Idris et al., 2012). However, it is understood if a CYP is recurrently absent from school they may not attain society's pre-defined markers of learning and social development (Department for Education, 2022a). Yet for a child with physical health conditions or neurodivergence, absences are increasingly frequent (Jackson, 2013; John et al., 2022). Here, effects of physical health conditions in educational settings are discussed.

### ***Socialising***

Hypermobility, pain and many other health conditions have significant social impacts. Due to symptomatic and illness-related absences, CYP miss out on social aspects of their education. Without a physical health condition, socialising may pose difficult for many neurodivergent CYP; specifically autistic CYP who may struggle with peer relationships (Calder et al., 2013; Kasari et al., 2011). However, the interaction



between neurodivergence and fatigue associated with physical health conditions as well as school absence, may make socialising increasingly difficult and force some neurodivergent CYP to not engage at all (National Autistic Society, 2020). This presents risks of neurodivergent CYP developing psychiatric conditions such as anxiety from social isolation and missing out on both peer and social learning at school (Jackson et al., 2018).

## Learning

*Attendance and Educational Attainment.* There is an established relationship between school attendance and educational attainment (i.e. the highest level of education that an individual has completed (Census Gov, 2022)), with pupils who attend more lessons generally attaining a higher grade point average (Newman-Ford et al., 2008). However, for CYP with physical health conditions, attendance is lower than those without medical appointments and illness-related absences with 2 in 5 pupils who have authorised school absences leaving school entirely (Hutchinson & Crenna-Jenning, 2019). Moreover, evidence suggests children with better emotional and physical wellbeing experience better academic attainment (Public Health England, 2014). It is already established emotional and physical wellbeing can be lacking within the neurodivergent population; therefore, educational attainment can also be assumed to be affected. For example, at every educational key stage and phase there is an attainment gap of 40% between CYP with special educational needs and disabilities, and their peers (Crossley & Hewitt, 2021). With similar patterns of attendance and attainment in neurodivergent CYP (May et al., 2021), it is clear neurodivergent CYP with physical health conditions are disadvantaged by factors out of their control. Thus, support to prevent such educational disadvantages are paramount.

*Cognitive Differences.* Cognitive functioning is important in education for facilitating attention, problem solving and memory (Morley et al., 2015). Neurodivergent CYP show differences in cognitive functioning comparative to neurotypical CYP which may cause difficulties for in-class learning, for example directing and shifting attention for autistic CYP (Clouder et al., 2020). However, when coupled with the further cognitive difficulties accompanying physical health conditions such as lower memory recall when experiencing chronic pain (Higgins et al., 2018), challenges to learning in scholastic settings can arise. Two examples of cognitive differences for neurodivergent CYP with physical health needs, include attention and memory.

CYP experiencing symptomatic pain may find their attention shifts from their lesson towards their pain (Voerman et al., 2017). Therefore, causing difficulty when concentrating on a lesson (Kosola et al., 2017); particularly for neurodivergent CYP who may already experience difficulties in shifting attention. CYP experiencing physical health conditions can experience “brain fog” and associated emotional difficulties such as anxiety, both of which can contribute to poorer memory function (Kosola et al., 2017). This can pose difficulties to learning whereby memory recall is heavily relied on for assessments; particularly for neurodivergent CYP with working memory difficulties (Kofler et al., 2018). Therefore, neurodivergent CYP with physical health conditions may appear to not reach educational attainment markers when associated physical challenges are not considered.



### ***CYP communication of physical health condition***

Typically, we expect an individual to communicate symptoms of physical health conditions either verbally by saying “I am in pain” or “I am feeling dizzy”, or non-verbally, through facial expressions like a grimaced face to indicate distress or pain (Hadjistavropoulos et al., 2011). However, for neurodivergent CYP, communication may differ and present difficulties in educational settings for school staff who struggle to identify physical health symptomatology; particularly when no diagnosis is involved. Thus, CYP are left without required scholastic care and support. Here, examples of communicative differences are discussed.

### ***Interoceptive differences***

To effectively communicate our feelings externally, we must be aware of our feelings internally – this is known as interoception (DuBois et al., 2016). For neurodivergent CYP, interoception is often defined as altered, meaning understanding of bodily signals is different to what is expected (DuBois et al., 2016). Therefore, difficulties in symptom communication may arise as if a CYP does not understand how they feel, as their ability to communicate this to someone else is limited. Further, differences when processing interoceptive signals like gastric signals may lead to mental health difficulties such as anxiety (Quadt et al., 2021), with further exacerbations when alexithymia (difficulty identifying own emotions) for example is present (Palser et al., 2018).

### ***Verbal (speaking) vs. non-verbal (non-speaking) communication***

Within the neurodivergent population, an individual’s communication may range from verbal (speaking) to non-verbal (non-speaking). For example, around 30% of autistic CYP are minimally speaking, meaning communication may involve only some words and phrases (Tager-Flusberg & Kasari, 2013).

The gold standard for reporting pain remains verbal self-report, however for those with communication differences, alternative methods to understand symptoms are needed.

Therefore, unless school staff understand how a neurodivergent CYP expresses and communicates pain, educational institutes may not effectively recognise and manage physical health condition symptoms. Examples of how to facilitate communication can be found in recommendations.

### ***Emotional and behavioural displays of physical health conditions***

Sadness and anger are examples of emotional displays for symptoms and subsequent symptomatic distress (Ruscheweyh et al., 2011). For example, when a CYP joints hurt, they may feel sad, frown or cry and as this pain turns to fatigue they may feel angry. In addition, behaviour can indicate symptom expression and distress including protective behaviours like rubbing the site of pain or self-injurious behaviours like self-scratching (Doody & Bailey, 2019; Wong & Widerstrom-Noga, 2021). Behaviours can occur prior, during, and following symptoms with autistic CYP displaying pain behaviours for longer than neurotypical CYP (Rattaz et al., 2013). Such emotional and behavioural displays may appear disruptive, causing CYP to be reprimanded in educational institutes without having knowledge of why these emotions and behaviours are occurring, only

increasing stress for the CYP. Therefore, knowledge and understanding of such emotional and behavioural displays is required.

