

Research priorities - Discussed at Learning Difficulties (Scotland) PSP workshop. Published September 2018

PSP Name	Total number of verified uncertainties identified by the PSP	Uncertainty	Date of the priority setting workshop	Rank of the uncertainty at the final workshop	Evidence (reference, and weblink where available, to the most recent relevant systematic reviews identified by the PSP) **
Learning Difficulties PSP	40	What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?	11th June 2018	1	<p>BM. Sutton, AA. Webster, MF. Westerveld (2018). A systematic review of school-based interventions targeting social communication behaviors for students with autism. Autism. doi: 10.1177/1362361317753564</p> <p>A. Booth, A. Scantlebury, A. Hughes-Morley, N. Mitchell, K. Wright, W. Scott, C. McDaid. (2017). Mental health training programmes for non-mental health trained professionals coming into contact with people with mental ill health: A systematic review of effectiveness. BMC Psychiatry. https://doi.org/10.1186/s12888-017-1356-5</p>
Learning Difficulties PSP	40	What is the best educational and community environment for children and young people with learning difficulties?	11th June 2018	2	<p>J. Andrews, M. Falkmer, S. Girdler. (2015). Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: a systematic review [with consumer summary]. Disability and Rehabilitation., 37(10): 825-833.</p> <p>J. J. Ellenkamp, E. P. Brouwers, P. J. Embregts, M. C. Joosen, J. van Weeghel. (2015). Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review</p> <p>BM. Sutton, AA. Webster, MF. Westerveld. (2018). A systematic review of school-based interventions targeting social communication behaviors for students with autism. Autism. doi: 10.1177/1362361317753564</p>
Learning Difficulties PSP	40	How can multiple types of professionals work together with parents and carers to improve identification, diagnosis, interventions and	11th June 2018	3	

Learning Difficulties PSP	40	Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?	11th June 2018	4	<p>I. Novak, C. Morgan, L. Adde, J. Blackman, et al. (2017). Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatrics. 171(9): 897-907. doi:10.1001/jamapediatrics.2017.1689</p> <p>M. Hadders-Algra, A.G. Boxum, T. Hielkema, E.G. Hamer. (2017). Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review. Developmental Medicine and Child Neurology. 59(3): 246-258. DOI: 10.1111/dmcn.13331</p> <p>K. H. Ryberg. (2015). Evidence for the Implementation of the Early Start Denver Model for Young Children With Autism Spectrum Disorder. Journal of American Psychiatric Nurses Association. 21(5): 327-337. DOI: 10.1177/1078390315608165</p>
Learning Difficulties PSP	40	What knowledge, skills and training do health, social work and "third sector" (e.g. charities and support services) professionals need to understand the best support to give children and young people with learning difficulties and their families/carers?	11th June 2018	5	<p>R. Spackman, A. Qureshi, D. Rai. (2016). A review of recommendations for medical undergraduate intellectual disability psychiatry teaching from UK reports. Advances in Mental Health and Intellectual Disabilities. 10(2): 158-163.</p> <p>M. Tatlow-Goldern, L. Prihodova, B. Gavin, W. Cullen, F. McNicholas. (2016). What do general practitioners know about ADHD? Attitudes and knowledge among first-contact gatekeepers: systematic narrative review. BMC Family Practice. 17(1): 129. doi: 10.118</p> <p>HT. Xie, L. Liu, J. Wang, K. E. Joon, R. Parasuram, J. Gunasekaran, C. L. Poh. (2015). The effectiveness of using non-traditional teaching methods to prepare student health care professionals for the delivery of mental state examination: a systematic review. JBI Database of Systematic Reviews and Implementation Reports. 13(7):177-212, JUL 2015</p>
					<p>L. Skotarczak and G. K. Lee. (2015). Effects of parent management training programs on disruptive behavior for children with a developmental disability: A meta-analysis. Research in Developmental Disabilities. 38: 272-287.</p>

Learning Difficulties PSP	40	How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis or identification in home, school and community contexts?	11th June 2018	6	<p>E. Vasilopoulou, J. Nisbet. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. Research in Autism Spectrum Disorders, 23: 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008</p> <p>N. Golfenshetin, E. Srulovici, B. Medoff-Cooper. (2015). Investigating Parenting Stress across Pediatric Health Conditions - A Systematic Review. Comprehensive Child & Adolescent Nursing. 39(1). https://doi.org/10.3109/01460862.2015.1078423</p>
Learning Difficulties PSP	40	How can we best identify early features, symptoms and signs of learning difficulties amongst children, young people and their families/carers?	11th June 2018	7	<p>J. L. Williams, J. Miciak, L. McFarland, J. Wexler. (2016). Learning disability identification criteria and reporting in empirical research: A review of 2001-2013. Learning Disabilities Research & Practice, 31(4): 221-229. DOI: 10.1111/ldrp.12119</p> <p>AF. El-Behadli, EN. Neger, EC. Perrin, RC. Sheldrick. (2015). Translations of Developmental Screening Instruments: An Evidence Map of Available Research. Journal of Developmental & Behavioral Pediatrics, 36(6): 471-483. DOI: 10.1097/DBP.0000000000000193</p> <p>L. Zwaigenbaum, ML. Bauman, D. Fein, et al. (2015). Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. Pediatrics, 136(suppl 1): S41-59. doi: 10.1542/peds.2014-3667D</p>
Learning Difficulties PSP	40	What is the best way to assess learning difficulties in children and young people?	11th June 2018	8	<p>N. Shishov, I. Melzer, S. Bar-Haim. (2017). Parameters and Measures in Assessment of Motor Learning in Neurorehabilitation: A Systematic Review of the Literature. Frontiers in Human Neuroscience, 11(82)</p> <p>K. Broome, P. McCabe, K. Docking, M. Doble. (2017). A Systematic Review of Speech Assessments for Children With Autism Spectrum Disorder: Recommendations for Best Practice. American Journal of Speech-Language Pathology, 26: 1011-1029. doi:10.1044/2017_AJSLP-16-0014</p> <p>L. Zwaigenbaum, ML. Bauman, D. Fein, et al. (2015). Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. Pediatrics, 136(suppl 1): S41-59. doi: 10.1542/peds.2014-3667D</p>

Learning Difficulties PSP	40	Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?	11th June 2018	9	<p>Z. Kileen, R. Bunch, JF. Kerrigan. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability Research: 61(5): 411-434. https://doi.org/10.1111/jir</p> <p>P. A. Gillen, M. Sinclair, W. G. Kernohan, C. M. Begley, A. G. Luyben. (2017). Interventions for prevention of bullying in the workplace. Cochrane Database of Systematic Review. DOI: 10.1002/14651858.CD009778.pub2</p> <p>M.A. Malli, R. Forrester-Jones, G. Murphy. (2015). Stigma in youth with Tourette's syndrome: a systematic review and synthesis. European Child & Adolescent Psychiatry, 25(2): 127-139. DOI 10.1007/s00787-015-0761-x</p>
Learning Difficulties PSP	40	Which strategies are effective in helping children and young people with learning difficulties live independent lives, including during times of transitions?	11th June 2018	10	<p>D. Hedley, M. Uljarevic, L. Cameron, S. Halder, A. Richdale, C. Dissanayake. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. Autism. 21(8): 929-941. DOI: 10.1177/136236</p> <p>J. J. Ellenkamp, E. P. Brouwers, P. J. Embregts, M. C. Joosen, J. van Weeghel. (2015). Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review</p> <p>J. D. Westbrook, C. J. Fong, C. Nye, A. Williams, O. Wendt, T. Cortopassi. (2015). Transition Services for Youth With Autism: A Systematic Review. Research on Social Work Practice. 25(1): 10-20. DOI: 10.1177/1049731514524836</p>
Learning Difficulties PSP	40	What are the factors contributing to the delay for children and young people with learning difficulties in referral for, and differences in, a learning difficulties assessment and diagnosis, support and interventions?	11th June 2018	11	<p>M. Naseem, AH Shah, MF. Khyani, Z. Khurshid, MS Zafar, S. Gulzar, AH Aljameel, HS. Khalil. (2017). Access to oral health care services among adults with learning disabilities: a scoping review. Annali di Stomatologia. 7(3): 52-59. doi: 10.11138/ads/2016.</p> <p>M. Jacobs, H. Downie, G. Kidd, L. Fitzsimmons, S. Gibbs, C. Melville. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. British Journal of Learning D</p>

					R. Balogh, C. A. McMorris, Y. Lunsky, H. Ouellette-Kuntz, L. Bourne, A. Colantonio, D. C. Goncalves-Bradley. (2016). Organising healthcare services for persons with an intellectual disability (Review). Cochrane Database of Systematic Review. DOI: 10.1002/14651858.CD007492.pub2
Learning Difficulties PSP	40	How does a learning difficulty affect or interfere with a child or young person's ability and experience in learning?	11th June 2018	12	J. McDaniel, K. D'Ambrose Slaboch, P. Yoder (2018). A meta-analysis of the association between vocalizations and expressive language in children with autism spectrum disorder. Research in Developmental Disabilities. vol. 72, 202-213. doi: 10.1016/j.ridd.2017.1 P. Peng and D. Fuchs. (2017). A Meta-Analysis of Working Memory Deficits in Children With Learning Difficulties: Is There a Difference Between Verbal Domain and Numerical Domain? Journal of Learning Disabilities. 49(1): 3-20 J. C. A. W. Peijnenborgh, P. M. Hurks, A. P. Aldenkamp, J. S. H. Vles and J. G. M. Hendriksen. (2016). Efficacy of working memory training in children and adolescents with learning disabilities: A review study and meta-analysis. Neuropsychological Rehabilitation, 26(5-6): 645-672. https://doi.org/10.1080/09602011.2015.1026356
Learning Difficulties PSP	40	Which family, school and community supports are effective in preparing children, young people and their families/carers to transition through different stages of schooling/education and through children and young people's services into adult services?	11th June 2018	13	A. Marsh, V. Spagnol, R. Grove, V. Eapen. (2017). Transition to school for children with autism spectrum disorder: A systematic review. World Journal of Psychiatry. 7(3): 184-196. doi: 10.5498/wjp.v7.i3.184 G. Young-Southward, C. Philo, S-A. Cooper. (2017). What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review. Journal of Applied Research in Intellectual Disabilities. 30(5): 805-823. DOI J. D. Westbrook, C. J. Fong, C. Nye, A. Williams, O. Wendt, T. Cortopassi. (2015). Transition Services for Youth With Autism: A Systematic Review. Research on Social Work Practice. 25(1): 10-20. DOI: 10.1177/1049731514524836

Learning Difficulties PSP	40	Why are children and young people with learning difficulties more likely to experience mental health problems?	11th June 2018	14	<p>M. Jacobs, H. Downie, G. Kidd, L. Fitzsimmons, S. Gibbs, C. Melville. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. British Journal of Learning D</p> <p>C. Walton, M. Kerr. (2015). Down syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. ADVANCES IN MENTAL HEALTH AND INTELLECTUAL DISABILITIES. 9(4): 151-162. DOI 10.1108/AMHID-11-2014-0037</p> <p>C. Walton & M. Kerr. (2015). Prader Willi syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. Advances in Mental Health and Intellectual Disabilities. 10(3) 172-184. DOI10.1108/AMHID-08-2015-0037</p>
Learning Difficulties PSP	40	What effect does having a formal label or a diagnosis have on children and young people living with a learning difficulty and those involved in their care and the public?	11th June 2018	15	<p>HH. Koester, S. Arthanat. (2017). Effect of diagnosis, body site and experience on text entry rate of individuals with physical disabilities: a systematic review. Disability and Rehabilitation, 13(3). https://doi.org/10.1080/17483107.2017.1369588</p> <p>C. A. Melville, A. Oppewal, E. L. Schafer, E. Freiburger, M. Guerra-Balic, et al. . (2017). Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities - A systematic review. Preventive Medicine, 97: 62-71. http://dx.doi.org/10.1016/j.ypmed.2017.04.008</p> <p>H. Galloway, E. Newman. (2017). Is there a difference between child self-ratings and parent proxy-ratings of the quality of life of children with a diagnosis of attention-deficit hyperactivity disorder (ADHD)? A systematic review of the literature. ADHD</p>
					<p>B. Perelmutter, K. K. McGregor, K. R. Gordon. (2017). Assistive technology interventions for adolescents and adults with learning disabilities: An evidence-based systematic review and meta-analysis. Computer & Education. 114: 139-163. http://dx.doi.org/10.1016/j.compedu.2017.04.008</p>

Learning Difficulties PSP	40	Which information and communication technologies (ICT) (e.g. augmentative and alternative communication (AAC) devices, ICT-based communication aids, assistive technology, iPads/writing aids/tablet/phone) are effective and how can they best be accessed by children and young people with learning difficulties?	11th June 2018	16	<p>M. Linden, C. Hawley, B. Blackwood, J. Evans, V. Anderson, C. O'Rourke. (2016). Technological aids for the rehabilitation of memory and executive functioning in children and adolescents with acquired brain injury. Cochrane Database of Systematic Review. DOI: 10.1002/14651858.CD011020.pub2</p> <p>Antonio Miguel Cruz, Adriana María Ríos Rincón, William Ricardo Rodríguez Dueñas, Daniel Alejandro Quiroga Torres & Andrés Felipe Bohórquez- Heredia. (2017). What does the literature say about using robots on children with disabilities? Disability, 12(5). https://doi.org/10.1080/17483107.2017.1318308</p>
Learning Difficulties PSP	40	How can we improve public awareness about learning difficulties and what is the impact of any improvement in awareness on the wellbeing of people with learning difficulties?	11th June 2018	17	<p>K. Boshoff, D. Gibbs, R. L. Phillips, L. Wiles, L. Porter. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. Child: Care, Health and Development. 42(6):</p> <p>H. A. Pelleboer-Gunnink, W. M. W. J. Van Oorsouw, J. Van Weeghel, P. J. C. M. Embregts. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability</p>
Learning Difficulties PSP	40	What are the best measures of outcomes (e.g. academic skills, peer relationships, quality of life, classroom participation) for children and young people with learning difficulties?	11th June 2018	18	<p>E. Vasilopoulou, J. Nisbet. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. Research in Autism Spectrum Disorders, 23: 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008</p> <p>T. Gomersall, S. Spencer, H. Basarir, et al. (2015). Measuring quality of life in children with speech and language difficulties: a systematic review of existing approaches. International Journal of Language Communication Disorder, 50(4): 416-435. DOI: 10</p> <p>C. Oh-Young and J. Filler. (2015). A meta-analysis of the effects of placement on academic and social skill outcome measures of students with disabilities. Research in Developmental Disabilities, 47: 80-92. doi: 10.1016/j.ridd.2015.08.014.</p>

Learning Difficulties PSP	40	Which parenting approaches and strategies are most helpful for young parents or carers who themselves have learning difficulties?	11th June 2018	19	<p>E. van den Broek, A. J. P. M. van Eijden, M. M. Overbeek, S. Kef, P. S. Sterkenburg, C. Schuengel. (2017). A systematic review of the literature on parenting of young children with visual impairments and the adaptations for Video-feedback Intervention to promote positive parenting (VIPP). Journal of Developmental and Physical Disability, 29(3): 503-545. doi: 10.1007/s10882-016-9529-6</p> <p>J. L. Park, K. L. Hudec, C. Johnston. (2017). Parental ADHD symptoms and parenting behaviours: A meta-analytic review. Clinical Psychology Review, 56: 25-39</p>
Learning Difficulties PSP	40	Which strategies are effective in increasing the support available for children and young people with learning difficulties, and their families/carers, in out-of-school activities?	11th June 2018	20	<p>A. M. McGarty, C. A. Melville. (2017). Parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities: A mixed methods systematic review. Research in Developmental Disabilities, 73: 40-57.</p>
Learning Difficulties PSP	40	How can we understand what it is like to live with learning difficulties from a child or young person's perspective?	11th June 2018	21	<p>Domeij, H. Fahlstrom, G. Bertilsson, G., et al. (2018). Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. Developmental Medicine & Child Neurology. DOI: 10.1111/dmcn.13696</p> <p>MA. Rashid, S. Lovick, NR. Llanwarne. (2017). Medication-taking experiences in attention deficit hyperactivity disorder: a systematic review. Family Practice, 1-9. https://doi.org/10.1093/fampra/cmx088</p> <p>S. Lindsay. (2016). Child and youth experiences and perspectives of cerebral palsy: a qualitative systematic review. Child: Care, Health and Development, 42(2): 153-175. doi:10.1111/cch.12309</p>
Learning Difficulties PSP	40	What strengths do children and young people with learning difficulties have?	11th June 2018	22	
Learning Difficulties PSP	40	What percentage of children and young people with learning difficulties receive the appropriate care and support that meets their needs at home.	11th June 2018	23	
					<p>J. McDaniel, K. D'Ambrose Slaboch, P. Yoder (2018). A meta-analysis of the association between vocalizations and expressive language in children with autism spectrum disorder. Research in Developmental Disabilities, vol. 72, 202-213. doi: 10.1016/j.ridd.2017.1</p>

Learning Difficulties PSP	40	How do learning difficulties affect the everyday life of children and young people living with a learning difficulty and those involved in their care?	11th June 2018	24	<p>P. Peng and D. Fuchs. (2017). A Meta-Analysis of Working Memory Deficits in Children With Learning Difficulties: Is There a Difference Between Verbal Domain and Numerical Domain? Journal of Learning Disabilities. 49(1): 3-20</p> <p>J. C. A. W. Peijnenborgh, P. M. Hurks, A. P. Aldenkamp, J. S. H. Vles and J. G. M. Hendriksen. (2016). Efficacy of working memory training in children and adolescents with learning disabilities: A review study and meta-analysis. Neuropsychological Rehabilitation, 26(5-6): 645-672. https://doi.org/10.1080/09602011.2015.1026356</p>
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Research priorities - Learning Difficulties (Scotland) PSP. Published September 2018

