| Final<br>Priority<br>Number | Research Question  | Originally submitted question   | Submitted by   | Research recommendation   | Recommendation from        | Source References to reliable up-to-date systematic review  | References to reliable up-to-date review which could be extended to include the uncertianity   | References to reliable out of date systematic review   | Protocol for a systematic review  | Ongoing controlled trials | Which types of treatments | Which outcomes?  |
|-----------------------------|--|---|--|---|----------------------------|---|--|--|---|---------------------------|---------------------------|--|
| Priority<br>18              | Does promoting public positive attitudes towards disability improve participation in recreation and lessure activities for children and young people with neurodisability? (JLA PSP Priority 18)   | e Teach society how to accept difference. Society is often far more disabling than the conditions themselves!<br>Training staff arross the board (sepcially in conditions such as autism) would be a very beneficial place to start.<br>Learn to understand sensory and processing differences and how best to approach these differences with each<br>individual concerned. Society would then learn tolerance, acceptance and may even adapt each environment<br>accordingly.   | 1 x parent ~ 1 x research recommendation                 | Collecting information on<br>knowledge, beliefs and<br>attitudes about disability can<br>help identify gaps in public<br>understanding that can be<br>bridged through education<br>and public information.<br>Governments, voluntary<br>organi-rations, and<br>professional associations<br>should consider running<br>social marketing campaigns<br>that change attitudes. | blications/2011/9789240685 | LIJLA Survey Scior K. Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. Research in developmental disabilities. 2011, 32 (6): 2164 - 2182-PMID: 21798712  | I loone  | none   | none  | none                      | Education and training    | Social participation;<br>Quality of Life                           |
| Priority 3                  | Are child-centred strategies to improve children's (i.e., peers)<br>attitudes towards disability (e.g., buddy or Circle of Friends etc)<br>effective to improve inclusion and participation within educational,<br>social and community settings? (JLA PSP Priority 3)         | Buddying by other children, social groups involving a mix of typical and disabled children: any sort of research to identify which factors in their peer relationships are most important for disabled children in making them feel good about themselves and contribute positively. Even children with ASD and learning difficulties can benefit from interaction with their peers - or so we believe? Wouldn't this be far better than 'therapies', psychological support, social workers in helping with their integration into society? ~  Does peer-focused intervention result in improved participation in leisure for CYP with disabilities? ~  Ways to improve societies understanding and valuing of such children  | 1 x parent ~ 2 x clinician                               |   |                            | JILA Survey Undsay S, Edwards A. A systematic review of disability awareness interventions for children and youth. Disability and Rehabilitation. April 2013, 35 (8): 623-646 (doi:10.3109/09638288.2012.702850)~PMID: 22831703   | none   | none   | none  | none                      | Education and training    | Social participation;<br>Quality of Life                           |
| Priority<br>14              | Are behavioural and sensory interventions (e.g. early intensive behavioural intervention, EarlyBird, encouraged socialisation with peers etc) effective in managing symptoms of Autistic Spectrum Disorder? (ILA PSP Priority 14)  | Do any of the alternative therapies out there actually work in supporting Autism? ~ Do interventions such as applied behavioural analysis/ Relationship developmental intervention / BIRD programme / biological interventions actually work in treating 'autism? ~ The impact on ABA( Aplied Behaviour Analysis) on young children with ASD compared with targeted support at school along neuro-typical children.   | 3 x parent   |   |                            | JLA Survey Reichow B, Steiner AM, Volkmar F. Social skills groups for people aged 6 to 21 with autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2012, Issue 7. Art. No.: CD008511.  DOI: 10.1002/14651858.CD008511.pub2.  | Makrygianni MK, Reed P. A meta-analytic review of the effectiveness of behavioural early intervention programs for children with Autistic Spectrum Disorders. Research in Autism Spectrum Disorders. October-December 2010, 4(4): 577–593  AND Reichow B, Doehring P, Hagopian L, Palka T, Phillips C. Behavioral approaches to managing sewere problem behaviors in children with autism spectrum and related developmental disorders. PROSPERO 2013:CR042013003105 | Diggle TTJ, McConachie H. Parent-mediated early intervention for young children with autism spectrum disorder. Cochrane Database of Systematic Reviews 2013, Issue 4. Art. No.: CD003496. DOI: 10.1002/14651858.CD003496.pub2                  | none  | none                      | Psychological therapy     | Management or change in symptoms                                   |