## Recommendations

Literature establishes that neurodivergent CYP are at greater risk of developing hypermobility and pain-related conditions/symptoms in addition to problems in receiving diagnoses or appropriate treatment. It is therefore clear, greater support must be in place for neurodivergent CYP who are either diagnosed with, or suspected to have, physical health conditions. However, the authors note the importance of CYP's voices being actively heard when deciding on and implementing these recommendations.

Presented, are recommendations of how educational institutes can support neurodivergent CYP's physical health conditions, addressing factors such as attendance, attainment, communication, and understanding. Recommendations include authors own, and The School Toolkit for EDS and JHS (2021c); a resource all educational institutes (i.e. mainstream, specialist) can access to improve JHS and EDS knowledge and understanding, and support affected CYP (The School Toolkit for EDS and JHS, 2021a).

### *Attendance and attainment*

CYP's school attendance can decline when physical health conditions are involved due to attending medical appointments, ill health, or the need to recover from illness-related challenges (Allison et al., 2019). Schools should be flexible in their policy to account for registering medical appointments and illness-related absences -- for example, authorising health-related absence through requested medical evidence (Department for Education, 2022b; The School Toolkit for EDS and JHS, 2021b). Such policies prevent CYP's attendance record from penalisation and in some instances distress and peer social isolation caused by not attaining a reward for "good" or "100%" attendance. The latter may exacerbate in the neurodivergent CYP population who may already feel socially isolated (Kwan et al., 2020). Therefore, policy adjustments are essential to both physical, and mental wellbeing of affected neurodivergent CYP.

However, just because a CYP is absent does not mean they do not want to learn. Facilitations must be inclusive to neurodivergent needs and physical health as outlined by the Department for Education (2013) on a case-by-case basis. For example, implementing blended learning using resources developed during the Covid-19 pandemic to allow students to learn without face-to-face teaching; including uploading lesson recordings to a central cloud system and use of a flexible robot for long-term absence (The School Toolkit for EDS and JHS, 2021b). However, it is recognised, limitations, such as lack of funding and loss of interactive learning, may present challenges when putting the latter into practice. If there is return from the absence, a CYP should not be rushed back into school, instead, flexible days, reduced timetable and pacing should be utilised to ease back into a routine – particularly for the sub-group of neurodivergent CYP whom thrive off routine. All of this is essential to maintain neurodivergent CYP's passion and their motivation to learn is kept alive, allowing them to attain the best they can.

### ***School environment***

It is important that schools create adjusted sensory environments that neurodivergent CYP can visit to reduce physical health-related distress and enable class participation and task engagement (Piller & Pfeiffer, 2016; The School Toolkit for EDS and JHS, 2021b, 2021c). Whilst sometimes not feasible without funding, examples of adjustments for the hall, corridor, or reception area provided by The School Toolkit for EDS and JHS (2021b) and supported by National Autistic Society (2019) include: reducing background noise, reducing/increasing light, tinted glasses, and providing printed information ahead of time. Additionally, schools should incorporate access to rest areas, utilise toilet passes, and incorporate pacing or movement breaks for those whose stamina may waiver due to fatigue, pain and/or GI problems (Rodriguez et al., 2022; The School Toolkit for EDS and JHS, 2021b).

### ***Managing and understanding pain***

Neurodivergent CYP will benefit if school staff are more mindful of pain communication differences and find ways to better understand this for pain management. For example, we recommend school staff enable CYP to have time and space to acknowledge their pain; particularly for neurodivergent CYP who experience larger interoceptive differences. Following this, a variety of tools such as drawing, acting, or even dancing should be provided to allow CYP to express their pain. Further communication tools may be used to aid in understanding pain, for example, appropriate personalised apps or tools such as augmentative and alternative communication (AAC), picture exchange communication system (PECS) cards, or feelings/reasons boards. However, the direct utility of these for pain communication has not been systematically tested and the most useful tool will be taking time to understand how the CYP communicates to find what is best suited. Furthermore, parents should be involved in understanding how a neurodivergent CYP communicates their pain to ensure that whilst at school, any flares or anxieties associated to their physical health condition are appropriately addressed. In addition, it is clear greater research is required to understand pain experiences and communication styles of neurodivergent CYP.

Interoceptive training teaches skills for understanding internal bodily signals through identification and appraisal, in turn reducing accompanying distress and allowing better communication of, for example, GI issues and pain (Price & Hooven, 2018). Quadt et al. (2021) has highlighted the validity of interoceptive training for the neurodivergent population with reduced anxieties in autistic adults following training. Therefore, to assist in neurodivergent CYP better recognising and understanding their symptoms to communicate to others, interoceptive training formatted for CYP is recommended.

### ***Training***

Training is usually offered to school staff to improve themes, such as understanding child development (Hamre et al., 2017), however, physical health awareness training should be implemented too. Here, training beneficial to school staff for understanding and identifying physical health conditions in neurodivergent CYP is suggested.

### ***Diagnostic pathways***

To facilitate CYP being placed on appropriate diagnostic or treatment pathways, schools should disseminate training amongst school staff to recognise neurodevelopmental conditions alongside EDS, JHS, pain, and GI symptomatology and co-occurring conditions. This training will be especially beneficial to CYP who struggle recognising, understanding, and communicating their symptoms – something that is sometimes exacerbated in the neurodivergent CYP population due to interoceptive differences (Garfinkel et al., 2016). Similarly, training for healthcare professionals and school staff must be developed and implemented for hypermobile screening in neurodivergent CYP to address the higher prevalence of JHS and EDS (Cederlöf et al., 2016; Ghibellini et al., 2015; Kirby & Davies, 2007; Savage et al., 2021). By doing so, treatment can be initiated earlier possibly preventing further physical health complications in adulthood (Demmler et al., 2019).

### ***Building trust with pupils***

Without a diagnosis of a physical health condition, CYP's symptoms may not be believed, meaning for example, CYP being forced to do PE despite experiencing poor proprioception, pain and/or other symptomatic hypermobile symptoms. As a result, CYP may find it difficult to discuss or disclose to professionals symptoms, even disregarding symptoms of non-importance entirely. To prevent this, reasonable adjustments should be made, for example an Individual Healthcare Plan (IHP) can be planned with parents/carers with no additional funding other than the notional budget. However, if learning is impacted adversely by such physical health needs, then an Education and Health Care Plan (EHCP) can be sought.