Original survey submissions within the published priorities

ID	Uncertainty	Original Uncertainty	Source of Uncertainty	Evidence (reference, and weblink where available, to the most recent relevant systematic review identified by the PSP) **
1	What are the causes of learning difficulties?	What are the underlying causes?	A professional	A. Pascal, P. Govaert, A. Oostra, G. Naulaers, E. Ortibus, C. van den Broeck. (2018). Neurodevelopmental outcome in very preterm and very-low-birthweight infants born over the past decade: a meta-analytic review. Developmental Medicine & Child Neurology.
		Understanding the possible causes of learning disabilities.	A professional	SL Prady, I. Hanlon, LK Fraser, A. Mikoxoka-Walus. (2017). A systematic review of maternal antidepressant use in pregnancy and short- and long-term offspring's outcomes. Archives of Women's Mental Health, p 1-14. DOI 10.1007/s00737-017-0780-3
		What has caused the learning disability	A parent/carer	CE Sanchez, C. Barry, A. Sabhlok, K. Russell, A. Majors, SH. Kollins, BF. Fuemmeler. (2017). Maternal pre-pregnancy obesity and child neurodevelopmental outcomes: a meta-analysis. Obesity Reviews. DOI: 10.1111/obr.12643
		What are the main causes of learning difficulties?	A parent/carer	S. J. Stock, L. Bricker, J. E. Norman, H. M. West. (2016). Immediate versus deferred delivery of the preterm baby with suspected fetal compromise for improving outcomes. Cochrane Database of Systematic Review, 7. DOI: 10.1002/14651858.CD008968.pub3
		What are the causes of learning difficulties?	A parent/carer	
		Causes of learning difficulties, investigations	A professional	
		To what extent is neurodiversity genetic, traumatic birth and down to other external factors?	An adult who experienced learning difficulties as a child, a parent/carer & a professional	
		Could genetic factors and social/recreational drug use lead to the development of learning difficulties/disability in a child.	A parent/carer	
		Causes for LD	A professional	
		1. what are the causes? Brain damage due to maternal alcohol use in pregnancy is something Im becoming more aware of. Cases presenting in young adults with histories of LD & impulsivity who have been given lots of other diagnosis - they lack the classic facial features so have been overlooked.	A professional	
		What was the cause?	A parent/carer	
		Identifying underlying causes- genetic etc- I think this is often overlooked and feel strongly that families should be offered investigations- not to change/fix child but to help families come to terms and/or plan for future.	A professional	
		ANY UNIFYING CAUSE	A professional	
		Causes especially ones in families, where there is no diagnostic genetic problem identified.	A professional	
		What are the causes of specific learning difficulties such as dyslexia, dyscalculia etc	A professional	
		I would like to know causes of autism (but realise that can lead to guilt if research finds it is caused by, for example, formula feeding or having a section).	A parent/carer	
		What causes autism?	A parent/carer	
		What is the cause of/diagnosis of the learning disability?	A parent/carer	
		What causes asd? How much does intervention help?	A parent/carer	
		Is there any genetic information relation to family members having autism?	A professional	
		What effects Class A drugs (e.g. Heroin, Crack cocaine) can have on an unborn baby's brain development?	A parent/carer	
		Causes would like to see research into bacterial issues, some stats on instances of lyme and h.pylori in people with LD. Rates of c sections, birth issues, age of parents etc. Common themes??	A parent/carer	
		Based on anecdotal evidence/feedback: Myself and a few other have had children under the age of 5 who received Chemotherapy and or radiotherapy for cancer. Unless the child has a clearly identifiable condition eg: Brain tumour or for e.g. hearing deficit due drug side effects, these children are not assessed for learning difficulties when they go to school. Given the nature and length of treatment I think all children in these circumstances should be routinely screened at some point. So my first question would be about chemotherapy and radiotherapy as a possible cause for learning difficulties.	A parent/carer	
		Causes of learning difficulties	A parent/carer	
		Causes	A parent/carer	
		Why do I have a condition?	Young person	
		Why do I have things like T.S.	Young person	
		What are the causes of developmental disabilities and what could be done to prevent them, or successfully treat them?	A parent/carer	
		As an expert in the subject of cerebral visual impairment I shall pose three questions and answer them as well: 1. Is cerebral visual impairment a common or significant cause of learning difficulties? Answer: The prevalence is likely to be in the region of 0.7% (qv Williams K Dutton GN on PubMed) It is highly significant because identification and implementation of matched parenting and teaching strategies can turn an affected child's life round.	A professional	
		Definitely genetic causes	A parent/carer	
Is there a genetic link	A parent/carer			
Causes would like to see research into bacterial issues, some stats on instances of lyme and h.pylori in people with LD. Rates of c sections, birth issues, age of parents etc. Common themes??	A parent/carer			
From personal experience, I believe that some of my friend's children have been quickly diagnosed with ADHD and/or "being on the spectrum" when a lot of the time they are playing up as their Mum's spends a lot of time on their phones and don't play with the child, or encourage reading skills, routines, etc. Have you also encountered this?	A professional			
More investigation of effect of genetics and environment on people with learning difficulties. Should be accept that genetics is sometimes the cause, or can we improve things if we alter things in the environment, particularly concerning diet, treatments, health and wellbeing approach.	A parent/carer			

2	What are the chances of learning difficulties being passed down to the next generation?	Will my dyslexic children pass dyslexia down to their children.	A parent/carer	D. Cotter, A. Kelso, A. Neligan. (2017). Genetic biomarkers of posttraumatic epilepsy: A systematic review. Seizure, 46: 53-58. http://dx.doi.org/10.1016/j.seizure.2017.02.002
		How are genetics involved, what can we learn from our parents with dyslexia	An adult who experienced learning difficulties as a child	PY. Yang, YJ. Menga, T. Li, Y. Huang. (2017). Associations of endocrine stress-related gene polymorphisms with risk of autism spectrum disorders: Evidence from an integrated meta-analysis. Autism Research, 10(11): 1722-1736. DOI: 10.1002/aur.1822 B. Tick, P. Bolton, F. Happe, M. Rutter, F. Rijdsdijk. (2016). Heritability of autism spectrum disorders: a meta-analysis of twin studies. Journal of Child Psychology and Psychiatry, 57(5): 585-595. doi:10.1111/jcpp.12499
3	How can we best identify early features of learning difficulties within individuals and families?	Can genetic conditions known to cause learning difficulties be identified in babies?	A parent/carer	HT. Xie, L. Liu, J. Wang, K. E. Joon, R. Parasuram, J. Gunasekaran, C. L. Poh. (2015). The effectiveness of using non-traditional teaching methods to prepare student health care professionals for the delivery of mental state examination: a systematic review. JBI Database of Systematic Reviews and Implementation Reports, 13(7):177-212, JUL 2015
		Current research suggests that children with autism can be diagnosed as early as infants based on how specific social interactions and eye gaze/attention. Is there any research like this being conducted on families with a history of learning disabilities?	An adult who experienced learning difficulties as a child	AF. El-Behadli, EN. Neger, EC. Perrin, RC. Sheldrick. (2015). Translations of Developmental Screening Instruments: An Evidence Map of Available Research. Journal of Developmental & Behavioral Pediatrics, 36(6): 471-483. DOI: 10.1097/DBP.0000000000000193
		Identifying underlying causes- genetic etc- I think this is often overlooked and feel strongly that families should be offered investigations- not to change/fix child but to help families come to terms and/or plan for future.	A professional	L. Zwaigenbaum, ML. Bauman, D. Fein, et al. (2015). Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. Pediatrics, 136(suppl 1): S41-59. doi: 10.1542/peds.2014-3667D
		Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; who informs the family of this; what age will this be decided upon; is it possible to change category; how does a genetic component affect this diagnosis, for example Down's syndrome	A parent/carer	
		Should all patients diagnosed with Learning Disability have access to genetic testing?	A professional	
		What are the second line investigations to make a diagnosis of causes that are amenable to specific genetic counselling	A professional	
		What are the first line investigations to screen for potentially treatable causes	A professional	
		Neurological differences in dyslexia and how it impacts on learning and how to overcome. Which a view to better understanding and effective learning strategies and approaches	A parent/carer	
		What parts of the brain are affected if you have a learning disability.	A professional	
		what are the physiological differences within the brain of someone with Asperger.	An adult who experienced with learning difficulties as a child	
		What are the most common learning difficulties a child with FAS is likely to have?	A professional	
		How can we differentiate learning and language difficulties from normal bilingual development when some of the characteristics are similar in the early stages of a child's development?	A professional	
		How can learning difficulties be assessed in children who are non-verbal	A parent/carer	
		In the younger child what assessments may be helpful in determining whether difficult behaviour is within normal development or is due to a learning disability?	A professional	
		What are the early signs of these specific learning difficulties and is there an easy way for teachers to screen early enough that strategies can be put in place before they fall behind with their work	A professional	
		Diagnosing dyslexia - How to recognise it.	An adult who experienced learning difficulties as a child	
		How to pick up on learning difficulties at an early stage, by being able to identify these difficulties and then going about exploring diagnosing these difficulties.	A professional	
		My daughter was induced due to umbilical cord resistance, she wasn't gaining weight during pregnancy and she had a low birth weight. It is now known that this can cause learning difficulties. I knew from age 2 that my daughter had Dyspraxia. Question 1. Why did it then take 6 years for my daughter to be diagnosed with Dyspraxia how can we diagnose and support children sooner?	A parent/carer	
		Are there any early indicators for learning difficulties that are missed regularly at preschool and nursery stage?	A professional	
		Why is children with dyslexia not tested at a younger age when it is known they have it.	A parent/carer	
		What are the best ages for formally diagnosing different learning difficulties?	A professional	
		What's the youngest age dyslexia and Irlens can be diagnosed.	A parent/carer	
		Why does it take professionals so long to diagnose learning disabilities when it is clear there is something so very wrong from an early age?	A parent/carer	
		Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; who informs the family of this; what age will this be decided upon; is it possible to change category; how does a genetic component affect this diagnosis, for example Down's syndrome	A parent/carer	
		the crucial importance of early intervention - put off by school saying they couldn't test for a spld- ie dyslexia until she was 7 - feel that crucial time had passed by - surely there are early detection strategies OR more specifically - what specific research has gone into early detection of specific learning difficulties-	A parent/carer	
		My daughter was induced due to umbilical cord resistance, she wasn't gaining weight during pregnancy and she had a low birth weight. It is now known that this can cause learning difficulties. I knew from age 2 that my daughter had Dyspraxia. Question 1. Why did it then take 6 years for my daughter to be diagnosed with Dyspraxia how can we diagnose and support children sooner?	A parent/carer	
		2. how can diagnosis be made sooner? (to allow timely interventions)	A professional	
		Why does it take till p5 in scotland to start tests for dyslexia? Is there any support out with school to help a child advance?	A parent/carer	
Early diagnosis of treatable/modifiable causes of learning difficulties	A professional - Paediatrician			
Help with early diagnosis, how to avoid the child falling through the gap as 'naughty'	A parent/carer			
Can learning difficulties be picked up sooner so that children have better access to intense early support to reach a better potential?	A parent/carer			
the crucial importance of early intervention - put off by school saying they couldn't test for a spld- ie dyslexia until she was 7 - feel that crucial time had passed by - surely there are early detection strategies OR more specifically - what specific research has gone into early detection of specific learning difficulties-	A parent/carer			
Should learning difficulties be diagnosed, and if so whose role is it and what would be best practice?	A professional			
How important is it, especially to parents, to get a diagnosis?	A parent/carer			
Can we evidence whether it is beneficial for a person to have a formal diagnosis of learning difficulty or not? (I find there are differing views in health and education about the benefit of a formal diagnosis).	A professional			
Why is there such a limited drive towards diagnosis? - it appears that only the most severe or articulate parents can gain a diagnosis. Diagnosis can give some relief and clarity, allowing clearer treatment and resource pathways, it can also increase parent carer advocacy and voice.	A professional			
Is there a stage where it's too late to see improvements in speech and learning in children with Downs Syndrome	A parent/carer			
I work in a school; how accurate is the diagnosis once it's made? And in the event if a misdiagnosis what steps are put in place to assist child, family and professionals?	A professional			
Does a diagnosis of ADHD help to motivate parents to put in more consistent behavioural strategies or does it demotivate them as they believe the child "can't help it" and only medication can make a difference.	A professional			
How can the social effects of having learning difficulties and a autistic spectrum disorder be differentially diagnosed?	A professional			

<p>I would like a more defined and consistent definition of Learning Disability that professionals and parents can use as a guide. Often Learning Disability is a vague term, and not every learning disability is the same. My son is severely physically disabled, but has a high level of understanding. He is often referred to as having learning disability, because he has a lot of physical barriers to learning. From that point of view, he could be described as having a learning disability, and of course, this then affects how he is treated and what he is taught, but I am not sure that I agree. I agree that my son needs to be taught in a different way because of his physical disabilities, but I don't agree that he should be taught at a different level from his peers. My partner, on the other hand has high functioning Asperger's Syndrome, and is treated in a normal way and expected to understand things his brain can't process. If you were to ask me which of these two people had a learning disability, I would say that it was my partner, and not my son. It is very frustrating for me as a parent because the term "Learning Disability" is used as a way to lump people together, and there is often an assumption of a lack of intelligence and understanding, which isn't always the case. I would like to see research leading to more definition and understanding of the different types of learning disability, so that people with different needs can get the help they need which is tailored for them. This might only happen if we moved away from the generic term "Learning Disabled".</p>	<p>A parent/carer</p>	
<p>How can we distinguish between a condition on the Autistic Spectrum and the adverse neuro-developmental effects of trauma and neglect in a child and does it matter?</p>	<p>A parent/carer</p>	
<p>Identifying learning disabilities when there is a diagnosis of ASD. When a diagnosis of ASD is given this is then the full focus of future interventions and LD often not identified or not openly discussed. Other dual diagnosis where LD is often given as a secondary diagnosis, but has a considerable impact on learning and levels of functioning.</p>	<p>A professional</p>	
<p>How does the pattern of cerebral visual impairment differ in the developmental disorders</p>	<p>A professional</p>	
<p>Can ADHD be accurately diagnosed in the presence of ongoing child protection concerns?</p>	<p>A professional</p>	
<p>What is the best way to screen for learning difficulties. How can a test distinguish the effects of anxiety from dyslexia/dysplasia etc</p>	<p>A parent/carer</p>	
<p>What is the best way to screen for learning difficulties. How can a test distinguish the effects of anxiety from dyslexia/dysplasia etc</p>	<p>A parent/carer</p>	
<p>How is anxiety linked to learning difficulties? Many students seem to have issues of anxiety in addition to their learning difficulties. Is this a part of the learning difficulty or a product of it?</p>	<p>A professional</p>	
<p>Question: Are children with autism at risk of autism? Answer: Yes. Many have dorsal stream dysfunction (see published literature). This is not an epiphenomenon, it is highly likely to be causative. Simultanagnostic vision leads to only a limited amount being seen. Unless understood this can be misinterpreted as lack of theory of mind, because the child affected cannot share attention for what is not available for the to see. Lack of ability to see the language of facial expression can be due to simultanagnostic vision and to associated dyskinetopsia. In this context, it is the we who lack the theory of mind of the child and misinterpret this as autism.</p>	<p>A professional</p>	
<p>What impact does autism have on learning disability and vice-versa?</p>	<p>A professional</p>	
<p>Are 'social conversation' difficulties in children always linked to ASD?</p>	<p>A parent/carer</p>	
<p>Relationship between disrupted attachment and features of autism</p>	<p>A professional</p>	
<p>How does disrupted early education – especially through school exclusion impact on the development of literacy skills, specially writing, reading</p>	<p>A professional</p>	
<p>What support is in place is a diagnosis is not given, as in you were 1 point short of qualifying for a diagnosis? Many services will not offer help or support without a diagnosis.</p>	<p>A parent/carer</p>	
<p>How can we diagnose, define and help those with learning difficulties who also have complex needs that may mask those difficulties?</p>	<p>A parent/carer</p>	
<p>We are seeing many more behavioural difficulties in schools. How can we ensure that behaviour does not get in the way of a true diagnosis?</p>	<p>A professional</p>	
<p>What can we do when we know that a child has potential because you have seen evidence of cognitive ability and understanding beyond what is expected or described as possible by practitioners and others? The problem presents as the child is not using that ability to the full.</p>	<p>A parent/carer</p>	
<p>Identifying learning disabilities when there is a diagnosis of ASD. When a diagnosis of ASD is given this is then the full focus of future interventions and LD often not identified or not openly discussed. Other dual diagnosis where LD is often given as a secondary diagnosis, but has a considerable impact on learning and levels of functioning.</p>	<p>A professional</p>	
<p>How many children with cerebral palsy have cortical (cognitive) visual impairment. What are the implications of this?</p>	<p>A professional</p>	
<p>How aware are teachers, speech and language therapist etc about the condition and the impact of this on learning and intervention.</p>	<p>A professional</p>	
<p>What are the factors which can prevent the diagnosis of LD?</p>	<p>A professional</p>	
<p>What are the barriers to children accessing neurodevelopmental assessments</p>	<p>A professional</p>	
<p>Why does my son not talk? He has no physical impairment to prevent him from verbalising, and he doesn't have autism or any other obvious social anxiety for not speaking.</p>	<p>A parent/carer</p>	
<p>Is a learning disability only given if you are below the required IQ level?</p>	<p>A professional</p>	<p>N. Shishov, I. Melzer, S. Bar-Haim. (2017). Parameters and Measures in Assessment of Motor Learning in Neurorehabilitation: A Systematic Review of the Literature. Frontiers in Human Neuroscience, 11(82)</p>
<p>Can the criteria for being diagnosed be changed? The threshold for being diagnosed. What support is in place is a diagnosis is not given as you were 1 point short.</p>	<p>A parent/carer</p>	<p>K. Broome, P. McCabe, K. Docking, M. Doble. (2017). A Systematic Review of Speech Assessments for Children With Autism Spectrum Disorder: Recommendations for Best Practice. American Journal of Speech-Language Pathology, 26: 1011-1029. doi:10.1044/2017_AJSLP-16-0014</p>
<p>Can the threshold for being diagnosed be changed?</p>	<p>A parent/carer</p>	<p>L. Zwaigenbaum, M.L. Bauman, D. Fein, et al. (2015). Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. Pediatrics, 136(suppl 1): S41-59. doi: 10.1542/peds.2014-3667D</p>
<p>Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; who informs the family of this; what age will this be decided upon; is it possible to change category; how does a genetic component affect this diagnosis, for example Down's syndrome</p>	<p>A parent/carer</p>	
<p>How to pick up on learning difficulties at an early stage, by being able to identify these difficulties and then going about exploring diagnosing these difficulties.</p>	<p>A professional</p>	
<p>What are the stages in diagnosing a learning difficulty or learning disability?</p>	<p>A professional</p>	
<p>What helps and identification and diagnosing learning difficulties.</p>	<p>A professional</p>	
<p>HOW TO DIAGNOSE AND DIFFERENTIATE VARIOUS STRANDS OF LEARNING DIFFICULTIES PARTICULARLY WHAT REQUIRED TO CONFIRM "LEARNING DISABILITY"</p>	<p>A professional</p>	
<p>What are the processes involved when diagnosing someone with autism?</p>	<p>A professional</p>	
<p>What testing should my daughter have to identify her issues?</p>	<p>A parent/carer</p>	
<p>What is the process for diagnosing a learning disability</p>	<p>A professional</p>	
<p>The best way to identify and diagnose learning difficulties.</p>	<p>A professional</p>	
<p>Identifying</p>	<p>A parent/carer</p>	
<p>Easy to use tool to diagnose a learning disability</p>	<p>A professional</p>	
<p>How do people go about having their learning disability diagnosed?</p>	<p>A professional</p>	
<p>How do we diagnose children with a learning difficulty.</p>	<p>A professional</p>	
<p>How accurate/reliable is the diagnosis of learning difficulties?</p>	<p>A parent/carer</p>	
<p>•identifying or diagnosing learning difficulties</p>	<p>A professional</p>	
<p>what is the best way to identify children with dyslexia as each authority has different methods</p>	<p>A professional</p>	
<p>Can we get tests which improve the accuracy of diagnosis?</p>	<p>A professional</p>	

4

What is the best way to assess learning difficulties in children and young people?