| Priority<br>19              | Are dietary modifications/restrictions (e.g. gluten, casein, dairy, meat etc) effective in managing symptoms of Autistic Spectrum Disorder? (ILA PSP Priority 19)  | Any evidence based interventions to improve the range of diet that children accept in Autism Spectrum disorders?  Are sensory assessments or ""diets" of value in children with or without autism?  Can diet/diet supplements have an effect on children with neurodisability as in some forms of epilepsy where diet can help control fits. Does diet have the same effect on behaviour?  Do dietary interventions have any long-term benefits for children on the autism spectrum?  Do gluten and casein free diets imgrove symptoms of autism spectrum disorders?  Does altering your child's diet affect the level of severity of their neurodisability? Explain (allow for all the different diets/ opinions with this question)  Does diet affect autism?  Giuten free diet for autism - any real evidence?  Giuten-free, Casein-free etc. diets for ASD - do they really have an impact, or is it a case of identifying Gastro-intestinal problems (seemingly common in ASD) in the children and finding the right treatment for it?  St shere any evidence milk and gluten free diets influence autism?  Proper studies on dietry interventions for ASD.  Research on treatments claiming to improve neurochemical transmissions in all groups affected by sensory processing difficulties/disorders/differences i.e. Physical/sensory integration; dietry/ nutritional/vitamins etc; medication based or any others.   Whit diet, esp proteins in grain, dairy and meat are problematic for autistic children. | G x parent ~ B x clinician ~ 1 x research recommendation | What is the efficacy of biomedical interventions, including diets and nutritional supplements? "Are there any specific dietary/non-pharmaceutical interventions that are more appropriate for children with specific forms of ASD, or particular types of comorbidity?  | SIGN 98                    | JIA Survey none   | none   | Millward C, Ferriter M, Calver SJ, Connell-Jones GG. Gluten-<br>and casein-free diets for autistic spectrum disorder.<br>Cochrane Database of Systematic Reviews 2008, Issue 2.<br>Art. No.: CD003498. DOI:<br>10.1002/14651858.CD003498.pub3. | none  | none                      | Diet                      | Management or change in symptoms                                   |
|                             | Are light therapies effective to manage sleep/improve day time functioning (learning) for children and young people with neurodisability?  | Does changing the lighting intensity and colour tone in classroom settings help children with neurodiverse conditions? Eg a) children with ADHD to concentrate for longer? b) children with dyslexia to read see written images more clearly and therefore speed up their reading time or reduce visual stress headaches? " Effect of Light boxes (light therapy) on sleep difficulties in children with neurodisability. " What is the effect of a sensory diet approach for children with sensory processing difficulties?  | 1 x parent ~ 2 x clinicians                              |   |                            | II.A Survey none  | In adults with dementia? Forbes D, Blake CM, Thiessen EJ, Peacock S, Hawranik P. Light therapy for improving cognition, activities of dally living, sleep, challenging behaviour, and psychiatric disturbances in dementia. Cochrane Database of Systematic Reviews 2014, Issue 2. Art. No.: CD003946. DOI: 10.1002/14651858.CD003946.pub4.  |  | Khan S, Heussler H, McGuire T, Dakin C, Pache D, Cooper D, et al. Melatonin for non-respiratory sleep disorders in children with neurodevelopmental disorders (Protocol).  Cochrane Database of Systematic Reviews 2011, Issue S. Art. No.: CD009140.  DOI: 10.1002/14651858.CD009140 |                           | Complementary therapies   | Physical functioning;<br>Social participation;<br>Quality of Life  |