Disbelief may be particularly difficult for neurodivergent CYP whom have already experienced a protracted diagnostic procedure for their neurodivergent diagnosis (Kentrou et al., 2019). The process of another extended diagnosis may bring back traumatic memories or create reluctance to pursue a diagnosis. In addition, neurodivergent CYP may experience other invalidating experiences from those in positions of power including perceptions of hypochondria, infantilization, and over dramatisation of symptoms (Doherty et al., 2020; Stanford, n.d.).

All of these experiences may act as barriers to greater health. Support from those around the child during this time, including teachers and other school staff may help reduce the impact of this process and allow CYP to talk about their health.

Teachers should receive training additionally to improve knowledge and understanding of physical health conditions aiding in creating a safe environment for CYP who recognise their symptoms to feel comfortable disclosing symptoms, and most importantly have their symptoms believed. By doing so, likelihood of trauma from disbelief may be reduced, and further exacerbation of physical health conditions during earlier years and throughout adulthood can be prevented (Langhinrichsen-Rohling et al., 2021).

### ***Support***

Parents and carers of CYP with physical health conditions must be supported too, particularly as they are more likely to experience mental health conditions than parents of CYP without physical health conditions (Bayer et al., 2021; Palermo & Eccleston, 2009). Support to alleviate stress surrounding education for parents can begin by

implementing recommendations presented here. However, schools can further assist by waiving the absence fines (Define Fine, 2021) and signposting parents to relevant support if schools do not have capacity to support.

## Future directions

Recommendations for supporting neurodivergent CYP with physical health conditions have been presented and must be followed, but, further research is paramount for developing new, and existing, recommendations. Studies must bridge the gap between what we know about physical health conditions in neurodivergent adults and what we do not know in neurodivergent CYP to identify key challenges to address. For example, research must identify symptoms, co-occurring conditions, and neurodivergent prevalence in symptomatic hypermobility. Whilst not an immediate solution, progress must begin to prevent implications continuing, worsening, and becoming increasingly detrimental to CYP's mental and physical wellbeing. It is clear voices of neurodivergent people must be central within this research to reflect priorities and lived experiences of these communities for the greatest impact. To conclude, whilst this paper highlights the importance in considering physical health conditions of neurodivergent CYP, more must be done to emphasise this conversation through research and policy in addition to screening neurodivergent CYP for hypermobility (and vice versa).

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Notes to contributors

*Bethany Donaghy* is an autistic PhD student at Liverpool John Moores University, studying under the Pro-Vice Chancellor Scholarship Award. Her current PhD project is studying pain in autistic children, and young people, with the aims of examining factors, which relate to pain experience and expression in autistic children and young people. Previously, Bethany has completed her BSc (Hons) in Applied Psychology and MSc in Brain and Behaviour at Liverpool John Moores University.

*Dr David Moore* is a Reader in Psychology in the Department of Psychology at Liverpool John Moores University. His research interests include the pain experiences and expression of autistic people throughout the lifespan.

*Jane Green* is a professional autism educationalist and ex-assistant Headteacher (MA Ed, Adv.Dip Ed.(Child Dev.) PGCE QTS and BSc (Hons) Psych.) She worked in all phases of education, Local Authorities and nationally. She founded and Chairs SEDSConnective, a neurodivergent and hypermobility charity, advocates in National Health programmes in education, health, social care, employment, and transport accessibility. Jane led the content for the first school toolkit for EDS and JHS published in May 2021. She publishes and presents in education/health and EBSA conferences internationally. She is disabled and autistic.