Can we have clear diagnosis, implications in the classroom /home, interventions which would help on a grid/worksheet for teachers to use.	A professional	
Despite having a team of professionals involved from 2007 (age 3) we had no diagnosis for our son and were told in 2010 we may never find out what was wrong. So we requested to be referred to the Communication Clinic at the Sick Kids where we received a diagnosis in 2011. It is key that the most relevant professional/s need to be involved with the parent and child from the earliest opportunity to ensure they receive informed input from professionals who specialise in the difficulties demonstrated. An understanding and diagnosis is key to be able to provide the correct support to the family and child at home, in education and the wider community. Without the correct understanding, how can the most appropriate and meaningful supports be put in place by parents and professionals?	A parent/carer	
I work in a school; how accurate is the diagnosis once it's made? And in the event if a misdiagnosis what steps are put in place to assist child, family and professionals?	A professional	
Could a Pathway for identifying and clearly diagnosing Learning Disability be developed in Lothian?	A professional	
Identifying learning difficulties in the financially challenging situation - as paediatrician we diagnose global delay/learning difficulties in preschool children. In school age population we have no educational psychologists doing any formal, standardised assessments of learning.	A professional	
what is the best clinical pathway for the diagnosis of learning disability?	A professional	
How does we diagnose and identify specific learning difficulties?	A professional	
How many areas have a pathway to assess and diagnose learning difficulties?	A professional	
Can tests be done to try and establish this	A parent/carer	
Should learning difficulties be diagnosed, and if so whose role is it and what would be best practice?	A professional	
My daughter is 6. She did not speak until she was almost 5. She struggled to learn her letters and couldn't read at P2. She knew 11 letter sounds. A SALT who practices the Johansen Method of retraining auditory processing was recommended to me. My daughter is 10 months in to what has been a very inexpensive treatment, she can read and write independently, is now entirely decipherable to anyone and she approaches people on the street and engages them in chat-such is her confidence. She is unrecognisable. How likely is it that this issue will be diagnosed in schools and treated? (Without this treatment which costs a fraction of the price of some common anticoagulants per month-people with altered auditory processing go on to live a fraction of their potential)	A parent/carer	
What are the most effective methods for assessing and identifying learning difficulties?	A professional	
Improving the diagnosis and assessment of children and young people, to give a more comprehensive picture of their difficulties and how these can be supported and treated.	A professional	
Identifying and diagnosing learning difficulties post cancer treatment (or any other similar treatment that can affect neuro psychometric pathways) can be difficult if there is no previous baseline (apart from the read child health booklet). I am sure there must be a way to identify high risk groups both pre and post treatment - I would think this would benefit from a meta analysis.	A parent/carer	
What is the cause of/diagnosis of the learning disability?	A parent/carer	
What are the processes (and are they robust) for identifying specific learning disorders such as dyslexia and dyscalculia.	A professional	
what is the best way to identify children with dyslexia as each authority has different methods	A professional	
Is there formal methods for diagnosing dyslexia in Edinburgh and the lothians?	A professional	
How can dyscalculia be better diagnosed?	A parent/carer	
What is the cause of/diagnosis of the learning disability?	A parent/carer	
What is the best way to screen for learning difficulties. How can a test distinguish the effects of anxiety from dyslexia/dysplasia etc.	A parent/carer	
Easier way of identifying a diagnosis, e.g. when my son was younger we had to wait until school age before getting the necessary help. Why not listen more carefully to the parents?	A parent/carer	
What measures could be put in place for detecting ADHD, and the slightly more subtle ADD, during primary school years?	A parent/carer	
How can we speed up the diagnostic process?	A professional	
Why does it take so long for a diagnosis	A professional	
Why does it take so long diagnosis an learning difficult?	A parent/carer	
Why does diagnosis take so long - years, rather than months - and what can parents do to support their kids before a diagnosis? One issue is that if your child is well behaved in school, but crying and hating the thought of going to school at home, homework tantrums etc, then it means you may have to be a bit of a "fussy" parent to help them access support. I think this is purely down to the lack of funding, which is probably the most important issue, though our son has been one of the lucky ones to access great support at his school.	A parent/carer	
How can we ensure that Learning Disabilities and Learning Difficulties are identified as early as possible?	A professional	
Is more going to be done in helping children and adults to get a dyspraxia diagnosis?	An adult who experienced learning difficulties as a child	
Could schools be given more opportunity to refer children they think may have learning difficulties. It can be a long drawn out process that can take years.	A parent/carer	
There are so many leaning difficulties can brain scans detect these	A parent/carer	
What are the more microscopic brain changes which have caused my son's LD? He has a very rare genetic condition and his brain scan only shows some lack of development of the corpus callosum and some other minor changes but nothing obvious of cause such as a significant LD	A parent/carer	
Would/should imaging (i.e. MRI/CT) have more of a routine part to play in diagnostics	A parent/carer	
Because educational and clinical psychology services are so stretched (virtually absent) can there be a validated on line tool for teachers, parents and community paediatricians to access? Could include adaptive functioning, IQ/ CAIDS Q type assessments, but also look at auditory processing, mental health (SDQ) etc etc	A professional	
Checklists have been shown to be effective in other healthcare settings at reducing risk and improving outcomes, and while they do not take the place of good clinical assessment, is there benefit of having a 'transition checklist' for 5, 11, and 15 yr olds. (could be separated in medical/ educational/ social sections)?	A professional	
What would be the impact of screening pupils for SpLDs by using Lucid's LASS?	A professional	
Detailed research to develop recognised standardised assessments for SLD children regarding sensory issues	A parent/carer	
Need to know how to refer and diagnose children with borderline difficulties	A professional	
What is the best way to identify and support mild learning difficulties, that may not immediately be apparent?	A professional	
There are sometimes young people with learning difficulties try to hide the issues they have from others and will go to great lengths to do so. How best can young people be identified as having learning difficulties especially when it is not immediately obvious to others?	A parent/carer	
What would a small scale screening programme for visual difficulties show - in relation to reading levels?	A professional	
How can we move away from a medical model and a reliance on cognitive assessments?	A professional	
Why many young people with moderate learning disabilities are un-diagnosed and struggling in mainstream education. Often resulting in psychiatric admissions. Effective treatments being changes in environments.	A professional	
Can dyspraxia be misdiagnosed as ASD?	A parent/carer	
Is there an increase in ADHD being recognised as a learning difficulty?	A professional	
Why do researchers automatically link LD with ASD without making it clear the latter does not necessarily have the former?	A parent/carer	
What is the appropriate tool for diagnosing ASD in girls, the presenting symptoms can be very different, is it possible to revisit diagnostic tools reflecting the work done to date on female characteristics?	A professional	
It would be helpful to have literature review into diagnosis of learning disability, who provides assessment and diagnosis, taking into account the role of clinical and educational psychology and other health, education and social work professionals contributions to assessment and diagnosis to support gold national standard and consistent practice in place :)	A professional	
Why does it take so long for health care and educational professionals to agree with parents or advise them that a diagnosis should be investigated?	A parent/carer	
How can I as a parent identify if there is a problem?	A parent/carer	

		Should learning difficulties be diagnosed, and if so whose role is it and what would be best practice? Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; what age will this be decided upon; is it possible to change category; how does a genetic component affect this diagnosis, for example Down's syndrome It would be helpful to have literature review into diagnosis of learning disability, who provides assessment and diagnosis, taking into account the role of clinical and educational psychology and other health, education and social work professionals contributions to assessment and diagnosis to support gold national standard and consistent practice in place :)	A professional	
		Who should be responsible for trying to diagnose a learning disability?	A parent/carer	
		I am aware that Educational Psychologists are responsible for diagnosing learning difficulties while the child is at school. What happens if the waiting list is so long that this assessment is not carried out in childhood?	A professional	
		Why does it take till p5 in Scotland to start tests for dyslexia? Is there any support out with school to help a child advance?	A parent/carer	
		Why don't we test for dyslexia on school entry? and use colour filters if they help or other methods straight away.	A professional	
		Why is dyslexia not diagnosed in primary school anymore? Schools in East Lothian have recently said it's not relevant to assess and diagnose until secondary however by that stage children have low self-esteem	A professional	
		If children can be diagnosed with specific learning difficulties early in nursery or primary school so that they have more time to learn to manage their condition in Primary School before the additional demands of High School kick in.	A professional	
		There is little consensus on the terminology used. Learning difficulties often used because testing for learning disability not regularly undertaken. Education psychologists in our area no longer do any formalised assessments for children so their IQ is not known therefore cant use definition of learning disability-IQ less than 70. But then cant access services for LD as adult until have testing to show IQ- Grrrrr. Why do ed psychs not test in school? Surely that would help identify strategies, strengths and weaknesses	A parent/carer	
		My daughter has been tested for Dyslexia but we were only told she shows very strong tendencies/traits not that she has this. My question is why is it so difficult for assessments to be done?	A parent/carer	
		Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; who informs the family of this; what age will this be decided upon; is it possible to change category; how does a genetic component affect this diagnosis, for example Down's syndrome	A parent/carer	
		Why are there polarised attitudes to cognitive assessment e.g. within educational psychology, clinical psychology and psychiatry? What impact do such different perspectives have on the patient journey through 'the system'?	A professional	
		Why are there polarised attitudes to cognitive assessment e.g. within educational psychology, clinical psychology and psychiatry? What impact do such different perspectives have on the patient journey through 'the system'?	A professional	
5	What effect does having a formal label or a diagnosis have on children and young people living with a learning difficulty and those involved in their care and the public?	Is the broad label of 'learning difficulties' still relevant or useful?	A professional	HH. Koester, S. Arthanat. (2017). Effect of diagnosis, body site and experience on text entry rate of individuals with physical disabilities: a systematic review. Disability and Rehabilitation, 13(3). https://doi.org/10.1080/17483107.2017.1369588
		Why is a diagnosis / label important and what is the role of a diagnosis in obtaining support?	A professional	C. A. Melville, A. Oppewal, E. L. Schafer, E. Freiberger, M. Guerra-Balic, et al. (2017). Definitions, measurement and prevalence of sedentary behaviour in adults with intellectual disabilities - A systematic review. Preventive Medicine, 97: 62-71. http
		Does the broad label of learning difficulties inform the support a child or young person will receive?	A professional	H. Galloway, E. Newman. (2017). Is there a difference between child self-ratings and parent proxy-ratings of the quality of life of children with a diagnosis of attention-deficit hyperactivity disorder (ADHD)? A systematic review of the literature. ADHD
		How do we differentiate Learning Difficulties and Disabilities? I would like a more defined and consistent definition of Learning Disability that professionals and parents can use as a guide. Often Learning Disability is a vague term, and not every learning disability is the same. My son is severely physically disabled, but has a high level of understanding. He is often referred to as having learning disability, because he has a lot of physical barriers to learning. From that point of view, he could be described as having a learning disability, and of course, this then affects how he is treated and what he is taught, but I am not sure that I agree. I agree that my son needs to be taught in a different way because of his physical disabilities, but I don't agree that he should be taught at a different level from his peers. My partner, on the other hand has high functioning Asperger's Syndrome, and is treated in a normal way and expected to understand things his brain can't process. If you were to ask me which of these two people had a learning disability, I would say that it was my partner, and not my son. It is very frustrating for me as a parent because the term "Learning Disability" is used as a way to lump people together, and there is often an assumption of a lack of intelligence and understanding, which isn't always the case. I would like to see research leading to more definition and understanding of the different types of learning disability, so that people with different needs can get the help they need which is tailored for them. This might only happen if we moved away from the generic term "Learning Disabled".	A professional	
		Research project on how to establish an effective database within Primary Care whereby every GP must consistently record whether a young person has a learning difficulty or learning disability. There should be clear criteria put in place for both these terms which are wrongly felt to be interchangeable and misunderstood even by health, social care and education professionals. Having a clear register based at GP level in every young persons record can then properly assist the young people to have the correct adjustments applied in their lives e.g. having their inability to read and interpret written information would clearly trigger GP Health Screening appointment letters to be sent out in symbolised / pictorial / larger font / printed on coloured paper / etc etc. Lets create a standard of inclusive, barrier free communication from childhood onward !!!	A professional	
		There is little consensus on the terminology used. Learning difficulties often used because testing for learning disability not regularly undertaken. Education psychologists in our area no longer do any formalised assessments for children so their IQ is not known therefore cant use definition of learning disability-IQ less than 70. But then cant access services for LD as adult until have testing to show IQ- Grrrrr. Why do ed psychs not test in school? Surely that would help identify strategies, strengths and weaknesses	A parent/carer	
		What is the current definition of learning difficulties and is this universally applied across all geographical areas and professions?	A professional	
		What distinguishes learning difficulty from learning disability	A professional	
		How can we reach a consensus on terminology? I note that Mindroom addresses Learning Difficulties - what does this mean to professionals, carers, those affected and the public?	A professional	
		What is the difference between a learning difficulty and a learning disability? Is this explained to the parents at the time of diagnosis?	A professional	
		Clarifying / sorting confusion in terminology and robust assessment tools for children & YP to identify / differentiate between learning difficulties / learning disability	A professional	
		My son is diagnosed with severe intellectual disability. No one really seems to be sure what this means	A parent/carer	
		Can we have clear diagnosis, implications in the classroom /home, interventions which would help on a grid/worksheet for teachers to use.	A professional	
		Does labelling a learning difficulty such as dyslexia have an impact on self esteem (ie if all the appropriate supports are in place does it matter whether or not the difficulty is given a name, which may help them to understand why they need the supports, or may make them feel stigmatised)	A professional	

		What support is in place is a diagnosis is not given, as in you were 1 point short of qualifying for a diagnosis? Many services will not offer help or support without a diagnosis.	A parent/carer	
		Can the criteria for being diagnosed be changed? The threshold for being diagnosed. What support is in place is a diagnosis is not given as you were 1 point short.	A parent/carer	
		Is funding preventing some children with border line dyslexia getting help? Leaving those with slight difficulties not getting help.	A parent/carer	
		What supports are available for children with learning difficulties compared to children with a formal diagnosis of learning disabilities?	A professional	
		Only priority one pupils get support since you have to be diagnosed with Autism or other conditions to be classed as a priority one many other children who just have slow processing skills and don't have allotted hours now miss out on support. I know this because I am an ASN and thanks to all the cuts many children are suffering and missing their chance of help. Not that Priority 2 or 3 even exists this is wrong and should be looked at again.	A professional	
		Which strategies are most effective for supporting children with undiagnosed support needs (e.g. where a parent is reluctant to seek formal diagnosis and therefore support available to those with a diagnosis is not available)?	A professional	
		How best to support children in school (especially those who mask their difficulties and appear 'fine')	A parent/carer	H. Galloway, E. Newman. (2017). Is there a difference between child self-ratings and parent proxy- ratings of the quality of life of children with a diagnosis of attention-deficit hyperactivity disorder (ADHD)? A systematic review of the literature. ADHD.
6	What are the best measures of outcomes (e.g. academic skills, peer relationships, quality of life, classroom participation) for children and young people with learning difficulties?	The effectiveness of the use of outcome measures with children with learning difficulties.	A professional	E. Vasilopoulou, J. Nisbet. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. Research in Autism Spectrum Disorders, 23: 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008
		Whether there is a rough rate of development for different severities or whether intensive therapeutic input can actually make a huge difference (I know it makes a minor but I'm asking huge) to the individual.	posi	T. Gomersall, S. Spencer, H. Basarir, et al. (2015). Measuring quality of life in children with speech and language difficulties: a systematic review of existing approaches. International Journal of Language Communication Disorder, 50(4): 416-435. DOI: 10
				C. Oh-Young and J. Filler. (2015). A meta-analysis of the effects of placement on academic and social skill outcome measures of students with disabilities. Research in Developmental Disabilities, 47: 80-92. doi: 10.1016/j.ridd.2015.08.014.
7	What strengths do children and young people with learning difficulties have?	My daughter is dyslexic. She's also a keen and successful chess player. It seems a large proportion of good chess players have dyslexia, asd or other additional support needs. Is this cause or effect, or both? I.e do certain brain wirings predispose a person to be good at chess, or is it the chess environment that attracts and holds these young people? Does playing chess increase results in other areas?	A parent/carer	
		What skills and assets do children and young people with learning difficulties have, that people without 'learning difficulties' do not have?	A professional	
		My son appears to have a good understanding of what is going on around him. He can follow instructions (if physically able to). He does not want to or possibly is unable to learn academically. Although he understands what I say to him he struggles to communicate with speech and sign language. Why does he only learn certain things?	A parent/carer	
		What are the positive aspects of learning difficulties and how to overcome the negative stereotypes?	An adult who experienced learning difficulties as a child	
		What is the positive side of living with disability in the family?	A professional	
		The effects of everyday life and education and relationships.	An adult who experienced learning difficulties as a child	M. B. Bjerrum, P. U. Pedersen, P. Larsen. (2017). Living with symptoms of attention deficit hyperactivity disorder in adulthood: a systematic review of qualitative evidence. JBI Database of Systematic Reviews and Implementation Reports, 15(4): 1080-1153.
		The every day effect of learning disability in adults - e.g., work, relationships, finance and general welfare	A parent/carer	J. Harden, R. Black, R. Chin (2016). Families' experiences of living with pediatric epilepsy: A qualitative systematic review. Epilepsy & Behavior, 60: 225-237. https://doi.org/10.1016/j.yebeh.2016.04.034
		The effect on everyday life.	A professional	A. Gjermestad, L. Luteberget, T. Midjo, A. E. Witso. (2017). Everyday life of persons with intellectual disability living in residential settings: a systematic review of qualitative studies. Disability & Society, 32(2): 213-232. https://doi.org/10.1080/09
		the effect of identifying learning difficulties on educational attainment	A professional	
		Implications for everyday life	A professional	
		Causes, effect and treatments	A parent/carer	
		How does having a Learning Difficulty impact your life and how can you improve this?	A professional	
		The effect on everyday life in relation to relationships and sexual health	A professional	
		What are the effects on everyday life	A professional	
		The effect on everyday life	A parent/carer	
		How can having a learning disability affect my child when in adult hood	A parent/carer	
		How will the disability affect the person in its adult life? We don't know is a very upsetting answer that leaves lots of uncertainties and frustration.	A parent/carer	
		Impact on toileting issues and any useful interventions	A parent/carer	
		The effect on everyday family life needs to be addressed more and help and support for those dealing with this, it can sometimes feel like the loneliest place in the world with no help and parents feel it is them who are being held responsible. Family support is essential and the greatest tool is to get them talking to each other. Earlier intervention and help is a must for families. The most crucial things are care, support and then treatments.	A parent/carer	
		Effects and impact of dyslexia in everyday life, school and work	A parent/carer	
		What effect will having dyslexia impact on a child's education?	A parent/carer	
		I was diagnosed as an adult as having dyslexia. Focus for support is during education. I'd like to know more about how dyslexia may effect my working life and contribution/or not as a tax payer. I'd also like to know more about how it may effect my emotions, how I interpret emotions, and consequently the kind of relationships I may or may not be having with people.	An adult who experienced learning difficulties as a child	
		How Tourette syndrome and associated disorders eg. ADHD, ASD, OCD, SENSORY PROCESSING, DYSLEXIA ETC. affects children's educational potential and experience.	A parent/carer	
		What is the incidence of sensory processing difficulties in the learning disability population, in terms of difficulties with sensory discrimination and sensory reactivity? e.g. with the touch system, a discriminative difficulty might be difficulty identifying differences in texture and shape using touch alone; and a reactivity issue may be over-reactivity to touch inputs leading to distress or discomfort with various touch sensations. Any of these can have an impact on an individual's functioning in their every day activities.	A professional	
		Relationships & sexual health etc when older. More difficult when living at home & limited social life.	A professional	
		What is the experience of classmates when a child with a high level of additional support need, associated with unpredictably distressed and distressing behaviour due to autism is in a mainstream classroom?	A professional	
		The effect of having mild LD on peer relationships through different stages of childhood	A professional	
		Psychosocial effect on CYP with learning difficulties. How do they feel etc- isolated; included; respected etc??	A professional	
		What affect does it have on their self esteem? And how to help this?	A parent/carer	
		How successfully do children with ADHD engage with creative activities and what can impact on success	A professional	
		the effect of having undiagnosed borderline or mild LD on educational success	A professional	
		what is the impact of undiagnosed LD for teenagers?	A professional	
		What is the impact (short and/or long term) of not having learning needs identified. Or, after those additional learning needs have been identified, what is the impact of not having the appropriate support.	A professional	
		How best to measure the impact of a learning difficulty on the child, family and professionals?	A parent/carer	
		Learning difficulties + interaction with peers with and without similar difficulties. - Would streaming help improve reception	A parent/carer	
8	How do learning difficulties affect everyday life of children and young people with a learning difficulty and those involved in their care?			