| Priority<br>25              | Do massage-based therapies improve functioning and wellbeing for<br>children and young people with neurodisability? (JLA PSP Priority<br>25)   | How effective are Complementary Therapies such as massage, reflexology, relaxation techniques in helping children and young people affected by neurodisability? " Is there good evidence that Bowen Technique is helpful for children and young people?" Should the Bowen method of reflexology be a standard treatment for children with cerebral palsy - to improve nerve pathway signals?  | 2 x parent ~ 1 x clinician                               |   |                            | JIA Survey none   | Massage for cerebral palsy "http://www.pencru.org/evidence/massageforcerebralpalsy   | none   | none  | none                      | Complementary therapies   | Physical functioning;<br>Wellbeing; Quality of<br>Life             |
|                             | Do nutritional supplements (e.g. omegas 3,6,9) reduce symptoms and improve functioning of children with Autistic Spectrum Disorder?  | Do any nutritional supplements actually make a difference to children with autism? " 'Eye-C' capsules/fliquid to aid sleep and concentration in children with Asperger's/Hyperactivity etc. When we first used this with our youngests on who has Asperger's/Secreted in prune juice which was used very successfully to aid his constipation problems) he slept through the night for the first time ever. Previously he (as per our instructions!) would stay in his bedroom as on his bed (he understoad at night time he was not allowed to leave his bed except for the toilet) reading, playing etc until he went to sleep. Afterwards, after bedtime story etc he sleep for the first time. " What dosage of Omega 3, 6,9 fish oils can be most useful for ASD children specifically, are the Omega oils from plants just as good, or not?   | 3 x parent ~ 1 x research recommendation                 | Dietary supplementation in<br>ADHD/HKD  | SIGN 112                   | JILA Survey  Sonuga-Barke EJ, Brandeis D, Cortese S, Daley D, Ferrin M, Holtmann M, et al. Nonpharmacological interventions for ADHD: systematic review and meta-analyses of randomized controlled traisl of idetary and psychological treatments. GroupAm J Psychiatry. 1. March 2013, 170(3):275-89. doi: 10.1176/applajp.2012.12070991.  AND  James S, Montgomery P, Williams K. Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2011, Issue 11. Art. No.: CD007992. DOI: 10.1002/14651858.CD007992.pub2. |  | Nye C, Brice A. Combined vitamin B6-magnesium treatment in autism spectrum disorder. Cochrane Database of Systematic Reviews 2005, issue 4. Art. No.: CD003497. DOI: 10.1002/14651858.CD003497.pub2.   | none  | none                      | Complementary therapies   | Management or change in symptoms                                   |
|                             | Does chiropracty improve gross/fine motor function of children with hemiplegia?  | Does visiting a chiropractor improve gross and fine motor skills for children with hemiplegia? & if so, how long does the improvement last?   | 1 x parent   |   |                            | JLA Survey none   | none   | none   | none  | none                      | Complementary therapies   | Physical functioning   |
|                             | Does nutritional supplementation with vitamin D improve motor function in children and young people with neurodisability?  | effect of vitamin D levels on motor development   | 1 x clinician  |   |                            | JLA Survey none   | none   | none   | none  | none                      | Complementary therapies   | Physical functioning   |
|                             | Does trampolining improve balance and coordination (motor function) in children and young people with neurodisability?   | Does trampolining / rebound therapy result in improved standing balance on land for young people with a neurodisability?  | 1 x clinician  |   |                            | JLA Survey none   | none   | none   | none  | none                      | Complementary therapies   | Physical functioning   |
|                             | Is horse riding an effective therapy to improve functioning and promote wellbeing in children and young people with neurodisability?   | Does horse riding improve core stability and balance in children with cerebral palsy? (Hemiplegia) " I would like to suggest Equine Experiential Learning, We run a charity known as intouch equestrian, working with children and young people from all walks of life. Our work involves helping to develop Social and Emotional Learning, at which the horses and ponies are great teachers. The young people learn confidence, communication skills and compassion which is transferrable to ""real" life. This work is non-ridden, but we also successfully use therapeutic riding and yoga on horseback for those with mild physical or non-verbal challenges.   | 1 x parent ~ 1 x other                                   |   |                            | JLA Survey Sung-Hui Tseng, Hung-Chou Chen, Ka-Wai Tam. Systematic review and meta-analysis of the effect of equine assisted activities and therapies on gross motor outcome in children with creebral palsy, Disability and Rehabilitation. 2013. 35(2): 89-99-PMID: 22630812   | Tseng SH, Chen HC, Tam KW. Systematic review and meta-<br>analysis of the effect of equine assisted activities and<br>therapies on gross motor outcome in children with<br>cerebral palsy. Disability and Rehabilitation. 2013. 35(2): 89  | directed hippotherapy rehabilitate children with cerebral palsy? Developmental Medicine and Child Neurology. 2007.   | none  | none                      | Complementary therapies   | Physical functioning;<br>Wellbeing; Quality of<br>Life             |
|                             | is ongoing (6 months) rhythm therapy (e.g. by drumming or<br>Interactive Metronome or dancing) effective to improve<br>handwriting and other functioning in children and adults with<br>Developmental Coordination Disorder (particularly the more mild<br>form) or dyspraxia? | Can teaching children rhythm eg by drumming or Interactive Metronome or dancing or similar significantly<br>benefit children and adults with Developmental coordination disorder / dyspraxia (particularly the more milder<br>form of DCD) over a significant time period eg 6 months and not 6 weeks? I am particularly interested in how this<br>can affect their handwriting compared to no handwriting practice. Physiotherapy is important but learning<br>rhythm is an aspect that is often missed.   | 1 x parent   |   |                            | JIA Survey none   | none   | none   | none  | none                      | Complementary therapies   | Physical functioning   |
|                             | Would teaching body awareness techniques early (The Alexander<br>Technique, yoga etc.) improve postural/sensory awareness (e.g<br>bladder control) for children and young people with<br>neurodisability?  | growth of neurons to be capable of coping with posture and the lack of spatial awareness in relation to same. My<br>question is, if the neurons aren't there, are there activities and processes which can stimulate growth of specific,<br>and helpful neurons? This is not just about the lack of spatial awareness, it is, for example, an issue, that my son<br>can't feel his bladder needs emptying until it is full.   |  |   |                            | JLA Survey none   | none   | none   | none  | none                      | Complementary therapies   | functioning  |
|                             | Do seizure alarms for children with epilepsy reduce Sudden<br>Unexpected Death in Epilepsy (SUDEPS) / improve seizure<br>management/feduce parent stress?  | For profound epilepsy syndromes in children epilepsy alarms are an essential and potentially les awing device for families. Increasingly families are relying on epilepsy alarms for peace of mind and the restoration of long lots sleep. But the medical profession is slow to accept that such devices have a place in caring for our children, altering them to a seizure and administering rescue medication as required. Additionally, parents and other family members benefit to oa she yet all worry about the risk of death whilst sleeping - Sudden Unexplained Death in Epilepsy Patients (SUDEP)   | recommendation   | Pros/cons of discussion of<br>SUDEP and its timing with<br>families   | SIGN 81                    | JLA Survey none  ILA Survey Chine N. Bringshim T. Arigins sole for autient construm disorders.  | Millions K Briggell & Bandall M Elling Williams  | none   | none  | none                      | Assistive technology      | Survival; Seizures Management or change in symptoms; Parent stress |
|                             | Is a small dose of stimulant medication helpful in children with<br>Autstick Spectrum Disorder (ASD) and learning disability to reduce<br>hyperactive behaviours?  | Is a small dose of stimulant medication helpful in children with ASD and LD to help reduce hyperactive behaviour  | 1 A CHINICIAN  |   |                            | JIA Survey Ching H, Pringsheim T. Aripjorazole for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2021, Issue 5. Art. No.: CD009043. DOI: 10.1002/14651858.CD009043.pub2.   | Williams K, Brignell A, Randall M, Silove N, Hazell P.<br>Selective serotonin reuptake inhibitors (SSRIs) for autism<br>spectrum disorders (ASD). Cochrane Database of<br>Systematic Reviews 2013, Issue 8. Art. No.: CD004677. DOI:<br>10.1002/14651858.CD004677.pub3.  | Jesner OS, Aref-Adib M, Coren E. Risperidone for autism<br>spectrum disorder. Cochrane Database of Systematic<br>Reviews 2007, Issue 1. Art. No.: CD005040. DOI:<br>10.1002/14651858.CD005040.pub2.  | noile   | поне                      | Drugs                     | Hyperactivity;<br>Management or<br>change in symptoms              |