## ORCID

*Bethany Donaghy*  <http://orcid.org/0000-0003-2695-8105>

*Jane Green*  <http://orcid.org/0000-0002-9261-1882>

## References

- Adib, N., Davies, K., Grahame, R., Woo, P., & Murray, K. J. (2005). Joint hypermobility syndrome in childhood. A not so benign multisystem disorder? *Rheumatology*, 44(6), 744–750. <https://doi.org/10.1093/rheumatology/keh557>
- Allison, M. A., Attisha, E., & Health, C. O. S. (2019). The link between school attendance and good health. *Pediatrics*, 143(2), e20183648. <https://doi.org/10.1542/peds.2018-3648>
- Atwell, K., Michael, W., Dubey, J., James, S., Martonffy, A., Anderson, S., Rudin, N., & Schragar, S. (2021). Diagnosis and management of hypermobility spectrum disorders in primary care. *The Journal of the American Board of Family Medicine*, 34(4), 838–848. <https://doi.org/10.3122/jabfm.2021.04.200374>
- Baeza-Velasco, C., Cohen, D., Hamonet, C., Vlamynck, E., Diaz, L., Cravero, C., Cappe, E., & Guinchat, V. (2018). Autism, joint hypermobility-related disorders and pain. *Frontiers in Psychiatry*, 9, 656–656. <https://doi.org/10.3389/fpsy.2018.00656>
- Baeza-Velasco, C., Sinibaldi, L., & Castori, M. (2018). Attention-deficit/hyperactivity disorder, joint hypermobility-related disorders and pain: expanding body-mind connections to the developmental age. *ADHD Attention Deficit and Hyperactivity Disorders*, 10(3), 163–175. <https://doi.org/10.1007/s12402-018-0252-2>
- Bayer, N. D., Wang, H., Yu, J. A., Kuo, D. Z., Halterman, J. S., & Li, Y. (2021). A national mental health profile of parents of children with medical complexity. *Pediatrics*, 148(2), e2020023358. <https://doi.org/10.1542/peds.2020-023358>
- Beighton, P., Solomon, L., & Soskolne, C. L. (1973). Articular mobility in an African population. *Annals of the Rheumatic Diseases*, 32(5), 413–418. <https://doi.org/10.1136/ard.32.5.413>
- Black, C. J., Drossman, D. A., Talley, N. J., Ruddy, J., & Ford, A. C. (2020). Functional gastrointestinal disorders: Advances in understanding and management. *The Lancet*, 396(10263), 1664–1674. [https://doi.org/10.1016/S0140-6736\(20\)32115-2](https://doi.org/10.1016/S0140-6736(20)32115-2)
- Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(12), 3063–3071. <https://doi.org/10.1007/s10803-014-2170-2>
- Calder, L., Hill, V., & Pellicano, E. (2013). ‘Sometimes I want to play by myself’: Understanding what friendship means to children with autism in mainstream primary schools. *Autism*, 17(3), 296–316. <https://doi.org/10.1177/1362361312467866>
- Cambridge Dictionary. (2021). *Neurodivergent*. Cambridge University Press. Retrieved 06/08/2021 from <https://dictionary.cambridge.org/english/neurodivergent>.
- Casale, R., Atzeni, F., Bazzichi, L., Beretta, G., Costantini, E., Sacerdote, P., & Tassorelli, C. (2021). Pain in women: A perspective review on a relevant clinical issue that deserves prioritization. *Pain and Therapy*, 10(1), 287–314. <https://doi.org/10.1007/s40122-021-00244-1>
- Casanova, E. L., Sharp, J. L., Edelson, S. M., Kelly, D. P., & Casanova, M. F. (2018). A cohort study comparing women with autism spectrum disorder with and without generalized joint hypermobility. *Behav Sci (Basel)*, 8(3), <https://doi.org/10.3390/bs8030035>
- Castori, M. (2012). Ehlers-Danlos syndrome, hypermobility type: An underdiagnosed hereditary connective tissue disorder with mucocutaneous, articular, and systemic manifestations. *ISRN Dermatology*, 2012, 1. <https://doi.org/10.5402/2012/751768>
- Cattalini, M., Khubchandani, R., & Cimaz, R. (2015). When flexibility is not necessarily a virtue: A review of hypermobility syndromes and chronic or recurrent musculoskeletal pain in children. *Pediatric Rheumatology*, 13(1), 40. <https://doi.org/10.1186/s12969-015-0039-3>
- Cederlöf, M., Larsson, H., Lichtenstein, P., Almqvist, C., Serlachius, E., & Ludvigsson, J. F. (2016). Nationwide population-based cohort study of psychiatric disorders in individuals with Ehlers-Danlos syndrome or hypermobility syndrome and their siblings. *BMC Psychiatry*, 16(1), 207. <https://doi.org/10.1186/s12888-016-0922-6>
- Census Gov. (2022). *Educational attainment*. <https://www.census.gov/topics/education/educational-attainment.html>.



- Chakraborty, P., Carpenter, K. L. H., Major, S., Deaver, M., Vermeer, S., Herold, B., Franz, L., Howard, J., & Dawson, G. (2021). Gastrointestinal problems are associated with increased repetitive behaviors but not social communication difficulties in young children with autism spectrum disorders. *Autism*, 25(2), 405–415. <https://doi.org/10.1177/1362361320959503>
- Clouder, L., Karakus, M., Cinotti, A., Ferreyra, M. V., Fierros, G. A., & Rojo, P. (2020). Neurodiversity in higher education: A narrative synthesis. *Higher Education*, 80(4), 757–778. <https://doi.org/10.1007/s10734-020-00513-6>
- Crossley, N., & Hewitt, D. (2021). *Inclusion: A principled guide for school leaders* (1 ed.). Routledge.
- Csecs, J. L. L., Iodice, V., Rae, C. L., Brooke, A., Simmons, R., Quadt, L., Savage, G. K., Dowell, N. G., Prowse, F., Themelis, K., Mathias, C. J., Critchley, H. D., & Eccles, J. A. (2022). Joint hypermobility links neurodivergence to dysautonomia and pain. *Frontiers in Psychiatry*, 12, <https://doi.org/10.3389/fpsy.2021.786916>
- Csecs, J. L. L., Iodice, V., Rae, C. L., Brooke, A., Simmons, R., Dowell, N. G., Prowse, F., Themelis, K., Critchley, H. D., & Eccles, J. A. (2020). Increased rate of joint hypermobility in autism and related neurodevelopmental conditions is linked to dysautonomia and pain. *medRxiv*, 2020.2009.2014.20194118. <https://doi.org/10.1101/2020.09.14.20194118>
- Dahan, A., van Velzen, M., & Niesters, M. (2014). Comorbidities and the Complexities of Chronic Pain. *Anesthesiology*, 121(4), 675–677. <https://doi.org/10.1097/aln.0000000000000402>
- Define Fine. (2021). Barriers to school attendance. In D. Fine.
- Demmler, J. C., Atkinson, M. D., Reinhold, E. J., Choy, E., Lyons, R. A., & Brophy, S. T. (2019). Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case-control comparison. *BMJ Open*, 9(11), e031365. <https://doi.org/10.1136/bmjopen-2019-031365>
- Department for Education. (2013). Ensuring a good education for children who cannot attend school because of health needs: Statutory guidance for local authorities. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/941900/health\\_needs\\_guidance\\_accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/941900/health_needs_guidance_accessible.pdf)
- Department for Education. (2022a). The link between absence and attainment at KS2 and KS4. <https://explore-education-statistics.service.gov.uk/find-statistics/the-link-between-absence-and-attainment-at-ks2-and-ks4>
- Department for Education. (2022b). School attendance: Guidance for maintained schools, academies, independent schools and local authorities. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1073591/School\\_attendance\\_guidance\\_May-2022.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1073591/School_attendance_guidance_May-2022.pdf)
- DiFrancisco-Donoghue, J., Southard, V., Margulies, M., Jung, M.-K., Allera, A., & Riley, B. (2022). Assessment of gastrointestinal function and its' effect on bone mineral density and body composition in hypermobility spectrum disorder and hypermobile Ehlers-Danlos syndrome. *Journal of Clinical Densitometry*, <https://doi.org/10.1016/j.jocd.2022.07.005>
- Doherty, A. J., Atherton, H., Bolland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open*, 4(3), <https://doi.org/10.3399/bjgpopen20X101030>
- Doody, O., & Bailey, M. E. (2019). Understanding pain physiology and its application to person with intellectual disability. *Journal of Intellectual Disabilities*, 23(1), 5–18. <https://doi.org/10.1177/1744629517708680>
- DuBois, D., Ameis, S. H., Lai, M.-C., Casanova, M. F., & Desarkar, P. (2016). Interoception in autism spectrum disorder: A review. *International Journal of Developmental Neuroscience*, 52(1), 104–111. <https://doi.org/10.1016/j.ijdevneu.2016.05.001>
- Eccles, J. A., Beacher, F. D. C., Gray, M. A., Jones, C. L., Minati, L., Harrison, N. A., & Critchley, H. D. (2012). Brain structure and joint hypermobility: Relevance to the expression of psychiatric symptoms. *British Journal of Psychiatry*, 200(6), 508–509. <https://doi.org/10.1192/bjp.bp.111.092460>
- Eccles, J., Iodice, V., Dowell, N., Owens, A., Hughes, L., Skipper, S., Lycette, Y., Humphries, K., Harrison, N., Mathias, C., & Critchley, H. (2014). Joint hypermobility and autonomic