		What is the incidence of CVI in children with autism e.g. optic ataxia and difficulties with depth perception. What is the impact? Is this underdiagnosed?	A professional	
9	How do learning difficulties affect the everyday life of children and young people living with a learning difficulty and those involved in their care?	What affects their ability to learn?	A parent/carer	J. McDaniel, K. D'Ambrose Slaboch, P. Yoder (2018). A meta-analysis of the association between vocalizations and expressive language in children with autism spectrum disorder. Research in Developmental Disabilities, vol. 72, 202-213. doi: 10.1016/j.ridd.2017.1
		Neurological differences in dyslexia and how it impacts on learning and how to overcome. Which a view to better understanding and effective learning strategies and approaches	A parent/carer	P. Peng and D. Fuchs. (2017). A Meta-Analysis of Working Memory Deficits in Children With Learning Difficulties: Is There a Difference Between Verbal Domain and Numerical Domain? Journal of Learning Disabilities, 49(1): 3-20
		How can you learn with a learning difficulties?	A professional	J. C. A. W. Peijnenborgh, P. M. Hurks, A. P. Aldenkamp, J. S. H. Vles and J. G. M. Hendriksen. (2016). Efficacy of working memory training in children and adolescents with learning disabilities: A review study and meta-analysis. Neuropsychological Rehabilitation, 26(5-6): 645-672. https://doi.org/10.1080/09602011.2015.1026356
		How does working memory impact on learning generally and what strategies are most effective in ameliorating it's impact?	A professional	
		How much of an impact does poor working memory have on learning? This question could also be particular to dyslexics.	A professional	
		What factors increase the likelihood of a child experiencing specific working memory difficulties?	A professional	
		Are executive functioning skills deficits linked to learning difficulties in general or a specific learning g difficulty (i.e. dyslexia)?	A professional	
10	What is the effect of living with a child or young person with learning difficulties, on members of their family or carers?	Effect on carers and families particularly siblings . . .	A professional	E. Vasilopoulou, J. Nisbet. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. Research in Autism Spectrum Disorders, 23: 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008
		What is the impact on the family unit when you have a child with learning difficulties?	A professional	J. Harden, R. Black, R. Chin (2016). Families' experiences of living with pediatric epilepsy: A qualitative systematic review. Epilepsy & Behavior, 60: 225-237. https://doi.org/10.1016/j.yebeh.2016.04.034
		Effects on families	A professional	JS. Lima-Rodriguez, MT. Baena-Ariza, I. dominguez-Sanchez, M. Lima-Serrano. (2017). Intellectual disability in children and teenagers: Influence on family and family health. Systematic review. Enfermeria Clinica. https://doi.org/10.1016/i.enfcli.2017.10.0
		I would like research to be undertaken which considers the impact that having a brother or sister with learning difficulties has on siblings. ((Specifically, asd)	A professional	
		The effects of Tourette's on siblings and family life and support for families who have children with tourette Syndrome.	A parent/carer	
		Does presumption of mainstream disadvantage some children?	A professional	J. Andrews, M. Falkmer, S. Girdler. (2015). Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: a systematic review [with consumer summary]. Disability and Rehabilitation, 37(10): 825-833
		Is presumptive mainstreaming really inclusive?	A professional	J. J. Ellenkamp, E. P. Brouwers, P. J. Embregts, M. C. Joosen, J. van Weeghel. (2015). Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review
		Should inclusion within a mainstream school always be the main goal for children with autism, or should there be more ASD provisions attached to primary and secondary schools, so an appropriate setting can accessed on a part or flexible basis if required.	A professional	BM. Sutton, AA. Webster, MF. Westerveld. (2018). A systematic review of school-based interventions targeting social communication behaviors for students with autism. Autism. doi: 10.1177/1362361317753564
		I am also interested in the reality of inclusion. I wonder if our schools are all maximising pupil potential, or is it simply geography, placing the children within the same classroom. I'm also interested in the In impact of inclusion upon peers, and how to ensure this is a positive experience for all pupils.	A professional	
		Is there a difference in provision between students with learning difficulties in state schools very private schools? - anecdotally it would seem that getting tested and then getting support is much more problematic in private schools?	An adult who experienced learning difficulties as a child	
		How are children with asn supported in the education system. Is it effective? Does it provide an education that is meaningful and beneficial? How does that impact on the wider school? Is it measurable?	A parent/carer	
		What do young people feel benefits them most when they require additional support in school?	A professional	
		What is the impact (short and/or long term) of not having learning needs identified. Or, after those additional learning needs have been identified, what is the impact of not having the appropriate support.	A professional	
		What is the effect of being in mainstream school on the health and wellbeing, particularly in self esteem, for students with general learning difficulties?	A professional	
		Children and young people with Learning Disability in mainstream schools, is there enough educated staff to look after their educational needs?	A professional	
		Why is my child who has a diagnosis of Anxiety (psychological not psychiatric) in a class of 35?	A parent/carer	
		Is there a correlation between the number of pupils and attainment of those with learning difficulties?	A professional	
		What is the impact of number of adults in a classroom and attainment of a child with learning difficulties?	A professional	
		The effect of school staffing/funding on the ability of children to access the support they need and make progress with their learning.	A parent/carer	
		What is the impact of using consistent visual supports on the daily working environments of adolescents/adults with LD - including community spaces such as shops, banks, post offices	A professional	
		What benefits can be identified in participants involved in collaborative work between children/young people with learning difficulties and those without learning difficulties? Who benefits most and how can this be measured?	A professional	
		Look at the importance of inclusion and a human rights approach for children and young people and the benefits to everyone.	A professional	
		All of the above and... Does inclusive education have a positive impact for children both those with difficulties and those without.	A professional	
		Is integration the best environment for children with learning difficulties ?	A professional	
		Are special Schools always the best option?	A professional	
		Evidence for effectiveness of specialist education settings vs mainstream education settings for moderate LD. What are the educational outcomes and longer term outcomes?	A professional	
		I am interested in interventions and approaches that support better inclusion of learners with additional support needs in mainstream classes.	A professional	
		How can children be best supported in a mainstream environment who have learning difficulties?	A professional	
How schools and education systems can become more inclusive to ensure that children and young people with learning difficulties are not immediately segregated from their communities.	A professional			
Investigate how and where successful inclusive practice is taking place, the drivers and the tools and methods and how these can be shared.	A professional			
If mainstream schools are to be continually encouraged for children with Learning Difficulties to attend, what support needs to be in place to ensure they are meeting the needs that a specialist school can provide? Such as on site physio, speech and language, up to date electronic equipment such as eye movement communication and computing aids, well trained ana's and teachers who have trained in Learning Disability not mainstream education	A professional			
What can be learned from inclusive work places that can be applied in educational settings?	A parent/carer			
With more and more positive diagnoses occurring as regards children with an ASD, what are the implications as regards mainstream education and how will these be provided for?	A professional			
Should children with ASD be encouraged to interact with their peers during breaks, to build relationships and make 'friendships' that at times they do not appear to want? Or should this be free time where everyone should be allowed to take the kind of break they want?	A professional			
how can we make the mainstream setting more inclusive on a very limited budget	A professional			
How are the needs of children with severe learning difficulties addressed in school and what treatments are available to them?	A professional			
How to put effective support in schools. How to help support families during the summer holidays which causes huge disruption for routines.	A professional			

What is the best educational and community environment for children and young people with learning difficulties?

Useful interventions for education.	A parent/carer	
Research into how best to support young people with Learning disabilities in school. I.e., how to tailor support rather than use generic treatment strategies.	A parent/carer	
My son has Downs Syndrome what can he be expected to achieve in education	A parent/carer	
Educational support is a huge factor when children are first starting out, the greatest support given during our time was from a speech therapist called Morag who was amazing and it was actually the speech and language therapist who offered the greatest help as a parent I had no idea the value of the speech dept, this should be highlighted more they were the one group of professionals who very quickly picked up on the problem for us as a family. Families should be aware of how crucial their input is.	A parent/carer	
How can we make sure that pupils with dyslexia can reach their full potential educationally	A parent/carer	
Which interventions really work to raise attainment?	A parent/carer	
Can we have clear diagnosis, implications in the classroom /home, interventions which would help on a grid/worksheet for teachers to use.	A professional	
How to implement strategies at both home and school, to offer a holistic approach for the child// young person.	A professional	
How can schools best support pupils with anxiety and other mental health issues given the huge rise in cases and the limited resources available?	A professional	
What helps children with ADHD/ADD concentrate in the classroom?	A parent/carer	
Development of an alternative curriculum for SLD / PMLD children based on individual needs - life skills etc and sensory requirements which comes with a better method of charting progress as p scales and whatever they are now are not detailed enough	A parent/carer	
What is the best differentiated life skills/sensory curriculum for pupils with profound and complex learning needs?	A professional	
what opportunities are available to young people after school? What support is available to help them to access further education.	A professional	
What opportunities are available in mainstream schools to further the education of all including those with learning difficulties, is an important question.	A professional	
how can we engage young people who fail continuously at school?	A parent/carer	
What would better facilitate reading skills developing in YP with LD? In my experience there is a moment in P5 when the professional is either released or lost.	A parent/carer	
Why many young people with moderate learning disabilities are un-diagnosed and struggling in mainstream education. Often resulting in psychiatric admissions. Effective treatments being changes in environments.	A professional	
My son has autism and learning difficulties which mean he is not reading at all just remembering the same book over and over. What kind of thing would help him?	A parent/carer	
Having seen the demotivating effect of constantly being confronted by phonics - what other ways can children access reading?	A professional	
How can we best help children with learning differences reach their full potential when reading and writing holds them back?	A parent/carer	
How to assist children with behavioural problems to access the curriculum	A professional	
What impact does placing a 'borderline' pupil with learning difficulties within a Support Department as opposed to keeping them in mainstream education?	A professional	
If it were to be adopted, what would the impact of R2L (reading to learn) www.reading4life.org be on the literacy levels in Scotland?	A professional	
Different coping strategies, what is the best learning methods for dyslexics - personally the internet and interactive learning was very useful for me but I'd like to know more about this.	An adult who experienced learning difficulties as a child	
How can young people with ADHD be most effectively supported at university?	A parent/carer	
How can I help my son develop academically in high school?	A parent/carer	
What research has been done to understand the best methods to use in higher education for dyslexics and exams . In high school there seems to be very little in the way of strategy or a warning point that there are problems and clear paths to change direction for individuals who are struggling. It feels very much a parent led education .	A parent/carer	
What is the most effective learning environment/educational setting for children and young people with autism spectrum conditions.	A professional	
How can we structure education to best support children with learning difficulties and help them to achieve?	A professional	
How can schools best adapt to help children with learning difficulties?	A parent/carer	
What helps - how well supported are children with learning difficulties in the classroom environment?	A professional	
Alternatives to traditional exams, eg oral	A parent/carer	
There are different "frameworks" for teaching ... e.g. synthetic phonics vs more traditional approach. Have these been properly defined, studied longitudinally against each other and evaluated for suitability for those with various learning difficulties? [Are we disadvantaging those with learning difficulties by adopting new strategies globally or the reverse]	A parent/carer	
As a parent I'd like clearer information about schools responsibilities to provide support, what kind of support is available and where to go when schools are unwilling/unable to provide support	A parent/carer	
what additional support is available at schools to allow my son to do his best, and how best to make sure he gets access to these?	A parent/carer	
How can we provide effective support for children at school in ways that prevent stigma, make reasonable adjustments and enable them to be independent learners and contributors? What would progress look like from EYs through primary, secondary school and post school outcomes?	A professional	
How can we shape school provision such that stigma is reduced?	A professional	
Managing stereotypes - supporting the education of all in supporting children with additional support needs?	A parent/carer	
Within a classroom setting, do frequent well planned movement breaks aid focus, concentration and improve behaviour?	A professional	
Question: Are primary school classrooms over cluttered? Answer: Classroom clutter is dealt with non-consciously in the posterior parietal area of the brain. This can easily be overloaded, impairing attentional and search functions particularly in young children, particularly those born prematurely who have periventricular white matter pathology in the posterior parietal area. The prevalence of CVI in children below 30 weeks is likely to be in the region of 30%. The same effects are seen in those born to mothers on methadone.	A professional	
Do young people with learning difficulties make more academic progress when taught in small groups rather than in mainstream classes in secondary schools?	A professional	
What is the impact of open plan classrooms on a child with learning difficulties' learning?	A professional	
How can young children in school who are waiting for a diagnosis of learning difficulty/dyslexia be best supported	A parent/carer	
How can schools (without specialist provision) be supported in consistently offering daily life skill experience and practice, supporting the child/young persons independence skills for those with more complex learning difficulties?	A professional	
How do mainstream secondaries provide a broad and balanced curriculum and appropriate qualifications for students who have limited understanding, short attention and cannot read?	A professional	
Are dyslexia difficulties compounded by rigid 'one size fits all' teaching (teaching to test) practises?	An adult who experienced learning difficulties as a child	
Dyslexics generally are quite visual in how they try and understand things. why is it impossible to find resources that show words like, and, or, of, if to, from etc in some sort of book or online. I feel that this would help dyslexics create pictures and lower stress levels if nothing else. This would help dyslexics as it has helped me but I had to create my own which was stressful and time consuming. It is simple but people researching dyslexia don't really want simple solutions.	An adult who experienced learning difficulties as a child	
Correlation of gross and fine motor difficulties with learning disabilities, and best interventions and community resources to support this.	A professional	