| is drug therapy (e.g. trihexyphenidyi) effective to control drooling for children and young people with neurodisability?   | What dribble med is the best and why? Is it fair to give them to disabled children given the potential side effects and how do we really know if they are being impacted by the side effects. ~ What is the efficacy of trihexyphenidyl in management of drooling?  | i x parent ~ 1 x clinician   |  |                       | JLA Survey Walshe M, Smith M, Pennington L. Interventions for drooling in children with cerebral palsy. Cochrane Database of Systematic Reviews 2012, Issue 11. Art. No.: CD008624. DOI: 10.1002/14651858.CD008624.pub3   | Rodwell K, Edwards P, Ware RS, Boyd R. Salivary gland botulinum toxin injections for drooling in children with cerebral palsy and neurodevelopmental disability: a systematic review. Developmental Medicine and Child Neurology. 2012. 54(11): 977-987  | none   | none | none  | Drugs                                    | Drooling;<br>Management or<br>change in symptoms   |
|--|---|--|--|-----------------------|---|--|--|------|---|--|--|
|  | Is taking aspirin beneficial for a child who has had a stroke with no known cause?  | 1 x parent   |  |                       | JLA Survey none   | none   | none   | none | none  | Drugs                                    | Survival; stroke   |
| who has had a stroke with no known cause?  What is the [long term] safety and effectiveness of  (psychostimulant) drug management for Attention Deficit  Hyperactivity Disorder (ADHD)? Does the psychostimulant maintain  effectiveness in the long term? | Does medication for ADHD really alter long term outcome? ~ What are the benefits and risks of long term use of psychostimulants for ADHD?   | ecommendation de expression de |  | SIGN 112              | JIA Survey Faraone SV, Buitelaa J. Comparing the efficacy of stimulants for ADHD in children and adolescents using meta-analysis European Child & Adolescent Psychiatry. April 2010 (Impact Factor: 3.7); 19(4):353-64. DOI:10.1007/s00787-009-0054-3. Epub 2009 Sep 10.7-PMID: 19763664  | Hanwella R, Senanayake M, de SilvaV. Comparative efficacy and acceptability of methylphenidate and atomoxetine in treatment of attention deficit hyperactivity disorder in children and adolescents: a meta-analysis, BMC Psychiatry. 2011. 11:176 doi:10.1186/1471-244X-11-176  | Donnelly M, Haby MM, Carter R, Andrews G, Vos T. Cost- effectiveness of dexampletamine and methylphenidate for the treatment of childhood attention deficit hyperactivity disorder. Australian and New Zealand Journal of Psychiatry 2004. 38(8): 592-601  | r    | none  | Drugs                                    | Management or change in symptoms   |
| 23 seizure management, especially in terms of adverse effects on learning, psychosis, anxiety, anger and rage? (JLA PSP Priority 23)   | How learning needs may be affected by epilepsy and the medications used to treat. "The effect of anti epiletic drugs on neurologically damaged adolesent young people with particular reference to increasing the susceptibility to psychosis, anxiety, anger and rage. Especially drugs such as toporamate and carbimazapine.  | ccommendation  st tr d a a A tr ss cc r ss cc r d cc r ss cc r ss ss tr tr cc cc cc d d cc tr  | compare in efficacy to the tandard AEDs in the reatment of newly liagnosed epilepsy? "What ire the initial and add-on AEDs of thoice in the reatment of the epilepsy vindromes with onset in inhidhood, for example, myoclonic astatic epilepsy and Dravet syndrome?" Does treatment response elate to cause in infantile passns? Does sender the response elate to cause in infantile passns? Does enter and response elate to cause in infantile passns? Does enter and response elate to cause in infantile passns? Does enter and response infantile passns? Does enter and response infantile passns? Poes enter and response infantile passns? Poes enter and response infantile passns? Poes enter the long-term feet of the passns? "What is the most established usually lasting onger than 30 minutes) | NICE CG 137 ~ SIGN 81 | JLA Survey none   | Appleton R, Macleod S, Martland T. Drug management for acute tonic-clonic convulsions including convulsive status epilepticus in children. Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.: CD001905. DOI: 10.1002/14651858.CD001905.pub2.   |  | none | none  | Drugs                                    | Management or change in symptoms; adverse effects or complications                         |