- hyperactivity: Relevance to neurodevelopmental disorders. *Journal of Neurology, Neurosurgery & Psychiatry*, 85(8), e3–e3. <https://doi.org/10.1136/jnnp-2014-308883.9>
- Engelbert, R. H. H., Juul-Kristensen, B., Pacey, V., de Wandele, I., Smeenk, S., Woinarosky, N., Sabo, S., Scheper, M. C., Russek, L., & Simmonds, J. V. (2017). The evidence-based rationale for physical therapy treatment of children, adolescents, and adults diagnosed with joint hypermobility syndrome/hypermobile Ehlers Danlos syndrome. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 175(1), 158–167. <https://doi.org/https://doi.org/10.1002/ajmg.c.31545>
- Failla, M. D., Gerdes, M. B., Williams, Z. J., Moore, D. J., & Cascio, C. J. (2020). Increased pain sensitivity and pain-related anxiety in individuals with autism. *Pain Reports*, 5(6), e861. <https://doi.org/10.1097/PR9.0000000000000861>
- Friedrichsdorf, S. J., Giordano, J., Desai Dakoji, K., Warmuth, A., Daughtry, C., & Schulz, C. A. (2016). Chronic pain in children and adolescents: Diagnosis and treatment of primary pain disorders in head, abdomen, muscles and joints. *Children*, 3(4), <https://doi.org/10.3390/children3040042>
- Garfinkel, S. N., Tiley, C., O’Keeffe, S., Harrison, N. A., Seth, A. K., & Critchley, H. D. (2016). Discrepancies between dimensions of interoception in autism: Implications for emotion and anxiety. *Biological Psychology*, 114, 117–126. <https://doi.org/10.1016/j.biopsycho.2015.12.003>
- Gazit, Y., Jacob, G., & Grahame, R. (2016). Ehlers–danlos syndrome—hypermobility type: A much neglected multisystemic disorder. *Rambam Maimonides Medical Journal*, 7(4), <https://doi.org/10.5041/RMMJ.10261>
- Gensemer, C., Burks, R., Kautz, S., Judge, D. P., Lavalley, M., & Norris, R. A. (2021). Hypermobile Ehlers-Danlos syndromes: Complex phenotypes, challenging diagnoses, and poorly understood causes. *Developmental Dynamics*, 250(3), 318–344. <https://doi.org/https://doi.org/10.1002/dvdy.220>
- Ghibellini, G., Brancati, F., & Castori, M. (2015). Neurodevelopmental attributes of joint hypermobility syndrome/Ehlers–Danlos syndrome, hypermobility type: Update and perspectives. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 169(1), 107–116. <https://doi.org/10.1002/ajmg.c.31424>
- Grahame, R., Bird, H. A., & Child, A. (2000). The revised (Brighton 1998) criteria for the diagnosis of benign joint hypermobility syndrome (BJHS). *The Journal of Rheumatology*, 27, 1777–1779.
- Green, J. (2020). Raising awareness of pupils with Ehlers-Danlos syndromes / Hypermobility spectrum disorders. *edpsy.org.uk*. <https://edpsy.org.uk/blog/2020/raising-awareness-of-pupils-with-ehlers-danlos-syndromes-hypermobility-spectrum-disorders/>.
- Hadjistavropoulos, T., Craig, K. D., Duck, S., Cano, A., Goubert, L., Jackson, P. L., Mogil, J. S., Rainville, P., Sullivan, M. J. L., Williams, A. C. C., Vervoort, T., & Fitzgerald, T. D. (2011). A biopsychosocial formulation of pain communication. *Psychological Bulletin*, 137(6), 910–939. <https://doi.org/10.1037/a0023876>
- Hamre, B. K., Partee, A., & Mulcahy, C. (2017). Enhancing the impact of professional development in the context of preschool expansion. *AERA Open*, 3(4), 233285841773368. <https://doi.org/10.1177/2332858417733686>
- Happé, F. G., Mansour, H., Barrett, P., Brown, T., Abbott, P., & Charlton, R. A. (2016). Demographic and cognitive profile of individuals seeking a diagnosis of autism spectrum disorder in adulthood. *Journal of Autism and Developmental Disorders*, 46(11), 3469–3480. <https://doi.org/10.1007/s10803-016-2886-2>
- Higgins, D. M., Martin, A. M., Baker, D. G., Vasterling, J. J., & Risbrough, V. (2018). The relationship between chronic pain and neurocognitive function. *The Clinical Journal of Pain*, 34(3), 262–275. <https://doi.org/10.1097/AJP.0000000000000536>
- Holingue, C., Poku, O., Pfeiffer, D., Murray, S., & Fallin, M. D. (2022). Gastrointestinal concerns in children with autism spectrum disorder: A qualitative study of family experiences. *Autism*, 26(7), <https://doi.org/10.1177/13623613211062667>
- Hornbuckle, W. E., Simpson, K. W., & Tennant, B. C. (2008). Gastrointestinal function. *Clinical Biochemistry of Domestic Animals*, 413–457. <https://doi.org/10.1016/B978-0-12-370491-7.00014-3>