		How can we best take account of family resilience/resources/capacity/needs in making judgements about how best of support as child or young person in ways that are consistent with responsible use of scarce resources and avoiding creating over dependence? How can we develop shared understanding of what is reasonable/appropriate?	A professional	
		with growing numbers of diagnosed children what measures will health and education take to continue to support these children	A professional	
		How can we help people with learning disabilities become more integrated into the community?	A professional	
		Every school will have a population of children affected by Learning Disabilities surrounding special awareness, muscle tone and co-sessions and won't get them again. Question 2 Would regular physical OT sessions in blocks at school as a class for a collective school population of those needing it be beneficial?	A parent/carer	
		How can we build better longevity and sustainability into support programmes and networks? Too often families manage to achieve support that works only to find a core element of it changes and an effective support structure collapses.	A parent/carer	
		Accessing health care resources and support	A parent/carer	
		Resources available and how they interact with each other	A parent/carer	
		Schools have so few resources that there does not appear to be any targeted resources to work with children, adolescents to help them understand diagnoses such as dyslexia and autism. Why not? Surely this would help reduce poor self esteem and secondary mental health problems	A parent/carer	
		If funds are limited (& we know they are) where would you prioritise spend? Would the aim be to help as many people as possible and therefore support those who are easier to help - or would you prioritise the more profoundly learning disabled with less prospects for a fulfilled outcome?	A parent/carer	
		Why is it so hard to get our children I to specialist schools when it's clearly what they need.	A parent/carer	
12	Which parenting approaches and strategies are most helpful for young parents or carers who themselves have learning difficulties?	Are there differences in the parenting strategies which are most effective for children with ADHD + ASD compared to those who don't have ASD?	A parent/carer	E. van den Broek, A. J. P. M. van Eijden, M. M. Overbeek, S. Kef, P. S. Sterkenburg, C. Schuengel. (2017). A systematic review of the literature on parenting of young children with visual impairments and the adaptations for Video-feedback Intervention to or J. L. Park, K. L. Hudec, C. Johnston. (2017). Parental ADHD symptoms and parenting behaviours: A meta-analytic review. Clinical Psychology Review. 56: 25-39.
		How to assess level of understanding and capability for adults with learning difficulties who become parents	A professional	
		Impact on parenting capacity and risk assessment of parents with learning difficulties.	A professional	
		Parents with learning disabilities and supported parenting approaches	A professional	
		What impact does a learning difficulty have if you are also a parent.	A professional	
		I find that if parents do not know their rights regarding learning difficulties and education, and does not shout loudly, very often the child does not benefit from their rights. It would be interesting to see if how the outcomes for learners are affected by parents being fully informed of their children's rights and being better enabled to demand them.	A professional	
13	What are the best practices in planning for future (i.e. transition) for young people as they leave school in order to achieve the best possible employment prospects?	Job applications - to declare or not to declare? If declare what point in the application process	Pilot study Paper questionnaire	D. Hedley, M. Uljarevic, L. Cameron, S. Halder, A. Richdale, C. Dissanayake. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. Autism. 21(8): 929-941. DOI: 10.1177/136236 J. J. Ellenkamp, E. P. Brouwers, P. J. Embregts, M. C. Joosen, J. van Weeghel. (2015). Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review J. D. Westbrook, C. J. Fong, C. Nye, A. Williams, O. Wendt, T. Cortopassi (2015). Transition Services for Youth With Autism: A Systematic Review. Research on Social Work Practice. 25(1): 10-20. DOI: 10.1177/1049731514524836
		How can health professionals promote active citizenship for people with learning difficulties from childhood into adult life to enable them to know how to participate?	A professional	
		I a therapist with dyslexia I think there still remain a lot of ignorance around this. It is simple not just spelling. I do wonder if the NHS as an employer could offer staff greater support around this?	A professional	
		How can organisations better provide good work experiences for pupils with learning difficulties?	A professional	
		Why their is no help for young adults with learning difficulties to get into decent employment.	A parent/carer	
		How can adults with ADHD be helped into work?	A parent/carer	
		How to help an adult who was a late diagnosed in a working situation	A parent/carer	
		How can we engage employers in understanding and working with young people with learning difficulties?	A parent/carer	
		Something around the access of employment opportunities/attitude of employers towards employing young people with learning difficulties leaving school.	A professional	
		What can be done to help employers give jobs to those with learning difficulties within their organisations?	A professional	
		Do young people feel attending meetings to discuss their additional support and education planning is helpful? Do they have any other suggestions of how they could be actively involved and consulted in the process without having to be in a meeting?	274903-274895-24513897	Domeij, H. Fahlstrom, G. Bertilsson, G., et al. (2018). Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. Developmental Medicine & Child Neurology. DOI: 10.1111/dmcn.13696
		I'd like to know if any research has been done on owning your identity as someone who has a learning difficulty. I struggle with mine and this isn't helpful to me or the people I work and live with.	274903-274895-24797440	MA, Rashid, S. Lovick, NR. Llanwarne. (2017). Medication-taking experiences in attention deficit hyperactivity disorder: a systematic review. Family Practice. 1-9. https://doi.org/10.1093/fampra/cmz088 S. Lindsay. (2016). Child and youth experiences and perspectives of cerebral palsy: a qualitative systematic review. Child: Care, Health and Development. 42(2): 153-175. doi:10.1111/cch.12309
		How can people with complex needs effect more change with regards to any aspect of their social, health or educational life?	A professional	
		How parents can get schools to provide the required support	A parent/carer	
		Why do people not try to look at the world from my child's perspective?	A parent/carer	
		What are the priorities of young people themselves for the interventions (or focus of the interventions) they receive?	A professional	
		What are the young people's biggest priority for learning/development i.e. is it academic or social? In school, they are often taught a curriculum which is not always (potentially) relevant or of interest/use to them. What are their priorities?	A professional	
		Are life skills more important to learn than curriculum based learning?	A professional	
		Why does diagnosis take so long - years, rather than months - and what can parents do to support their kids before a diagnosis? One issue is that if your child is well behaved in school, but crying and hating the thought of going to school at home, homework tantrums etc, then it means you may have to be a bit of a "fussy" parent to help them access support. I think this is purely down to the lack of funding, which is probably the most important issue, though our son has been one of the lucky ones to access great support at his school.	A parent/carer	L. Skotarczak and G. K. Lee. (2015). Effects of parent management training programs on disruptive behavior for children with a developmental disability: A meta-analysis. Research in Developmental Disabilities. 38: 272-287.
		Post diagnostic support for parents is poor for all conditions but especially Foetal alcohol spectrum disorder, ADHD and dyslexia. What can be done to improve this? Why is it not more joined up as children often have more than one diagnoses and surely it is the behaviour and emotional distress that needs treatment and understanding rather than the label. Please ask professionals to stop blaming parenting and work with us to support our kids achieve to best of their ability and be happy	A parent/carer	E. Vasilopoulou, J. Nisbet. (2016). The quality of life of parents of children with autism spectrum disorder: a systematic review. Research in Autism Spectrum Disorders. 23: 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008
		The potential effects on everyday life needs to be outlined to parents and professionals and include possible effects re education, relationships, health and wellbeing. There needs to be a key lead professional as the central point of communication for the child and family in health and education. Not all parents have the necessary time, skills, expertise or confidence to carry out this role especially when faced with a room of professionals. Talking about your own child's difficulties is a very emotive and exhausting topic. Cohesion between all professionals is key to success with the family and child. Often it seems the parent is the driving force and the key professional sharing and communicating with the various agencies in the best interests of their child.	A parent/carer	N. Golfenshetin, E. Srulovici, B. Medoff-Cooper. (2015). Investigating Parenting Stress across Pediatric Health Conditions - A Systematic Review. Comprehensive Child & Adolescent Nursing. 39(1). https://doi.org/10.3109/01460862.2015.1078423
		Interventions, therapies, treatments, care and support for child and parents should be sign posted to parents together with a lead professional who specialises in the area of diagnosis and also hears and is proactive to the reality of the parental and child concerns. Apologies, these are obviously statements rather than questions. But hopefully you can take from these what you need.	A parent/carer	
		Why were we not told that having a child with a learning disability would change all our lives so dramatically and as parents we would have to forfeit our own lives include our jobs and standard/quality of living?	A parent/carer	
		Interventions, therapies, treatments, care and support for child and parents should be sign posted to parents together with a lead professional who specialises in the area of diagnosis and also hears and is proactive to the reality of the parental and child concerns. Apologies, these are obviously statements rather than questions. But hopefully you can take from these what you need.	A parent/carer	
		What are the factors which prevent parents from accessing support or parenting groups where there child has LD?	A professional	

15	How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis, or identification, in home, school and community contexts?	Could more support and help be provided for parents/carers of children with developmental disabilities, where information could be shared, strategies, treatments or therapies recommended?	A parent/carer	
		How do I access support for me? I need help coping with the struggles of caring for three children with a variety of special needs.	A parent/carer	
		How can we best improve access to services?	A parent/carer	
		What are the most effective ways to engage parents in their children's speech, language and communication development?	A professional	
		What simple and effective neuroplasticity exercises can be done at home by a non-trained parent?	A parent/carer	
		How can I help my children at home that have different needs	A parent/carer	
		What support can a parent give to their child outside school to maximise learning opportunities?	A parent/carer	
		How can parents support children with ADHD outside the classroom?	A parent/carer	
		Why does it take till p5 in scotland to start tests for dyslexia? Is there any support out with school to help a child advance?	A parent/carer	
		What other real support do children and families have access to out with schools	A professional	
		How can parents of children with asn be best supported in schools? (have often felt that i am constantly raising the same issues - don't feel confident that systems/support always deliver the best for my daughter- think a lot of staff forget that my daughter has asn - how can they be reminded without sounding like a broken record???)	A parent/carer	
		Why does it take so long for health care and educational professionals to agree with parents or advise them that a diagnosis should be investigated?	A parent/carer	
		Who is responsible for making a diagnosis of learning disability? Is it a medical or educational diagnosis? Who decides if it is mild, moderate or severe; who informs the family of this; what age will this be decided upon; is it possible to change category; how does a genetic componen affect this diagnosis, for example Down's syndrome	A parent/carer	
		What are the best ways to talk about potential learning difficulties with parents?	A professional	
		Why isn't there a more streamlined way to alert and inform parents about available support services?	An adult who experienced learning difficulties as a child & a parent/carer	
		The effects of Tourette's on siblings and family life and support for families who have children with tourette Syndrome.	A parent/carer	
		How could families of people with learning difficulties be supported more adequately in order to have a better quality of family life?	A parent/carer	
		How to support parents better in being able to understand their child's difficulties- and strengths- and how to ensure they have the support they need.	A professional	
		More information about assessment process	A professional	
		What helps the family and the young person to understand the diagnosis	A professional	
		How can I help my extended family understand my Child's ADHD so they could effectively help and support her.	A parent/carer	
		Where can I get some helpful tips in helping my child with ADHD be all they can be.	A parent/carer	
		What interventions are effective in improving parent/carer efficacy in supporting children with ADHD at home?	A professional	
		What are the best interventions that parents can deliver at home themselves?	A parent/carer	
		with these interventions is it best to train the parents or work directly with the child?	A professional	
		Who, or what, gives parents/carers confidence to continue to support their child's learning/well being throughout childhood and into adulthood?	A professional	
		To what extent can specialist inputs improve the functioning of previously dysfunctional one or two parent families and consequently improve the life chances of children?	A professional	
		Does parent mentoring make a significant difference to child and parent and family wellbeing and functioning? (other parents, volunteers, working to structured programme, eg with 'record book'/ APP, giving narrative and reference points and positive reinforcement of strategies and information.?)	A professional	
		Are there better ways to support and treat those caring for a child with disabilities, who may suffer from long term grief, situational depression, and social isolation?	A parent/carer	
		How can siblings of children with ASD be best supported?	A parent/carer	
		What commonalities are there in examples of best practice of care and support as reported by children/young people, and families? i.e. what do children/young people and families report to be the most supportive practices? What professionals are involved? How did the professionals work with the children and families, what was the most helpful and important aspects of the professionals' work with the children/young people and families as reported by the children/young people and families themselves.	A professional	
		How to develop and achievable best practice model in supporting children in resource constrained environments; this could be at home, school, in the wider community.	A parent/carer	
		What supports are available for parents, carers and families of children with learning difficulties/disabilities?	A professional	
		What help can I get	A child or young person	
		The effect on everyday family life needs to be addressed more and help and support for those dealing with this, it can sometimes feel like the loneliest place in the world with no help and parents feel it is them who are being held responsible. Family support is essential and the greatest tool is to get them talking to each other. Earlier intervention and help is a must for families. The most crucial things are care, support and then treatments.	A parent/carer	
		Once a learning disability has been identified it would be helpful if research could be done on which pathway works best for each disability	A parent/carer	
		How to really make a difference at the very beginning, straight after diagnosis..from the baby/child with Ld's but also for their parent(s). It seems this still doesn't seem to work well... what do people really need at the beginning..how will it save money later in..as getting it right earlier in terms of prognosis; health support; therapeutic support; family support; welfare rights etc..	A professional	
		How to facilitate good communication in networks supporting young people with learning disability and challenging behaviour particularly focusing on getting the right support for families	A professional	
		What sort of support would be beneficial for children and parents during and post treatment - it would be helpful not to over medicalise it but sometimes this is not always possible as treatments can go on for a lifetime.	A parent/carer	
		Has this support had a positive impact on your life?	A professional	
		available support services	A professional	
		Where to find additional support for families where a child has learning difficulties	A professional	
		Interested in how to signpost to the most appropriate support	A professional	
		What kind of support should a child with autism be getting?	A parent/carer	
		Why is it so hard to find help or answers	A parent/carer	
		what kind of environment helps young people with ASD function at their best - how can we teach parents/ carers/others how to create and maintain this.	A professional	
		Support in Community for CYP with learning difficulties - psychosocial support/intervention to help them through everyday life etc.	A professional	
		What support can be made more available for adults with ADHD to integrate into society?	A parent/carer	
		How can adults be supported to live within their community and in the workplace?	A parent/carer	
		How can work places better adjust to the demands of ADHD in adults who need to work to support themselves?	A parent/carer	
What helps - can direct speech and language therapy intervention be effective with children with learning difficulties or are they better supported by strategies implemented in their everyday environment?	A professional			
If information leaflets can be produced in a more appropriate format for use for young mums with literacy issues and if they are effective in communicating important messages.	A professional			
How can I help my child so he has the same opportunities as neurotypical children?	A parent/carer			
If psychological input was offered as a "matter of courage" to parents of children with a LD. Would there be greater uptake of counselling?	A parent/carer			

16	Which strategies are effective in increasing the support available for children and young people with learning difficulties, and their families/carers, in out-of-school activities?	How to put effective support in schools. How to help support families during the summer holidays which causes huge disruption for routines.	A professional	A. M. McGarty, C. A. Melville. (2017). Parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities: A mixed methods systematic review. Research in Developmental Disabilities. 73: 40-57. https://doi.org/10.1016/j.ridd.2017.08.014
		Lack of out of school activities/groups for young people with autism and learning difficulties.	A professional	
		How can we best support young people to participate in out of school activities such as clubs?	A professional	
		What are the most effective strategies for encouraging pupils with additional support needs to participate in extra curricular activities.	A professional	
		Research to support how children transition to young adult, understand what works best and what doesn't,,,,,and ensure that families have access to the transition plansResearch to support how children transition to young adult, understand what works best and what doesn't,,,,,and ensure that families have access to the transition plans+G73:G91	A parent/carer	A. Marsh, V. Spagnol, R. Grove, V. Eapen. (2017). Transition to school for children with autism spectrum disorder: A systematic review. World Journal of Psychiatry. 7(3): 184-196. doi: 10.5498/wjp.v7.i3.184
		Finding out more about what happens when going from paediatric to adults	A child or young person	G. Young-Southward, C. Philo, S-A. Cooper. (2017). What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review. Journal of Applied Research in Intellectual Disabilities. 30(5): 805-823. DOI
		How can we improve transitions from child to adult services for people with learning disabilities?	A professional	J. D. Westbrook, C. J. Fong, C. Nye, A. Williams, O. Wendt, T.Cortopassi(2015). Transition Services for Youth With Autism: A Systematic Review. Research on Social Work Practice. 25(1): 10-20. DOI: 10.1177/1049731514524836
		Best ways to support transition into adulthood.	A professional	
		There is a need for better transition for young people leaving school and going in to adult life clubs, jobs etc.	A professional	
		Why are there so few appropriate pathways for young people with learning disabilities to be able to follow a route of their choosing into adulthood and employment?	A professional	
		Can they access young people mental health services without having to go through a G.P and have it marked against them? Is peer group and 1 to 1 available to help them cope with transitions? And this question also for help for their parents and carers? (In for second question)	A child or young person	
		How to help the person long term? As a child, a teenager and an adult?	A parent/carer	
		How can older pupils with dyslexia be better supported to cope with secondary school	A parent/carer	
		What can/should be put in place for people with significant needs post school.	A professional	
		To consider best practice for young people with learning difficulties transitioning to post-school life (what do they need for success)?	A professional	
		Is there a better transition between leaving school and been an adult.	A professional	
		Why do the teams not follow up if a person ceases to have any input once finished education?	A parent/carer	
		Why there is no recognised pathway for transition of children with learning difficulties?	A professional	
		What services are available to young people and young adults with learning difficulties when they are no longer in formal education?	A professional	
		In my own experience my son attended a special needs school and did very well there but upon leaving school and having had a disastrous experience at college found himself with no meaningful help for a considerable time and many of his friends have had similar experiences.How can young people be best supported after finishing school at 18 years of age?	A parent/carer	
		More planning should take place when children with learning disabilities prepare to leave school & home. How can this be taken more seriously, political & government will.	A parent/carer	
		How support assists transition and school placement. The bigger picture, sleepness nights, biting fingers etc	A parent/carer	
		Gathering world wide research to publicise, debate and agree the mandatory Framework of Support which should be applied to all children with Learning Difficulties (and Learning Disabilities) to safely experience and develop the life skills which they need to transition into adult, independent life. These could cover topics such as independent travel / personal & IT safety / legal issues / financial management / welfare & grant supports / preparation for either higher education / preparation to enter the job market or apprenticeship pathway or volunteering opportunity / self governance of their own health / relationships and sexual health support / citizenship / etc etc My particular interest in this stems from my role in Adult Learning Disability services where I observe a range of young adults (including those with a learning difficulty) coming through the school system and its associated very 'medical model' applied to those with identified additional needs . My impression is that from S2 onwards young people need to be supported to develop their life skills and follow their dreams, but are significantly hampered by their parents and professionals stifling their ambitions by concerns about health and safety / risks / attainability etc etc in such a way as to quell any real ambition to be independent , active citizens. I feel strongly that the 'sweet spot' for such a framework of support lies within the 14-18 age group and should be applied as both part of the school curriculum and during a summer camp process BUT the framework itself should be delivered by external staff as 'life coaches' AND some of these life coaches should be peer mentors.	A professional	
		When a primary School documents a child's needs, why do Secondary schools seem to disregard them / not take them into account / explain them away in the secondary setting?	A parent/carer	
		After transition what community supports provide best outcomes for young adults e.g. Supported accomodation; Community living (in communities with other adults with LD); Institutional Care	A professional	
		why do some young people's problems escalate so much through adolescence	A professional	
		How can transition from child services to adult services be made less stressful for the individual with learning disabilities and their family members?	A parent/carer	
		Is there a central resource/ place or papers written on Coping strategies for different stages in your life -teen - adult . With dyslexia and. ADHD tendencies .	A parent/carer	
		Continuing education in LD - why do we stop school at 18 when developmentally they may be at a younger age.	A professional	
		How support assists transition and school placement. The bigger picture, sleepness nights, biting fingers etc	A parent/carer	
		Do children and young people feel that their views have enough influence in how support is put in place around them?	A professional	
		How can young adults with LD and or autism influence the design of a PIP assessment system that reflects the true needs of the person without degradation and judgement by others.	A professional	
		For complex cognitive delay how can we incorporate choice making effectively to enhance quality of life: Can we measure that the choices are understood and therefore appropriately decided between?	A parent/carer	H. Zaal-Schuller, MA, De Vos, FV, Weals, JB, Van Goudoever, DL, Willems. (2015). End-of-life decision-making for children with severe developmental disabilities: The parental perspective. Research in Developmental Disabilities. 49-50. doi: 10.1016/j.ridd.2015.08.014
		Is there a benefit to introducing choice making at a specific age or is it a case of 'the earlier the better'?	A parent/carer	
		As an ASN practioner with a number of years experience these are some of the issues/questions: How best to manage and support young people and their families from an early age prior to schooling	A professional	I. Novak, C. Morgan, L. Adde, J. Blackman, et al. (2017). Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatrics. 171(9): 897-907. doi:10.1001/jamapediatrics.2017.1689
		when are the interventions best given? at what age and what works best.	A professional	M. Hadders-Algra, A.G. Boxum, T. Hielkema, E.G. Hamer. (2017). Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review. Developmental Medicine and Child Neurology.59(3): 246-258. DOI: 10.1111/dmcn.13331

19	Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?	Early intervention. Immediate solutions or support.	A parent/carer	K. H. Ryberg. (2015). Evidence for the Implementation of the Early Start Denver Model for Young Children With Autism Spectrum Disorder. Journal of American Psychiatric Nurses Association. 21(5): 327-337. DOI: 10.1177/1078390315608165
		Evidence based interventions for early years LD, when identified.	A professional	
		What is the best point/age to offer interventions to people with learning difficulties (i.e. age at which they are most receptive)?	A professional	
		When should interventions be put in place?	A professional	
		Have you analysed the long term outcome of early intervention in both the profoundly learning disabled and those with lesser learning disabilities? Where does early intervention make the most difference?	A parent/carer	
		When are the interventions best given? at what age and what works best.	A professional	
		Is it possible to identify children at risk of having dyslexia before starting school for earlier intervention.	A parent/carer	
		"Early intervention" is often cited as being best practice but are there also other key times/levels of readiness when a child/adult should be supported by specific interventions?	A professional	
		Examine the impact of direct and indirect discrimination and exclusion on children and young people, their families and the community	A professional	
		How can the benefits system better reflect the emphasis or potential? If this was done what affect might this have on the self esteem and mental health of young people with LD?	A parent/carer	
		Have you analysed the long term outcome of early intervention in both the profoundly learning disabled and those with lesser learning disabilities? Where does early intervention make the most difference?	A parent/carer	
		Is the most important goal for young people with learning disabilities getting into supported employment opportunities?	A professional	
		How can People with significant needs be part of the community after leaving school.	A professional	
		How can people with significant needs be valued within the local community on leaving school	A professional	
		How can we provide effective support for children at school in ways that prevent stigma, make reasonable adjustments and enable them to be independent learners and contributors? What would progress look like from F.Ys through primary, secondary school, and post school outcomes?	A professional	
		Evidence for effectiveness of specialist education settings vs mainstream education settings for moderate LD. What are the educational outcomes and longer term outcomes?	A professional	
		How do we set the right expectations for a child with a learning difficulty's learning trajectory?	A professional	
		How big a difference does individual support have in attainment for children with learning difficulties?	A parent/carer	
		How to put effective support in schools. How to help support families during the summer holidays which causes huge disruption for routines.	A professional	
		Useful interventions for education.	A parent/carer	
		Research into how best to support young people with Learning disabilities in school. I.e., how to tailor support rather than use generic treatment strategies	A parent/carer	
		My son has Downs Syndrome what can he be expected to achieve in education	A parent/carer	
		Educational support is a huge factor when children are first starting out, the greatest support given during our time was from a speech therapist called Morag who was amazing and it was actually the speech and language therapist who offered the greatest help as a parent I had no idea the value of the speech dept, this should be highlighted more they were the one group of professionals who very quickly picked up on the problem for us as a family. Families should be aware of how crucial their input is.	A parent/carer	
		How can we make sure that pupils with dyslexia can reach their full potential educationally	A parent/carer	
		Which interventions really work to raise attainment?	A parent/carer	
		Can we have clear diagnosis, implications in the classroom /home, interventions which would help on a grid/worksheet for teachers to use.	A professional	
		What opportunities are available to young people after school? What support is available to help them to access further education.	A professional	
		What opportunities are available in mainstream schools to further the education of all including those with learning difficulties, is an important question.	A professional	
		Continuing education in LD - why do we stop school at 18 when developmentally they may be at a younger age.	A professional	
		Continuing education in LD - why do we stop school at 18 when developmentally they may be at a younger age.	A professional	
		What are the long term outcomes for children and young people who have attended specialist provision designed to meet their social and emotional needs through early adulthood and beyond?	A professional	
		How important is early intervention (therapies, education) how much and what intervention?	A parent/carer	
		How to make best use of limited resources (e.g. public sector services) to support children, young people and their families when a learning need has been identified.	A professional	B. Smits-Engelsman, S. Vincon, R. Blank, V. H. Quadrado, H. Polatajko, P. H. Wilson. (2018). Evaluating the evidence for motor-based interventions in developmental coordination disorder: A systematic review and meta-analysis. Research in Developmental Dis. S. Ghai, I. Ghai, A. O. Effenberg. (2018). Effect of rhythmic auditory cueing on gait in cerebral palsy: a systematic review and meta-analysis. Neuropsychiatric Disease and Treatment, vol. 14, 43-59. doi: 10.2147/NDT.S148053
		What helps	A parent/carer	
		What helps. Interventions. Etc.	A professional	MB. Saquetto, FF. Pereira, RS. Queiroz, et al. (2018). Effects of whole-body vibration on muscle strength, bone mineral content and density, and balance and body composition of children and adolescents with Down syndrome: a systematic review. Osteoporosis International. https://doi.org/10.1007/s00198-017-4360-1 T. A. M. Bouwens van der Vlis, O. E. M. G. Schijns, F. L. W. V. J. Schaper, et al. (2018). Deep brain stimulation of the anterior nucleus of the thalamus for drug-resistant epilepsy. interventions be planned. https://doi.org/10.1007/s10143-017-0941-x
		What helps?	A professional	
		what helps	A professional	BM. Sutton, AA. Webster, MF. Westerveld (2018). A systematic review of school-based interventions targeting social communication behaviors for students with autism. Autism. doi: 10.1177/1362361317753564
		What helps - interventions, therapies, treatments, care and support.	A professional	N. Fleeman and P. M. Bradley. (2018). Care delivery and self-management strategies for children with epilepsy. Cochrane Database of Systematic Review. 3. DOI: 10.1002/14651858.CD006245.pub4+1Collection of SR and MA (2015 - 2018) 07Mar18. Anne.xlsx12015 onwards.'\$B\$14:\$D\$514 Y. Xiao, M. Luo, J. Wang, H. Luo. (2018). Losigamone add-on therapy for focal epilepsy (Review). Cochrane Database of Systematic Review. 1. DOI: 10.1002/14651858.CD009324.pub4
		Can we have examples of good practice regarding interventions?	A professional	
		interventions to support learning eg reading, trials of therapies, day to day tasks	A parent/carer	M. J. Sankar, J. Sankar, P. Chandra. (2018). Anti-vascular endothelial growth factor (VEGF) drugs for treatment of retinopathy of prematurity. Cochrane Database of Systematic Review. 1. DOI: 10.1002/14651858.CD009734.pub3
		•what helps (e.g. interventions, therapies, treatments, care and support)	A professional	S. Pandey, P. Srivanitchapoom, R. Kirubakaran, BD. Berman. (2018). Botulinum toxin for motor and phonic tics in Tourette's syndrome. Cochrane Database of Systematic Review. 1. DOI: 10.1002/14651858.CD009734.pub3
		What strategies can help a child with learning disability	A parent/carer	
		Evidence based interventions and therapies which can be readily accessed and do not cost vast sums of money	A professional	
		Evidence for best interventions and what is most likely to help - can we prove that there will be a better outcome in the context of a long term allocation social worker for example?	A professional	
		Interventions - what strategies are the most useful	A professional	

What interventions are shown to improve quality of life for people with a learning disability?	An adult who experienced learning difficulties as a child	
Support	A parent/carer	
What help is available going forward?	A parent/carer	
How to help the person affected?	A parent/carer	
How does having a Learning Difficulty impact your life and how can you improve this?	A professional	
Strategies for support	A parent/carer	
Best support strategies for individuals with learning disabilities at different ages and stages.	A professional	
What research evidence is there to demonstrate specific interventions are effective?	A professional	
How robust is that evidence?	A professional	
What theories support each intervention?	A professional	
Interventions - both for the family (What can they do to help?) and for the young person - what strategies can we give them to help them to manage?	A professional	
what interventions work best?	A professional	
Interventions/ best approach for therapists.	A professional	
I would like to find out the types of treatment, therapies and interventions used throughout the world and what the success rates for such treatments are.	A professional	
Treatment options	A parent/carer	
Investigation into which therapies and supports seem to be the most effective in supporting children and adults with learning difficulties, as a parent I have tried many therapies with my sons, some conventional some less so, but often feel as if the current recommended supports such as OT, SLT etc are being reduced due to financial pressures of the council/services to a point where they are not effective. Would private purchase of these services be worth it, or should we looking at alternative therapies in combination with conventional services?	A parent/carer	
interventions to support identified difficulties / disability which have been evidenced to be effective	A professional	
What are the best interventions that can be used to support children with learning difficulties?	A professional	
Improving the diagnosis and assessment of children and young people, to give a more comprehensive picture of their difficulties and how these can be supported and treated.	A professional	
What happens when your teenager becomes very ill with stress due to dyslexia, falling behind and thus creating panic attacks and social isolation. Where do you get help or the resource to get them an education so that they can leave school with something to take into their adult life?	A parent/carer	
How to help child overcome learning difficulties?	A parent/carer	
It would be helpful to scope out the assessment and interventions that various health, education and social work staff complete with regard to physical health, mental health, psychological intervention, communication, family support etc - what works and where are the gaps and areas for further development to support national good and consistent practice.	A professional	
Does labelling a learning difficulty such as dyslexia have an impact on self esteem (ie if all the appropriate supports are in place does it matter whether or not the difficulty is given a name, which may help them to understand why they need the supports, or may make them feel stigmatised)	A professional	
Correlation of gross and fine motor difficulties with learning disabilities, and best interventions and community resources to support this.	A professional	
What intervention and support are available for the child and family	A professional - Nurse	
What is the best treatment for dyslexia?	A parent/carer	
Neurological differences in dyslexia and how it impacts on learning and how to overcome. Which a view to better understanding and effective learning strategies and approaches	A parent/carer	
What are the things in the life of a young teenager with dual diagnoses of autism and LD that make a positive difference to self esteem?	A professional	
How can we raise self esteem when they experience so much failure?	A parent/carer	
What affect does it have on their self esteem? And how to help this?	A parent/carer	
What are the best therapies to help with low self esteem associated with autistic spectrum disorder?	A parent/carer	
Strategies to boost confidence and self esteem in children who have been excluded from school.	A professional	
How to raise self esteem when parents will not come onboard.	A professional	
self worth situations where younger sibling beginning to obviously outstrip older.	A parent/carer	
What are the causes of developmental disabilities and what could be done to prevent them, or successfully treat them?	A parent/carer	
Will my child be able to go on and lead a "normal" life?	A parent/carer	
How can we work with the more unusual presentations of my son's LD that make learning difficult? For example he is obsessed with buttons to the extent that he can't learn to use IT as he cannot help himself but press the off button, and he appears to have no concept of imagination.	A parent/carer	
How can we improve processing speed and accuracy? (shown in a range of disorders).	A professional	
How to help an adult who has Asperger with looking after his own flat	A parent/carer	
What are the most successful types of intervention that improve a person's independence?	A parent/carer	
Treatments Care/support Evidence to support promoting independence & particularly the effects this has on local councils budgets - if young people are supported early in their lives they stand a better chance of being independent & a contribute more to society when they are adults	A parent/carer	
How dose one communicate with an adult who has Asperger	A parent/carer	
What interventions help increase communication and specifically participation outcomes for older children and teenagers?	A professional	
What different techniques are out there to help children learn and communicate?	A parent/carer	
Which interventions are effective in improving communication in children with learning difficulties?	A professional	
What evidence is available to support best practice for working with and developing language and communication for children and young people with learning difficulties?	A professional	
How to support pupils who have social problems and have done programmes but without any effect on their anti social behaviour.	A professional	
What are the best techniques to help a parson with behavioural issues?	A professional	
What are the best treatments (pharmacological, psychological, behavioural) for challenging behaviours in people with learning disabilities?	A professional	
Interventions and treatment for children and young people with severe challenging behaviour - physical aggression towards self and others	A professional	
What is the best way to manage behaviour with ASD pupils?	A professional	
Behaviour support for families	A professional	
How best to cope when child on meltdown How to stop child self harming Available services in area	A parent/carer	
Best way of dealing with the challenging & frustrating behaviour	A professional	
Which behavioural management techniques are most effective for families and who is best placed to provide this support?	A professional	
how can you stop violent and aggressive behaviour?	A parent/carer	
Learning difficulties and behavioural issues generalised interventions and techniques don't always work for behavioural children - Are there any other strategies schools could use with this in mind?	A professional	
What are the most effective ways to prevent wandering (getting lost, getting on the wrong bus, etc.) in children with learning difficulties?	A parent/carer	
Can daily movement programmes help to improve attention?	A professional	
Interventions to support physical activity and mental health for those with LD but also carers	A parent/carer	
Do targeted interventions for specific LD really work	A professional	
will we ever find any medical or pharma treatment which can improve the functioning of the brain or concentration or other, even to a small extent?	A parent/carer	
What medical treatment is available to improve potential outcomes? I.e. medication to help short term memory loss, attention span, reduce risk of alzheimers etc	A parent/carer	
Why is his attention span so short?	A parent/carer	
How can we measure the response to medical treatment to know if it is being effective?	A professional	
Is there any future treatment (medical) that could change the level of learning disability to be less severe	A parent/carer	
Can medicines to manage ADHD also help children & young people with inattention related to their development?	A professional	

20 How can interventions be planned for children and young people with learning difficulties and complex needs?

ADHD medication in the LD population - who benefits?	A professional	
What helps...would like to see further research into bio medical interventions methyl b vitamins and digestive enzymes etc. The gut brain stuff that is very popular but always comes with the tag line...more research is needed.	A parent/carer	
Treatment to reduce the cognitive effects of Downs Syndrome.	A parent/carer	
What non-pharmacological interventions are effective in improving academic outcomes for children with ADHD?	A professional	
What non-pharmacological interventions are effective in improving the health and wellbeing of children with ADHD?	A professional	
LD and psychiatric comorbidity - nature, assessment, treatment	A professional	
Practical solutions and advice to every day problems eg toileting, eating, responding to instructions, etc.	A parent/carer	
Impact on toileting issues and any useful interventions	A parent/carer	
What are the most effective ways to teach children and adolescents with learning difficulties self-hygiene (getting a bath, a shower, wearing clean clothing, etc.) ?	A parent/carer	
What best way to get my son to be hygienic? Due to lack of understanding he doesn't see importance.	A parent/carer	
How does working memory impact on learning generally and what strategies are most effective in ameliorating it's impact	A professional	
How to help children with memory problems to learn the links between sounds and symbols which will help them to access spoken language and reading	A professional	
How to help Asperger adult who is quite able but acts impulsively, without considering the consequences of their actions (petty theft from shops).	A parent/carer	
what kind of environment helps young people with ASD function at their best - how can we teach parents/ carers/others how to create and maintain this.	A professional	
How can interventions be linked to wellbeing and GIRFEC that tackle speech, language, communication and swallowing needs?	A professional	
Each young person with learning difficulties is unique and the issues they will face with their individual learning difficulties will be different too.What are the best coping strategies for everyday life situations that can be adapted to the individual?	A parent/carer	
How can we best support children and young people to form friendships/develop the social communication skills.	A professional	
How can we help with relationships?	A parent/carer	
How to help a child form friendships and maintain a friendship?	A parent/carer	
How can schools help pupils with additional support needs develop friendships with other pupils?	A professional	
Can you help them have normal relationships?	A parent/carer	
What are the most effective interventions for young people with learning difficulties for developing their social interaction skills?	A professional	
Is there any place for insisting a person with Autism uses words to communicate?	A professional	
1. How to communicate with a child with intellectual disability, especially if they cant talk. How may they express themselves and how can their voice be heard	A professional	
Could we do an up to date systematic review of interventions targeting social interaction/relationship building adolescents with LD +/-or ASD?	A professional	
What helps the person with the learning difficulty learn and socialise? Known strategies	A parent/carer	
What barriers are there to these strategies being available to people with learning difficulties?	A parent/carer	
Relationships & sexual health etc when older. More difficult when living at home & limited social life.	A professional	
How do we address needs on the area of sexual health + relationships in adolescents with LD e.g. understanding of content, boundaries	A professional	
How is a young man/woman with learning difficulties introduced to sex and relationships when they are not known to a 'system or network' which is able to support them? They must feel changes in body, however if no one discusses things with them - what do they do and how is this dealt with?	A parent/carer	
Sexual health	A parent/carer	
Relationships & sexual health etc when older. More difficult when living at home & limited social life.	A professional	
What interventions are most effective in supporting young people with learning difficulties to develop understanding of relationships and sexual health?	A professional	
how well can a person with Asperger identify which emotion is being shown from a face.	An adult who experienced learning difficulties as a child	
Mentoring services for young people to negotiate organisational aspects of daily life at home + at work - Do they exist?	A parent/carer & a professional	
What are the most effective strategies/treatments/interventions/therapies so support these individuals in school/work/at home?	A professional	
Do interventions for adults differ from those setforth for children?	An adult who experienced learning difficulties as a child	
For children with poor concentration whwat is the most effective strategy/treatment method to improve this?	A professional	
What is the impact of auditory memory on learning? Are there any interventions which are effective to support this?	A professional	
How can working memory difficulties be improved and supported?	A professional	
Are any interventions effective for working memory problems?	A parent/carer	
Can research offer any help in attachment difficulties- in many cases these imitate ASD conditions but there must be some differences in approach to educating young people with these very different conditions?	A professional	
Are there any effective nutritional interventions that may help with the management of ADHD?	An adult who experienced learning difficulties as a child & a parent/carer	
What research is being done into the effects of diet (specifically gf/cf, gluten free/casein free) improving the behaviour of asd, ADHD ?	A parent/carer	
What is the best way to support emotional wellbeing in children and young people with learning difficulties?	A professional	
How are the emotional needs of children being assessed and met, for example, a child's eroded self-esteem &/or shame due to learning difficulties? Eg, my son is a people pleaser and he is nowhere near honest about how he feels about school when being assessed by his teachers, educational psychologist etc.	A parent/carer	
How can we control temper tantrums and emotional "meltdowns"?	A professional	
How can we support the emotional development of young people with learning disabilities?	A professional	
Which interventions work best for young children who have difficulty expressing anger?	A professional	
How are the emotional needs of children being assessed and met, for example, a child's eroded self-esteem &/or shame due to learning difficulties? Eg, my son is a people pleaser and he is nowhere near honest about how he feels about school when being assessed by his teachers, educational psychologist etc.	A parent/carer	
What is the best way to help with childhood anxiety?	A parent/carer	
What educational interventions can help children with severe anxiety-based learning difficulties.	A parent/carer	
Does improvement in reflexive eye movements as a result of movement programmes lead to improvements in reading?	A professional	
What causes asd? How much does intervention help?	A parent/carer	
How children can be helped via OT, counselling etc in school and at home	A parent/carer	
What is the value of Occupational therapy interventions in LD?	A professional	
How much speech therapy should children receive each week to see improvements	A parent/carer	
How counselling/other alternative therapies (CBT, Hypnotherapy) etc. might be used to help and support people with LD's, just as they are used for people without LD's.	A professional	
Effectiveness of therapies - looking at the wider picture not just the effect of a specific intervention, but also how therapy intervention/interaction in general (OT, SLT, PT) might impact on empowering the parents/carers to feel comfortable/competent at managing their child's condition and enabling them to participate in family and community life.	A professional	