- Hutchinson, J., & Crenna-Jenning, W. (2019). *Unexplained pupil exits from schools: A growing problem?* [https://epi.org.uk/wp-content/uploads/2019/04/EPI\\_Unexplained-pupil-exits\\_2019.pdf](https://epi.org.uk/wp-content/uploads/2019/04/EPI_Unexplained-pupil-exits_2019.pdf).
- Ibrahim, S. H., Voigt, R. G., Katusic, S. K., Weaver, A. L., & Barbaresi, W. J. (2009). Incidence of gastrointestinal symptoms in children with autism: a population-based study. *Pediatrics*, 124(2), 680–686. <https://doi.org/10.1542/peds.2008-2933>
- Idris, F., Hassan, Z., Ya'acob, A., Gill, S. K., & Awal, N. A. M. (2012). The role of education in shaping youth's national identity. *Procedia - Social and Behavioral Sciences*, 59, 443–450. <https://doi.org/10.1016/j.sbspro.2012.09.299>
- Jackson, M. (2013). The special educational needs of adolescents living with chronic illness: A literature review. *International Journal of Inclusive Education*, 17(6), 543–554. <https://doi.org/10.1080/13603116.2012.676085>
- Jackson, S. L. J., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 643–650. <https://doi.org/10.1007/s10803-017-3315-x>
- John, A., Friedmann, Y., DelPozo-Banos, M., Frizzati, A., Ford, T., & Thapar, A. (2022). Association of school absence and exclusion with recorded neurodevelopmental disorders, mental disorders, or self-harm: A nationwide, retrospective, electronic cohort study of children and young people in Wales, UK. *The Lancet Psychiatry*, 9(1), 23–34. [https://doi.org/10.1016/S2215-0366\(21\)00367-9](https://doi.org/10.1016/S2215-0366(21)00367-9)
- Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social networks and friendships at school: Comparing children with and without ASD. *Journal of Autism and Developmental Disorders*, 41(5), 533–544. <https://doi.org/10.1007/s10803-010-1076-x>
- Kempert, H., Nelson, L., & Heines, R. (2019). Clinical observations of adolescent chronic pain with coordination difficulties: Physical and psychosocial implications. *Pediatric Pain*, 21(3), 40–48.
- Kentrou, V., de Veld, D. M., Mataw, K. J., & Begeer, S. (2019). Delayed autism spectrum disorder recognition in children and adolescents previously diagnosed with attention-deficit/hyperactivity disorder. *Autism*, 23(4), 1065–1072. <https://doi.org/10.1177/1362361318785171>
- Kindgren, E., Quiñones Perez, A., & Knez, R. (2021). Prevalence of ADHD and autism spectrum disorder in children with hypermobility spectrum disorders or hypermobile ehlers-danlos syndrome: A retrospective study. *Neuropsychiatric Disease and Treatment*, Volume 17, 379–388. <https://doi.org/10.2147/NDT.S290494>
- Kirby, A., & Davies, R. (2007). Developmental coordination disorder and joint hypermobility syndrome ? Overlapping disorders? Implications for research and clinical practice. *Child: Care, Health and Development*, 33(5), 513–519. <https://doi.org/10.1111/j.1365-2214.2006.00694.x>
- Kofler, M. J., Sarver, D. E., Harmon, S. L., Moltisanti, A., Aduen, P. A., Soto, E. F., & Ferretti, N. (2018). Working memory and organizational skills problems in ADHD. *Journal of Child Psychology and Psychiatry*, 59(1), 57–67. <https://doi.org/10.1111/jcpp.12773>
- Kosola, S., Mundy, L. K., Sawyer, S. M., Canterford, L., van der Windt, D. A., Dunn, K. M., & Patton, G. C. (2017). Pain and learning in primary school: A population-based study. *PAIN*, 158(9), 1825–1830. <https://doi.org/10.1097/j.pain.0000000000000984>
- Kovacic, K., Chelimsky, T. C., Sood, M. R., Simpson, P., Nugent, M., & Chelimsky, G. (2014). Joint hypermobility: A common association with complex functional gastrointestinal disorders. *The Journal of Pediatrics*, 165(5), 973–978. <https://doi.org/10.1016/j.jpeds.2014.07.021>
- Kumar, B., & Lenert, P. (2017). Joint hypermobility syndrome: Recognizing a commonly overlooked cause of chronic pain. *The American Journal of Medicine*, 130(6), 640–647. <https://doi.org/10.1016/j.amjmed.2017.02.013>
- Kwan, C., Gitimoghaddam, M., & Collet, J.-P. (2020). Effects of social isolation and loneliness in children with neurodevelopmental disabilities: A scoping review. *Brain Sciences*, 10(11), 786. <https://doi.org/10.3390/brainsci10110786>
- Langhinrichsen-Rohling, J., Lewis, C. L., McCabe, S., Lathan, E. C., Agnew, G. A., Selwyn, C. N., & Gigler, M. E. (2021). They've been BITTEN: Reports of institutional and provider betrayal and links with Ehlers-Danlos Syndrome patients' current symptoms, unmet needs and healthcare

- expectations. *Therapeutic Advances in Rare Disease*, 2, <https://doi.org/10.1177/26330040211022033>
- Lipsker, C. W., Bölte, S., Hirvikoski, T., Lekander, M., Holmström, L., & Wicksell, R. K. (2018). Prevalence of autism traits and attention-deficit hyperactivity disorder symptoms in a clinical sample of children and adolescents with chronic pain. *Journal of Pain Research*, 11, 2827–2836. <https://doi.org/10.2147/JPR.S177534>
- Malfait, F., Francomano, C., Byers, P., Belmont, J., Berglund, B., Black, J., Bloom, L., Bowen, J. M., Brady, A. F., Burrows, N. P., & Castori, M. (2017). The 2017 international classification of the Ehlers–Danlos syndromes. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 175(1), 8–26. <https://doi.org/10.1002/ajmg.c.31552>
- Mannion, A., & Leader, G. (2014). Gastrointestinal symptoms in autism spectrum disorder: A literature review. *Review Journal of Autism and Developmental Disorders*, 1(1), 11–17. <https://doi.org/10.1007/s40489-013-0007-0>
- May, F., Ford, T., Janssens, A., Newlove-Delgado, T., Emma Russell, A., Salim, J., Ukoumunne, O. C., & Hayes, R. (2021). Attainment, attendance, and school difficulties in UK primary school-children with probable ADHD. *British Journal of Educational Psychology*, 91(1), 442–462. <https://doi.org/10.1111/bjep.12375>
- McGee, M. (2012). Neurodiversity. *Contexts*, 11(3), 12–13. <https://doi.org/10.1177/1536504212456175>
- McKeown, C., Hisle-Gorman, E., Eide, M., Gorman, G. H., & Nylund, C. M. (2013). Association of constipation and fecal incontinence with attention-deficit/hyperactivity disorder. *Pediatrics*, 132(5), e1210–e1215. <https://doi.org/10.1542/peds.2013-1580>
- McLeod, J. D., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders*, 49(6), 2320–2336. <https://doi.org/10.1007/s10803-019-03910-8>
- Moore, D. J. (2015). Acute pain experience in individuals with autism spectrum disorders: A review. *Autism*, 19(4), 387–399. <https://doi.org/10.1177/1362361314527839>
- Morley, J. E., Morris, J. C., Berg-Weger, M., Borson, S., Carpenter, B. D., Del Campo, N., Dubois, B., Fargo, K., Fitten, L. J., Flaherty, J. H., & Ganguli, M. (2015). Brain health: The importance of recognizing cognitive impairment: an IAGG consensus conference. *Journal of the American Medical Directors Association*, 16(9), 731–739. <https://doi.org/10.1016/j.jamda.2015.06.017>
- Murray, K. J. (2006). Hypermobility disorders in children and adolescents. *Best Practice & Research Clinical Rheumatology*, 20(2), 329–351. <https://doi.org/10.1016/j.berh.2005.12.003>
- National Autistic Society. (2019). Reasonable adjustments for autistic pupils' sensory differences. <https://www.autism.org.uk/advice-and-guidance/professional-practice/adjustments-sensory>.
- National Autistic Society. (2020). *Autistic fatigue and burnout*. <https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/autistic-adults>.
- National Institute for Health and Care Excellence (NICE). (2020). *NICE impact children and young people's healthcare*. <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-children-and-young-peoples-health-care#:~:text=When%20discussing%20children%20and%20young,in%20transition%20to%20adults'%20services>.
- Newman-Ford, L., Fitzgibbon, K., Lloyd, S., & Thomas, S. (2008). A large-scale investigation into the relationship between attendance and attainment: A study using an innovative, electronic attendance monitoring system. *Studies in Higher Education*, 33(6), 699–717. <https://doi.org/10.1080/03075070802457066>
- Newton, B. J., Southall, J. L., Raphael, J. H., Ashford, R. L., & LeMarchand, K. (2013). A narrative review of the impact of disbelief in chronic pain. *Pain Management Nursing*, 14(3), 161–171. <https://doi.org/10.1016/j.pmn.2010.09.001>
- Palermo, T. M., & Eccleston, C. (2009). Parents of children and adolescents with chronic pain. *PAIN*, 146(1–2), 15–17. <https://doi.org/10.1016/j.pain.2009.05.009>

- Palser, E. R., Palmer, C. E., Galvez-Pol, A., Hannah, R., Fotopoulou, A., & Kilner, J. M. (2018). Alexithymia mediates the relationship between interoceptive sensibility and anxiety. *PLoS One*, 13(9), e0203212. <https://doi.org/10.1371/journal.pone.0203212>
- Pepe, G., Giusti, B., Sticchi, E., Abbate, R., Gensini, G. F., & Nistri, S. (2016). Marfan syndrome: Current perspectives. *The Application of Clinical Genetics*, 9, 55–65. <https://doi.org/10.2147/TACG.S96233>
- Piller, A., & Pfeiffer, B. (2016). The sensory environment and participation of preschool children with autism spectrum disorder. *OTJR: Occupation, Participation and Health*, 36(3), 103–111. <https://doi.org/10.1177/1539449216665116>
- Price, C. J., & Hooven, C. (2018). Interoceptive awareness skills for emotion regulation: Theory and approach of mindful awareness in body-oriented therapy (MABT). *Frontiers in Psychology*, 9(798), <https://doi.org/10.3389/fpsyg.2018.00798>
- Price, K., & Butler, U. (2001). Bowel and bladder management in children with disabilities. *Current Paediatrics*, 11(2), 143–148. <https://doi.org/10.1054/cupe.2000.0158>
- Public Health England. (2014). *The link between pupil health and wellbeing and attainment*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/370686/HT\\_briefing\\_layoutvFINALvii.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/370686/HT_briefing_layoutvFINALvii.pdf)
- Quadt, L., Garfinkel, S. N., Mulcahy, J. S., Larsson, D. E. O., Silva, M., Jones, A.-M., Strauss, C., & Critchley, H. D. (2021). Interoceptive training to target anxiety in autistic adults (ADIE): A single-center, superiority randomized controlled trial. *EClinicalMedicine*, 39, 101042. <https://doi.org/10.1016/j.eclinm.2021.101042>
- Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil, J. S., Ringkamp, M., Sluka, K. A., Song, X.-J., Stevens, B., Sullivan, M. D., Tutelman, P. R., Ushida, T., & Vader, K. (2020). The revised international association for the study of pain definition of pain: Concepts, challenges, and compromises. *PAIN*, 161(9), 1976–1982. <https://doi.org/10.1097/j.pain.0000000000001939>
- Rattaz, C., Dubois, A., Michelon, C., Viellard, M., Poinso, F., & Baghdadli, A. (2013). How do children with autism spectrum disorders express pain? A comparison with developmentally delayed and typically developing children. *PAIN*, 154(10), 2007–2013. <https://doi.org/10.1016/j.pain.2013.06.011>
- Rodriguez, B., Hochstrasser, A., Eugster, P. J., Grouzmann, E., Müri, R. M., & Z'Graggen, W. J. (2022). Brain fog in neuropathic postural tachycardia syndrome may be associated with autonomic hyperarousal and improves after water drinking. *Frontiers in Neuroscience*, 16, 968725. <https://doi.org/10.3389/fnins.2022.968725>
- Ross, J., & Grahame, R. (2011). Joint hypermobility syndrome. *BMJ*, 342(jan20 1), cc7167. <https://doi.org/10.1136/bmj.c7167>
- Ruscheweyh, R., Nees, F., Marziniak, M., Evers, S., Flor, H., & Knecht, S. (2011). Pain catastrophizing and pain-related emotions. *The Clinical Journal of Pain*, 27(7), 578–586. <https://doi.org/10.1097/AJP.0b013e31820fde1b>
- Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Forsyth, K., McCartney, D., & Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628–634. <https://doi.org/10.1177/1362361315617879>
- Sala, R., Amet, L., Blagojevic-Stokic, N., Shattock, P., & Whiteley, P. (2020). Bridging the gap between physical health and autism spectrum disorder. *Neuropsychiatric Disease and Treatment*, 16, 1605–1618. <https://doi.org/10.2147/NDT.S251394>
- Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism*, 22(1), 51–61. <https://doi.org/10.1177/1362361317709970>
- Savage, G., Csecs, J., Davies, G., Critchley, H., & Eccles, J. (2021). #3085 Relationship between variant connective tissue (hypermobility) and autism sensory processing: externally oriented thinking as a mediator. *Journal of Neurology, Neurosurgery & Psychiatry*, 92(8), A7.2–A7A8. <https://doi.org/10.1136/jnnp-2021-BNPA.19>
- The School Toolkit for EDS and JHS. (2021a). *About the toolkit*. <https://theschooltoolkit.org/>.