		What Psychological therapies are effective for people with learning disabilities and autism? (building on previous research and using broader inclusion criteria so that RCTs can be used)	A professional	
		What therapies are best to improve cognitive abilities in people with learning difficulties?	A parent/carer	
		Investigation into which therapies and supports seem to be the most effective in supporting children and adults with learning difficulties, as a parent I have tried many therapies with my sons, some conventional some less so, but often feel as if the current recommended supports such as OT, SLT etc are being reduced due to financial pressures of the council/services to a point where they are not effective. Would private purchase of these services be worth it, or should we looking at alternative therapies in combination with conventional services?	A parent/carer	
		Which people with LD gain most benefit from Creative Therapies?	A professional	
		Interest in therapeutic interventions and what constitutes an outcome. Never felt that these (S<, physio etc) were clearly explained or what they actually could/did do for my son	A parent/carer	
		What are the interventions in managing severe to profound LD CAMHS kids: what's the evidence?	A professional	
		How can we develop therapies to help people with learning difficulties, that fit into daily life?	A parent/carer	
		Do you think autism can ever be cured? The gene isolated and removed?	A parent/carer	
		Is Art Therapy/Art Psychotherapy an effective intervention for a young person with complex health needs e.g. ASD, ADHD, ODD, trauma, during their transition between services?	A professional	
		What are the agents of change in Art Therapy/Art Psychotherapy intervention when working with young people with complex needs during transition between services?	A professional	
		What are the specific therapeutic benefits that an Art Therapy/Art Psychotherapy intervention can make for this group during transition between services e.g. child to adult services?	A professional	
		My daughter is 6. She did not speak until she was almost 5. She struggled to learn her letters and couldnt read at P2. She knew 11 letter sounds. A SALT who practices the Johansen Method of retraining auditory processing was recommended to me. My daughter is 10 months in to what has been a very inexpensive treatment , she can read and write independently, is now entirely decipherable to anyone and she approaches people on the street and engages them in chat-such is her confidence. She is unrecognisable. How likely is it that this issue will be diagnosed in schools and treated? (Without this treatment which costs a fraction of the price of some common anticoagulants per month-people with altered auditory processing go on to live a fraction of their potential)	A parent/carer	
		Is there any proof that programmes like "Son-Rise" etc actually work or can have a profound effect on individuals on the spectrum?	A parent/carer	
		What is the impact of Ayres Sensory Integration intervention on the communication outcomes for young people?	A professional	
		Can CBT approaches be used effectively to manage Tourettes tics and behaviours in school age pupils?	A professional	
		How well is Positive Behaviour Support being implemented in schools and colleges for the benefit of young people who challenge services?	A professional	
		Is it possible to teach mindfulness/meditation to someone with autism and learning difficulties to try to reduce stress and anxiety?	A parent/carer	
		There is a lot of information available about meditation, yoga and mindfulness - are these activities able to change children's difficult behaviour habits?	A professional	
		To provide a strategic break down on how to help children with CVI in both mainstream and special schools so it becomes less of a by product of the VI world and is given the same significance as other equally problematic visual impairments.	An adult who experienced learning difficulties as a child	
		Whether there is a rough rate of development for different severities or whether intensive therapeutie input can actually make a huge difference (I know it makes a minor but I'm asking huge) to the individual.	A parent/carer	
		How does anxiety, in relation to a specific subject (i.e. maths) develop and how can we help children overcome this anxiety?	A professional	
		Many people with learning difficulties have poor movement coordination. Does targeting and working on movement skills, including praxis / motor planning improve problem solving in other functional areas as well as their movement coordination?	A professional	
		What can be done nationally to help those pupils with dyslexia who have also experienced ACEs- Adverse Childhood Experiences & find full engagement with learning a challenge?	A professional	
		More investigation of effect of genetics and environment on people with learning difficulties. Should be accept that genetics is sometimes the cause, or can we improve things if we alter things in the environment, particularly concerning diet, treatments, health and wellbeing approach.	A parent/carer	
		Drug therapies currently in use elsewhere are not encouraged here.	A parent/carer	
		If funds are limited (& we know they are) where would you prioritise spend? Would the aim to be to help as many people as possible and therefore support those who are easier to help - or would you prioritise the more profoundly learning disabled with less prospects for a fulfilled outcome?	A parent/carer	
		What support/training is available for young people who are interested in representing others e.g. hate crime, decisions made that affect a range of disabled young people – consultation? And how do we ensure that outcomes are influenced?	A child or young person	S. R. Chestnur, T.L. Wei, L. Barnard-Brak, D. M. Richman. (2017). A meta-analysis of the social communication questionnaire: Screening for autism spectrum disorder. Autism, 21(8): 920-928. DOI: 10.1177/1362361316660065
21	How do learning difficulties affect interaction between children and young people and their peers, including within online social networks such as Facebook and Snapchat?	Learning difficulties + interaction with peers with and without similar difficulties. - Would streaming help improve reception	A parent/carer	J. P. Hardee, L. Fetters. (2017). The effect of exercise intervention on daily life activities and social participation in individuals with Down syndrome: A systematic review. Research in Developmental Disabilities, 62: 81-103. https://doi.org/10.1016/j.ridd.2017.01.016
		Help in understanding their conditions? Peer group networks?	A child or young person	S. Caton, M. Chapman. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. Journal of Intellectual Developmental Disabilities, 41: 125-139
		How can we make more people understand about my difficulties e.g. My class mates.	A child or young person	J. A. Gates, E. Kang and M. D. Lerner. (2016). Efficacy of group social skills interventions for youth with autism spectrum disorder: A systematic review and meta-analysis. Clinical Psychology Review, 52: 164-181. http://dx.doi.org/10.1016/j.cpr.2017.01.010
		I am also interested in the reality of inclusion. I wonder if our schools are all maximising pupil potential, or is it simply geography, placing the children within the same classroom. I'm also interested in the In impact of inclusion upon peers, and how to ensure this is a positive experience for all pupils.	A professional	
		How children and young people can be supported to share their difficulties - and successes! - with their peers	A professional	
		What helps the person with the learning difficulty learn and socialise? Known strategies	A parent/carer	
		What barriers are there to these strategies being available to people with learning difficulties?	A parent/carer	
22	How can we make best use of resources to support children, young people and their families when a learning difficulty has been identified?	How to make best use of limited resources (e.g. public sector services) to support children, young people and their families when a learning need has been identified.	A professional	R. Al-jawahiri, E. Milne. (2017). Resources available for autism research in the big data era: a systematic review. PeerJ, E2880. DOI 10.7717/peerj.2880
23	How can toy manufacturers identify the needs of children with learning difficulties and produce toys that meet these needs?	Could toy manufacturers identify and provide toys specifically for those with learning difficulties?	A parent/carer	
24	What resources help children and young people with learning difficulties understand their condition?	Is there any literature to help a child with learning difficulties to under stand their condition e.g. Epilepsy	A professional	R. Al-jawahiri, E. Milne. (2017). Resources available for autism research in the big data era: a systematic review. PeerJ, E2880. DOI 10.7717/peerj.2880
		What happens to people when their parents die?	A parent/carer	D. Hedley, M. Ujjarevic, L. Cameron, S. Halder, A. Richdale, C. Dissanayake. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. Autism, 21(8): 929-941. DOI: 10.1177/1362361316660065
		What happens to people when their parents die?	A professional	J. J. Ellenkamp, E. P. Brouwers, P. J. Embregts, M. C. Joosen, J. van Weeghel. (2015). Work Environment-Related Factors in Obtaining and Maintaining Work in a Competitive Employment Setting for Employees with Intellectual Disabilities: A Systematic Review

		How can the acting head insist on pushing my son to an overstretched CAMHS when we have worked with and shared with the school all progress made with a clinical psychologist?	A parent/carer	
27	Which information and communication technologies (ICT) (e.g. augmentative and alternative communication (AAC) devices, ICT-based communication aids, assistive technology, iPads/ writing aids/tablet/phone) are effective and how can they best be accessed by children and young people with learning difficulties?	Is the notion of prerequisites for the provision of AAC (augmentative and alternative communication) devices and support (for example by the NHS) a valid one?	A parent/carer	B. Perelmutter, K. K. McGregor, K. R. Gordon. (2017). Assistive technology interventions for adolescents and adults with learning disabilities: An evidence-based systematic review and meta-analysis. Computer & Education. 114: 139-163. http://dx.doi.org/10
		Interventions is a big part of moving forward positively. I would love to see more positivity in schools at an early age, utilising software at a young age and building that into the curriculum. Just as importantly, teaching the teachers pre-qualification is essential.	A parent/carer	M. Linden, C. Hawley, B. Blackwood, J. Evans, V. Anderson, C. O'Rourke. (2016). Technological aids for the rehabilitation of memory and executive functioning in children and adolescents with acquired brain injury. Cochrane Database of Systematic Review. D
		Can very early access to ICT based communication aids improve long term ability to communicate?	A parent/carer	Antonio Miguel Cruz, Adriana Maria Rios Rincón, William Ricardo Rodriguez Duenas, Daniel Alejandro Quiroga Torres & Andrés Felipe Bohórquez- Heredia. (2017). What does the literature say about using robots on children with disabilities? Disability
		How can assistive technology best support people with Learning Difficulties?	A professional	
		Can technology help?	A parent/carer	
		Looking into new equipment and teaching methods which can help people with learning disabilities and give them opportunities to learn in ways that work for them.	A parent/carer	
		How can ICT be used to improve ttaient of dyslexic learners?	A parent/carer	
		How can using ICT improve life for dyslexic people?	A parent/carer	
		How can technology/computers assist in minimising the impact of some learning difficulties (particularly dyslexia)	A professional	
		Could iPads or writing aids be offered at school? This really helps when kids struggle to process info, write	A child or young person	
How effective are high tech AAC devices for individuals with LD and ASD in supporting social communication (beyond requesting?)	A professional			
What is the impact of Ipad/tablet/phone use on the development of social communication	A professional			
28	What are, and how common are, the physical and mental health conditions that often present alongside learning difficulties in children and young people?	Comorbidities in learning disability.	A professional	J. Downs, AM. Blackmoe, A. Epstein, R. Skoss, et al. (2017). The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: a systematic review and meta-analysis. Developmental Medicine & Child Neurology. 60(1): 30
		What is the frequency of co-occurrence of cerebral visual impairment in the developmental disorders (ASD, ADD, DCD and Dyslexia)	A professional	S. Flynn, L. Vereenoooghe, R. P. Hastings, D. Adams, S-A. Cooper, N. Gore, C. Hatton, et al. (2017). Measurement tools for mental health problems and mental well-being in people with severe or profound intellectual disabilities: A systematic review. Clini
		What is the most common co-occurring difficulty with dyslexia?	An adult who experienced learning difficulties as a child	C. Walton, M. Kerr. (2015). Down syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. ADVANCES IN MENTAL HEALTH AND INTELLECTUAL DISABILITIES. 9(4): 151-162. DOI 10.1108/AMHID-11-2014-0037
		LD and psychiatric comorbidity - nature, assessment, treatment	A professional	C. Walton & M. Kerr. (2015). Prader Willi syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. Advances in Mental Health and Intellectual Disabilities. 10(3) 172-184. DOI10.1108/AMHID-08-2015-0037
29	Why are children and young people with learning difficulties more likely to experience mental health problems?	investigate the link between self harm, bpd and undiagnosed LD	A professional	M. Jacobs, H. Downie, G. Kidd, L. Fitzsimmons, S. Gibbs, C. Melville. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. British Journal of Learning D
		I was diagnosed as an adult as having dyslexia. Focus for support is during education. I'd like to know more about how dyslexia may effect my working life and contribution/or not as a tax payer. I'd also like to know more about how it may effect my emotions, how I interpret emotions, and consequently the kind of relationships I may or may not be having with people.	An adult who experienced learning difficulties as a child	C. Walton, M. Kerr. (2015). Down syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. ADVANCES IN MENTAL HEALTH AND INTELLECTUAL DISABILITIES. 9(4): 151-162. DOI 10.1108/AMHID-11-2014-0037
		I see in the next page it says - adult who experienced learning difficulties as a child. If you are an adult who has dyslexia you experience those difficulties now. the coping mechanisms that I learned as a child, can in themselves cause me difficulty in the present. my whole personality may be contorted to try and avoid or cope with life and I can stay largely unaware of this. why do we focus on the learning difficulties?	An adult who experienced learning difficulties as a child	C. Walton & M. Kerr. (2015). Prader Willi syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. Advances in Mental Health and Intellectual Disabilities. 10(3) 172-184. DOI10.1108/AMHID-08-2015-0037
		Can there be more awareness amongst educational professionals that self-harm and eating disorders amongst young teenage girls can be a sign of untreated anxiety related to ASD? How can this be screened for before it manifests itself as a mental health issue?	A professional	
		Why many young people with moderate learning disabilities are un-diagnosed and struggling in mainstream education. Often resulting in psychiatric admissions. Effective treatments being changes in environments.	A professional	
		Are there correlations between dyslexia and depression when late diagnosis occurs?	An adult who experienced learning difficulties as a child	
30	What are the triggers, mechanisms and relationships of physical and mental health conditions that often present alongside learning difficulties in children and young people?	To understand the triggers of generalised social anxiety (GSA) particularly in young children and the impact of GSA on their learning.	A professional	M. Romero-Gonzalez, S. Chandler, E. Simonoff. (2017). The relationship of parental expressed emotion to co-occurring psychopathology in individuals with autism spectrum disorder: A systematic review. Research in Developmental Disabilities. 72: 152-165. ht
		What is the nature of the link between motor development and learning difficulties?	A professional	M. Jacobs, H. Downie, G. Kidd, L. Fitzsimmons, S. Gibbs, C. Melville. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. British Journal of Learning D
		Correlation of gross and fine motor difficulties with learning disabilities, and best interventions and community resources to support this.	A professional	C. Walton, M. Kerr. (2015). Down syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. ADVANCES IN MENTAL HEALTH AND INTELLECTUAL DISABILITIES. 9(4): 151-162. DOI 10.1108/AMHID-11-2014-0037
		Are executive functioning skills deficits linked to learning difficulties in general or a specific learning g difficulty (i.e. dyslexia)?	A professional	C. Walton & M. Kerr. (2015). Prader Willi syndrome: systematic review of the prevalence and nature of presentation of unipolar depression. Advances in Mental Health and Intellectual Disabilities. 10(3) 172-184. DOI10.1108/AMHID-08-2015-0037
		what are the causes of significant co-morbidity with depression and anxiety disorders	A professional	
		What is the impact of auditory memory on learning? Are there any interventions which are effective to support this?	A professional	
		Are youngsters with dyslexia more likely to suffer from anxiety and poor mental health?	A parent/carer	
		How does dyslexia affect young people's anxiety?	A parent/carer	
		How strong is the relationship between dyslexia and social anxiety?	A parent/carer	
		The role of anxiety in learning disability - impairing functioning and affecting assessment outcomes	A professional	
		How does anxiety, in relation to a specific subject (i.e. maths) develop and how can we help children overcome this anxiety?	A professional	
		Greater understanding on the incidence and impact of comorbidities.	A professional	
		What is the benefit of optimal management of epilepsy in LD?	A professional	
	How does dyslexia affect people's sleep patterns?	A parent/carer	J. Nation, M. Brigger. (2017). The Efficacy of Adenotonsillectomy for Obstructive Sleep Apnea in Children with Down Syndrome: A Systematic Review. Otolaryngology- Head and Neck Surgery. Vol. 57(3), 501-408. DOI: 10.1177/0194599817703921 http://otojournal.org	

31	sleep in children and young people and what are the best ways of treating these sleep difficulties?	How does dyslexia affect sleep patterns?	A parent/carer	Z. Farhoos, JW. Isley, AA. Ong, et al. (2017). The Efficacy of Adenotonsillectomy for Obstructive Sleep Apnea in Children with Down Syndrome: A Systematic Review. Laryngoscope. Vol. 127(6), 1465-1470. https://doi.org/10.1177%2F0194599817703921
		What are the best evidence-based interventions for sleep pattern maintenance in PWLD?	A professional	L. J. Priday, C. Byrne, V. Totsika. (2017). Behavioural interventions for sleep problems in people with an intellectual disability: a systematic review and meta-analysis of single case and group studies. Journal of Intellectual Disability Research. 61(1):
		What impact other symptoms have on her learning difficulties e.g. SPD, reflux,	A parent/carer	AS. Weitlauf, N. Sathe, ML. McPheeters, et al. (2017). Interventions Targeting Sensory Challenges in Autism Spectrum Disorder: A Systematic Review. Pediatrics. 139(5): e20170347. doi: 10.1542/peds.2017-0347
		What impact other symptoms have on her learning difficulties e.g. SPD, reflux,	A parent/carer	
		What is the incidence of sensory processing difficulties in the learning disability population, in terms of difficulties with sensory discrimination and sensory reactivity? e.g. with the touch system, a discriminative difficulty might be difficulty identifying differences in texture and shape using touch alone; and a reactivity issue may be over-reactivity to touch inputs leading to distress or discomfort with various touch sensations. Any of these can have an impact on an individual's functioning in their every day activities.	A professional	H. M. Leong, M. Carter and J. Stephenson. (2015). Systematic review of sensory integration therapy for individuals with disabilities: Single case design studies Research in Developmental Disabilities. 40: 51-62. https://doi.org/10.1016/j.ridd.2015.09.0
		Can sensory seeking behaviours be present without them being linked to ASD?	A parent/carer	H. M. Leong, M. Carter and J. Stephenson. (2015). Systematic review of sensory integration therapy for individuals with disabilities: Single case design studies. Research in Developmental Disabilities. 47: 334-351. https://doi.org/10.1016/j.ridd.2015.09.022
		My sensory difficulties heightened after the birth of my son - why is this and have other mothers with sensory processing disorder experienced this?	An adult who experienced learning difficulties as a child, a parent/carer & a professional	
		I am a sensory avoider and my son a sensory seeker - What parent child insttucion could help us cope better as I become overwhelmed by the dynamics + touch?	An adult who experienced learning difficulties as a child, a parent/carer & a professional	
		What helps to overcome learning difficulties, specifically sensory loss How can these therapies be included in education setting	A parent/carer	
		My physical relationship with my partner has ceased due to my tactile defensiveness. What intervention could be used to help me overcome this and why is there not more support for adults with sensory processsing difficulties?	An adult who experienced learning difficulties as a child, a parent/carer & a professional	
		How to reduce the tactile sensitivity experienced by Asperger adult which limits choice of clothes and footwear.	A parent/carer	
		Can sensory integration enahnce speech therapy?	A professional	
		How many children with cerebral palsy have cortical (cognitive) visual impairment. What are the implications of this? How aware are teachers, speech and language therapist etc about the condition and the impact of this on learning and intervention.	A professional	
		What is the incidence of CVI in children with autism e.g. optic ataxia and difficulties with depth perception. What is the impact? Is this underdiagnosed?	A professional	
		Is there a difference in optimum prescription formulae for hearing aid fitting for individuals with intellectual disabilities?	A professional	
		Should hearing aids issued to individuals with an intellectual disability be set to a higher SNR than used for with current prescription formulae?	A professional	
		Why such a long wait for referral to a Clinical Psychologist for young mothers with a learning difficulty who have not been in the service as a child, to inform parenting assessments - the child can not wait? These mothers often where not seen by CAMS due to they themselves being neglected by parents not accessing this service for their child now adult / young person.	A professional	M. Naseem, AH Shah, MF. Khiyani, Z. Khurshid, MS Zafar, S. Gulzar, AH Aljameel, HS. Khalil. (2017). Access to oral health care services among adults with learning disabilities: a scoping review. Annali di Stomatologia. 7(3): 52-59. doi: 10.11138/ads/2016.
		Why does it take so long for diagnosis?	A parent/carer	M. Jacobs, H. Downie, G. Kidd, L. Fitzsimmons, S. Gibbs, C. Melville. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. British Journal of Learning D
		Why does it take so long for a learning difficulty to be recognised or formally diagnosed? Asked because there seems to be reluctance on the part of education to acknowledge difficulties leading to a very slow response to putting appropriate support into place to support individual pupils.	A professional	R. Balogh, C. A. McMorris, Y. Lunsky, H. Ouellette-Kuntz, L. Bourne, A. Colantonio, D. C. Goncalves-Bradley. (2016). Organising healthcare services for persons with an intellectual disability (Review). Cochrane Database of Systematic Review. DOI: 10.1002/14651858.CD007492.pub2
		If there is a variance in diagnosis of learning difficulties by SIMD, what other risk factors, including poverty & LAAC specifically, also impact on levels of diagnosis?	A professional	
		Why there is no consistency in any diagnosis , support or interventions. Constant battle on an already stressful situation. No regular support or time given. Resources too thinly dread for the amount of people needing help.	A parent/carer	
		Why is the NHS extremely slow when it comes to early diagnosis and intervention of children with learning difficulties? For example, i have a little sister who is 9 years old now. She has been walking on her toes since she started walking at the age of 1 and a half, but there has been no proper action taken to try and stop this, or even relatively useful info given to try rectify this by the NHS. At the start of this academic year we were told about a special type of boots called Pedro boots which are designed to try and stop walking on the toes, and only near of the end of this academic year a physiotherapist came to assess the situation before half heartedly accepting to order these boots for us. Referring to this scenario, why were steps like this not taken at an earlier age for my sister? Do these doctors not fully consider the consequences the long term effect this toe walking can have on her feet, ankles, legs, etc in the future?	A parent/carer	
		Why is there no consistency in the way learning difficulties are diagnosed? Different areas/schools do their own thing.	A professional	
		Why access to health for children with learning difficulties depends on post code lottery and quite variable across the country?	A professional	
		Why is there inequality in access to services	A professional	
		Why is help not the same in all schools even tho in the same council	A parent/carer	
		It often takes a long time to confirm that a child has a learning difficulty, why is this and can the process be speeded up in any way?	A professional	
		Why does a child with dyslexia not get the same support as other children do.	A parent/carer	
		Why do school have differing interventions in dealing with pupils with learning difficulties ?	A professional	
		Why are local authorities and education departments slow to give the support that is required after diagnosis of the child	A parent/carer	
		a child with dyslexia needs there own reading material that is different from main stream class. Why are they not offered this so they can move forward with the curriculum	A parent/carer	
		Why is there a much poorer standard of overall support once young people leave the educational/child system, e.g. social work and health care provision?	A child or young person	
		Why are children having to wait too long for help and support for mental health issues?	A parent/carer	
		Why is it so difficult to access relevant support as a parent of children with different conditions that impact on their learning?	A parent/carer	
		Why does it take so long to get help? It was noticed in nursery that my child had problems and still have to consistently chase up for help. I kept him back 1 year and is now going to P3.	A parent/carer	
		Why is support not automatically offered to the carers	A parent/carer	
		What are the personal and professional characteristics of teachers who have a proven track record of successfully educating children with additional support needs? What are the implications for pre-service training and professional development?	A professional	BM. Sutton, AA. Webster, MF. Westerveld (2018). A systematic review of school-based interventions targeting social communication behaviors for students with autism. Autism. doi: 10.1177/1362361317753564
		What are the early signs of these specific learning difficulties and is there an easy way for teachers to screen early enough that strategies can be put in place before they fall behind with their work	A professional	
		Can there be more awareness amongst educational professionals that self-harm and eating disorders amongst young teenage girls can be a sign of untreated anxiety related to ASD? How can this be screened for before it manifests itself as a mental health issue?	A professional	
		How could we effectively train teachers and support assistants in recognising children with ADHD thus able to support them effectively in school.	A parent/carer	
		What is the most practical and effective way to train classroom teachers about supporting pupils with ADHD and identifying pupils with possible ADHD?	A parent/carer	

34	What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?	If my child is to be presumed as a mainstream pupil, what level of training will her teacher have to be able to competently cope with her learning difficulties?	A parent/carer			
		Why is the subject so badly understood with the teaching facilities around the country? Especially in Primary schools.	A parent/carer			
		How can we communicate to schools/education establishments how learning difficulties affect young people beyond their defined learning difficulty - organisational skills; coping mechanisms; focussing and tiredness	A parent/carer			
		Why does it seem to be such a fight to get secondary teachers in particular to understand needs of your child?	A parent/carer			
		How can we ensure that educators understand how to support young people to reach their potential when they have barriers to learning such Sensory processing difficulties?	A professional			
		Experienced teachers. Better understanding of needs.	A parent/carer			
		Why are PSA's who spend the most time with young people with learning difficulties/autism not properly trained or no scope to train as professionals to work with the young people they spend all day with who have extreme complex needs.	A professional			
		Why is there not more training for school staff?	A parent/carer			
		Are support staff supporting people with learning disabilities appropriately trained around all aspects i.e additional health problems they may have i.e epilepsy, autism?	A parent/carer			
		How to train teachers in school about dyslexia, that it's not just about reading and spelling	An adult who experienced learning difficulties as a child			
		Why does it take the education system so long to do anything about learning difficult?	A parent/carer			
		How can we better educate teachers on the difficulties pupils face?	A parent/carer			
		Do you think educational professionals are adequately trained in supporting individuals with learning difficulties and if not how could this be put in place?	A parent/carer			
		How education staff are supported and educated in Tourettes Syndrome and its associated disorders and how it affects their learning.	A parent/carer			
		Despite having a team of professionals involved from 2007 (age 3) we had no diagnosis for our son and were told in 2010 we may never find out what was wrong. So we requested to be referred to the Communication Clinic at the Sick Kids where we received a diagnosis in 2011. It is key that the most relevant professional/s need to be involved with the parent and child from the earliest opportunity to ensure they receive informed input from professionals who specialise in the difficulties demonstrated. An understanding and diagnosis is key to be able to provide the correct support to the family and child at home, in education and the wider community. Without the correct understanding, how can the most appropriate and meaningful supports be put in place by parents and professionals?	A parent/carer			
		How to get teachers to tea ch in a more varied learning style	An adult who experienced learning difficulties as a child			
		What can be done to ensure that special needs kids will be educated the way they learn?	An adult who experienced learning difficulties as a child			
		Can there be research into accommodating children's different learning styles and if it shows an improved outcome in what they have understood and gained knowledge on?	A parent/carer			
		Interventions is a big part of moving forward positively. I would love to see more positivity in schools at an early age, utilising software at a young age and building that into the curriculum. Just as importantly, teaching the teachers pre-qualification is essential.	A parent/carer			
		Looking into new equipment and teaching methods which can help people with learning disabilities and give them opportunities to learn in ways that work for them.	A parent/carer			
		Often in the educational setting, teachers need to have practical suggestions as to how to proceed with the learning environment of particular children. Could research identify the best way of dealing with each set of difficulty.	A professional			
		Are secondary teachers differentiating sufficiently for young people with learning difficulties?	A professional			
		Can it be made part of teacher training that they all understand how to teach children with all manner of learning difficulties	A parent/carer			
		Teachers to be given more training on supporting learning difficulties S.E.N training should be done automatically.	A parent/carer			
		More education for professionals in health and teaching, and also for the general public about the different kinds of learning disabilities a person might have.	A parent/carer			
		What are the most effective interventions to improve school staff's ability to facilitate learning among children and young people who are considered to have learning difficulties?	A professional			
		How confident do teachers/parents feel to support children's learning needs in the classroom/at home?	A professional			
		Training requirements for staff in ASN schools to support dealing with very complex medical interventions	A professional			
		Children and young people with Learning Disability in mainstream schools, is there enough educated staff to look after their educational needs?	A professional			
		What is the role of an educational psychologist and how is the role perceived by families and other professionals?	A professional			
		How can my teachers inform my class	A child or young person			
		35	What knowledge, skills and training do health, social work and "third sector" (e.g. charities and support services) professionals need to understand the best support to give children and young people with learning difficulties and their families/carers?	How many children with cerebral palsy have cortical (cognitive) visual impairment. What are the implications of this? How aware are teachers, speech and language therapist etc about the condition and the impact of this on learning and intervention.	A professional	R. Spackman, A. Qureshi, D. Rai. (2016). A review of recommendations for medical undergraduate intellectual disability psychiatry teaching from UK reports. Advances in Mental Health and Intellectual Disabilities. 10(2): 158-163.
				Do we as professionals have the knowledge and skills in looking after children & young people with Learning Disabilities?	A professional	M. Tatlow-Goldern, L. Prihodova, B. Gavin, W. Cullen, F. McNicholas. (2016). What do general practitioners know about ADHD? Attitudes and knowledge among first-contact gatekeepers: systematic narrative review. BMC Family Practice. 17(1): 129. doi: 10.118
				Children and Families Social Workers, Adult Social Workers, Educational Psychologists and Learning Disability Nurses should work together / alongside one another, to complete a robust risk assessment of parenting capacity, and review whenever necessary - a pathway for this and procedures for practice would be good. I am a health visitor and my only option when voluntary service input and Early Years Centre input is not enough or coming to an end, the only option is a Children and Families Social Work assessment - if they will accept the referral - I am in the middle of trying to arrange this at present and too much of the assessment is falling on me with me and I have a limited working knowledge of the risk factors associated with parenting with a learning difficulty and I have studed level 11 child protection certificate. Why is it not a more robust multi professional risk assessment for a plan of supporting parents with learning difficulties to parent and gatekeeping skills (I am thinking of a mother who already has a child adopted - accommodated and now is struggling with to keep a toddler safe?	A professional	HT, Xie, L. Liu, J. Wang, K. E. Joon, R. Parasuram, J. Gunasekaran, C. L. Poh. (2015). The effectiveness of using non-traditional teaching methods to prepare student health care professionals for the delivery of mental state examination: a systematic review. JBI Database of Systematic Reviews and Implementation Reports. 13(7):177-212, JUL 2015
What guidance should be given to professionals as to dealing with families regarding potential outcomes of living with a learning disability.	A parent/carer					
A special fund to be created to prolong respite care for children/adults/carers to enable care to take place throughout the year. Specialist social work staff to be further trained. This should be an emotional issue although its not seen as important. (*Second sentence - In-scope)	A parent/carer					
Why are LD Nurses only for Adults? Surely with their training and expertise it would be more beneficial to bring them in earlier rather than later.	A professional					
Why there is not enough training and education for primary care physicians for diagnosis and management of children with learning diability?	A professional					
I don't remember being taught about learning difficulties at university as part of my children's nursing degree, is there plans for sessions/modules regarding this to be taught within the course? This would be beneficial as you receive very little training on the job.	A professional					
36	Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?			What are the most effective ways to prevent bullying (getting bullied) in children with learning difficulties?	A parent/carer	Z. Kileen, R. Bunch, JF. Kerrigan. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability Research: 61(5): 411-434. https://doi.org/10.1111/jir
				What can be done to stop special needs kids being bullied?	An adult who experienced learning difficulties as a child	P. A. Gillen, M. Sinclair, W. G. Kernohan, C. M. Begley, A. G. Luyben. (2017). Interventions for prevention of bullying in the workplace. Cochrane Database of Systematic Review. DOI: 10.1002/14651858.CD009778.pub2

		How to address stigma.. not just a bad kid.	A parent/carer	M.A. Malli, R. Forrester-Jones, G. Murphy. (2015). Stigma in youth with Tourette's syndrome: a systematic review and synthesis. European Child & Adolescent Psychiatry. 25(2): 127-139. DOI 10.1007/s00787-015-0761-x
		What is the level of self-efficacy and self-esteem of young people with learning difficulties compared to those without?	A professional	
37	How can we improve public awareness about learning difficulties and what is the impact of any improvement in awareness on the wellbeing of people with learning difficulties?	Why does society in general assume that people with learning disabilities are not talented?	A professional	K. Boshoff, D. Gibbs, R. L. Phillips, L. Wiles, L. Porter. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. Child: Care, Health and Development. 42(6):
		I see in the next page it says - adult who experienced learning difficulties as a child. If you are an adult who has dyslexia you experience those difficulties now. the coping mechanisms that I learned as a child, can in themselves cause me difficulty in the present. my whole personality may be contorted to try and avoid or cope with life and I can stay largely unaware of this. why do we focus on the learning difficulties?	An adult who experienced learning difficulties as a child	H. A. Pelleboer-Gunnink, W. M. W. J. Van Oorsouw, J. Van Weeghel, P. J. C. M. Embregts. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability
		What are the positive aspects of learning difficulties and how to overcome the negative stereotypes?	An adult who experienced learning difficulties as a child	H. A. Pelleboer-Gunnink, W. M. W. J. Van Oorsouw, J. Van Weeghel, P. J. C. M. Embregts. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. Journal of Intellectual Disability
		How to address stigma.. not just a bad kid.	A parent/carer	
		Why is my child measured against someone's idea of what normal should be, rather than be celebrated for who they are?	A parent/carer	
		Managing stereotypes - supporting the education of all in supporting children with additional support needs?	A parent/carer	
		What are the most effective interventions for changing negative attitudes towards children and young people with learning difficulties?	A professional	
		I would like to see more support to be given for learning difficulties - and for other children to be made aware of differences.	A parent/carer	
		How can we educate the public about learning disabilities?	A professional	
		How to educate the general public?	A parent/carer	
		More education for professionals in health and teaching, and also for the general public about the different kinds of learning disabilities a person might have.	A parent/carer	
		Has the incidence of learning disabilities increased or is that people are more aware of it?	An adult who experienced learning difficulties as a child	
		How can the wider community be educated to accept people with different abilities?	A parent/carer	
		My son is diagnosed with severe intellectual disability. No one really seems to be sure what this means	A parent/carer	
		What can be done to raise more awareness among both kids and adults?	An adult who experienced learning difficulties as a child	
		Why are service providers such as shop keepers, bus/ taxi drivers, catering services not trained in awareness? Are police and nursing staff?	A professional	
		How to educate the general public?	A parent/carer	
		How can we improve the rate of society's understanding, and acceptance of, disability so that discrimination is not an issue?	A professional	
		Why do so few people really understands cerebral visual impairment?	A parent/carer	
		Will more be done to educate people (employers) about dyspraxia? That it is not just a clumsiness but effects thinking, hearing, touch, perception etc?	An adult who experienced learning difficulties as a child	
How can we better disseminate knowledge and understanding of what Fragile X Syndrome is among health professionals? There still seems to be a lot of ignorance out there.	A parent/carer			
More education for professionals in health and teaching, and also for the general public about the different kinds of learning disabilities a person might have.	A parent/carer			
Could all be made aware of sensitive hearing and how it affects me, I need a quiet space sometimes	A child or young person			
How has society's view of people with learning difficulties changed over the last 20years or so? What effect have factors such as the inclusion agenda in education; changing legislation (e.g Equalities Act); media portrayal, recent government cuts on disability benefits, etc., had on this view?	A professional			
How do Scotland's non-disabled young people think about people with learning disabilities/difficulties and their inclusion or positive action to encourage their participation in society?	A professional			
Are there any difference in the way learning difficulties are perceived by young people, parents/carers and professionals	A professional			
38	How common are learning difficulties and the physical and mental health conditions that often present alongside learning difficulties in children and young people? Have they increased? If so, why has there been an increase?	Prevalence studies	A professional	L. Strasser, M. Downes, J. Kung, JH. Cross, M. de Hann. (2017). Prevalence and risk factors for autism spectrum disorder in epilepsy: a systematic review and meta-analysis. Developmental Medicine and Child Neurology. 60(1): 19-29. DOI: 10.1111/dmcn.13598
		What is the true prevalence of LS in Scotland and is it rising?	A professional	J. Robertson, D. Chadwick, S. Baines, E. Emerson, C. Hatton. (2017). Prevalence of Dysphagia in People With Intellectual Disability: A Systematic Review. Intellectual Developmental Disabilities. 55(6):877-391. https://doi.org/10.1352/1934-9556.55.6.377
		Has the incidence of learning disabilities increased or is that people are more aware of it?	An adult who experienced learning difficulties as a child	R. Northway, M. Brown, L. Taggart, M. Truesdale-Kennedy. (2016). Diabetes prevalence and experience amongst people with intellectual disabilities: A systematic review. Journal of Intellectual Disability Research. 60: 716-716. https://doi.org/10.1016/i rid
		Is the number of individuals with dyslexia growing and if so by how much and why? (Statistics have shown 1 in 10 at the moment)	A professional	
		Greater understanding on the incidence and impact of comorbidities.	A professional	
		LD and psychiatric comorbidity - nature, assessment, treatment	A professional	
		Socioeconomic status and learning difficulties	A professional	
39	What percentage of children and young people with learning difficulties receive the appropriate care and support that meets their needs at home, in clinic, in education and at work?	Do published statistics relating to young people diagnosed with a learning difficulty, as defined by this survey, vary significantly by SIMD?	A professional	
		What is the prevalence of Foetal Alcohol Spectrum Disorders in Scotland	A professional	
		How many children and young people with learning difficulties receive the appropriate care that meets their needs at home, in education, at work, with health needs?	A professional	
		Investigate how and where successful inclusive practice is taking place, the drivers and the tools and methods and how these can be shared.	A professional	
		What percentage of people with learning difficulties are able to hold down a part-time or full-time job?	A parent/carer	
		What percentage of pupils with learning difficulties find sustainable employment?	A professional	
		How many young people who require learning support go on to live reasonably normal lives - whilst those with more profound learning disabilities require long term care and support?	A parent/carer	
Research project on how to establish an effective database within Primary Care whereby every GP must consistently record whether a young person has a learning difficulty or learning disability. There should be clear criteria put in place for both these terms which are wrongly felt to be interchangeable and misunderstood even by health, social care and education professionals. Having a clear register based at GP level in every young persons record can then properly assist the young people to have the correct adjustments applied in their lives e.g. having their inability to read and interpret written information would clearly trigger GP Health Screening appointment letters to be sent out in symbolised / pictorial / larger font / printed on coloured paper / etc etc. Lets create a standard of inclusive, barrier free communication from childhood onward !!!	A professional			

** The systematic reviews listed here are only a selected number of the literature being reviewed.

**Indicative Questions
Summary**

No.	Themes	Indicative Questions (Overarching)	Single Questions	TOTAL
1	Causes	2	0	2
2	Identification & Diagnosis	6	0	6
3	Effect on Everyday Life	7	0	7
4	What Helps	10	3	13
5	Co-Occurring Conditions	5	0	5
6	Variations in the Availability and Quality of Provision	1	0	1
7	Professional Training & Development	2	0	2
8	Public Awareness	2	0	2
9	Statistics	2	0	2
	TOTAL	37	3	40

(including 1 sensory processing question)