- The School Toolkit for EDS and JHS. (2021b). *Reasonable adjustments in school*. <https://theschooltoolkit.org/reasonable-adjustments/>.
- The School Toolkit for EDS and JHS. (2021c). *The school toolkit*. <https://theschooltoolkit.org/>.
- The School Toolkit for EDS and JHS. (2021d). What are hypermobility, JHS and EDS? <https://theschooltoolkit.org/what-are-jhs-and-eds/>.
- Sharp, H. E. C., Critchley, H. D., & Eccles, J. A. (2021). Connecting brain and body: Transdiagnostic relevance of connective tissue variants to neuropsychiatric symptom expression. *World Journal of Psychiatry*, 11(10), 805–820. <https://doi.org/10.5498/wjp.v11i10.805>
- Singh, P., Agnihotri, A., Pathak, M. K., Shirazi, A., Tiwari, R. P., Sreenivas, V., Sagar, R., & Makharia, G. K. (2012). Psychiatric, somatic and other functional gastrointestinal disorders in patients with irritable bowel syndrome at a tertiary care center. *Journal of Neurogastroenterology and Motility*, 18(3), 324–331. <https://doi.org/10.5056/jnm.2012.18.3.324>
- Smith, T. O., Easton, V., Bacon, H., Jerman, E., Armon, K., Poland, F., & Macgregor, A. J. (2014). The relationship between benign joint hypermobility syndrome and psychological distress: a systematic review and meta-analysis. *Rheumatology*, 53(1), 114–122. <https://doi.org/10.1093/rheumatology/ket317>
- Stanford, S. D. (n.d.). Dehumanization, dismissal, and disparities: An analysis of harmful trends in Healthcare providers' interactions with Autistic Patients.
- Tager-Flusberg, H., & Kasari, C. (2013). Minimally verbal school-aged children with autism spectrum disorder: The neglected end of the spectrum. *Autism Research*, 6(6), 468–478. <https://doi.org/10.1002/aur.1329>
- Treede, R. D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Cohen, M., Evers, S., Finnerup, N. B., First, M. B., & Giamberardino, M. A. (2019). Chronic pain as a symptom or a disease: The IASP classification of chronic pain for the international classification of diseases (ICD-11). *Pain*, 160(1), 19–27. <https://doi.org/10.1097/j.pain.0000000000001384>
- Vaughan, S., McGlone, F., Poole, H., & Moore, D. J. (2020). A quantitative sensory testing approach to pain in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 50(5), 1607–1620. <https://doi.org/10.1007/s10803-019-03918-0>
- Voerman, J. S., de Klerk, C., Vander Heyden, K. M., Passchier, J., Idema, W., Timman, R., & Jolles, J. (2017). Pain is associated with poorer grades, reduced emotional well-being, and attention problems in adolescents. *The Clinical Journal of Pain*, 33(1), 44–50. <https://doi.org/10.1097/AJP.0000000000000367>
- Vu, J., Kushnir, V., Cassell, B., Gyawali, C. P., & Sayuk, G. S. (2014). The impact of psychiatric and extraintestinal comorbidity on quality of life and bowel symptom burden in functional GI disorders. *Neurogastroenterology & Motility*, 26(9), 1323–1332. <https://doi.org/10.1111/nmo.12396>
- Whitney, D. G., & Shapiro, D. N. (2019). National prevalence of pain among children and adolescents with autism spectrum disorders. *JAMA Pediatrics*, 173(12), 1203–1205. <https://doi.org/10.1001/jamapediatrics.2019.3826>
- Wong, M. L., & Widerstrom-Noga, E. (2021). Chapter 33 - Pain evaluation and management in neurodevelopmental conditions. In C. R. Martin, V. R. Preedy, & R. Rajendram (Eds.), *Diagnosis, management and modeling of neurodevelopmental disorders* (pp. 379–388). Academic Press. <https://doi.org/10.1016/B978-0-12-817988-8.00033-6>.
- Young, S., Hollingdale, J., Absoud, M., Bolton, P., Branney, P., Colley, W., Craze, E., Dave, M., Deeley, Q., Farrag, E., & Gudjonsson, G. (2020). Guidance for identification and treatment of individuals with attention deficit/hyperactivity disorder and autism spectrum disorder based upon expert consensus. *BMC Medicine*, 18(1), 146. <https://doi.org/10.1186/s12916-020-01585-y>