| 11 therapies (e.g. Cognitive Behavioural Therapy) to treat anxiety in  | Do medications aimed at reducing anxiety (and thereby aggression) work long term in children with severe autism?  Does the management of anxiety with medication in children with autism beneficial and what are the side effects?  Long term impact\(\)side effects of risperidone vs sertraline vs fluoxetine for associated anxiety - comparative effectiveness and longterm side-effects - is mono or multiple therapy best? ~  Which medication helps best for anxiety in autism? ~  CBT is recognised as an effective treatment for children with ASD especially if it has been specifically modified for them. Why then can into a cross this form yASD children? ~  Use of Cognitive Behavioural therapy for repetitive behaviours in autism. ~  What cognitive behavioural therapy for repetitive behaviours in autism? ~  What is the evidence for CBT to treat anxiety in adolescents with autism? | a<br>N<br>tt<br>o<br>r<br>r<br>L<br>L<br>p   | rurher risperidone studies and systematic reviews/meta analysis " More research is needed on he use of fluoextine and other selective servotonin euptake inhibitors." ong term effectiveness of medication, including obtential synergistic effects with other interventions.  | SIGN 98               | JLA Survey Lang R, Regester A, Lauderdale S, Ashbaugh K, Haring A. Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. Developmental Neurorehabilitation. 2010. 13(1): 53-63~PMID:20067346  | White AH. Cognitive behavioural therapy in children with autistic spectrum disorders. In Bazian Ltt (Ed) STEER: Succinct and Timely Evaluated Evidence Reviews 2004; 4 Ed). Bazian Ltd and Wessex Institute for Health Research & Development, University of Southampton AND Hurwitz R, Blackmore R, Hazell P, Williams K, Woolfenden S. Tricyclic antidepressants for autism spectrum disorders (ASD) in children and adolescents. Cochrane Database of Systematic Reviews 2012, Issue 3. Art. No.: CD008372. DOI: 10.1002/14651858.CD008372.pub2 | pharmacological therapies for young people and adults with autism spectrum disorder (ASD): a critical appraisal of   | none | none  | Drugs; Psychological<br>therapy          | Anxiety;<br>Management or<br>change in<br>symptoms: adverse<br>effects or<br>complications |
| behavioural strategies and/or drugs (e.g. melatonin) to manage<br>sleep disturbance in children and young people with neurodisability<br>(outcomes include time to onset, duration, and reducing impact on<br>family)? (JLA PSP Priority 10)               | Does melatonin improve sleep patterns? ~ rules Melatonin the drug of choice to regulate sleep patterns in children with severe neurodisability when this  | x parent ~ 7 x clinician ~ 1 x research Necessarch Necessarch  | vlelatonin use.  | SIGN 98               | JIAS Survey  Galland BC, Elder DE, Taylor BJ. Interventions with a sleep outcome for children with cerebral palsy or a post-trammatic Prain injury. A systematic review. Sleep Medicine Reviews. 2012. 16(6):561-73. doi: 10.1016/j.smrv.2012.01.007. PMID:22609124  AND  Khan S, Heussler H, McGuire T, Dakin C, Pache D, Cooper D, et al. Melatonin for non-respiratory sleep disorders in visually impaired children. Cochrane Database of Systematic Reviews 2011, Issue 11.  Art. No.: CD008473. DOI: 10.1002/14651858.CD008473.pub2 | Montgomery P, et al. The use of Melatonin in children with   | treatment in children with neurodevelopmental disabilities   |      | Identification of Free-<br>kunning Rhythms in<br>Bilmd<br>Children-NCT00688935*<br>"Oregon Health and<br>Science University.<br>Melatonin Studies of<br>Bilmd Children.<br>Registered 3 June 2008 | Drugs                                    | Sleep; Parent stress   |
| 17 promote integrated health, social care, education) improve school<br>attendance, reduce admissions, and parents' satisfaction and   |   | ei<br>o<br>yy<br>H<br>st<br>aa<br>Ti   | Are particular models of envice provision more fetetule in improving utcomes for children and outcomes for children and coung people with ASD? Yow are transitions, at all tages from pre-school to dulthood, best managed? The role of multidisciplinary or multiagency teams.  | SIGN 98               | JLA Survey Parker G, Bernard S, Gridley K, Aspinal F, Light K. Rapid Systematic Review of International Evidence on Integrated Models of Care for People with Long-term Neurological Conditions, (February 2010) Technical Report Project 08/1610/124 Queen's Printer and Controller of HMSO 2010*http://www.york.ac.uk/inst/spru/research/pdf/LTNCReview.pcf   | specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: a systematic review. PLOS Medicine. 2013. 10(12): e1001572 "PMID: 24358029   | Mayo-Wilson E, Montgomery P, Dennis JA. Personal assistance for children and adolescents (0-18) with both physical and intellectual impairments. Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.: CD006859. DDI: 10.1002/14651888.CD06859.pub2. AND Montgomery P, Mayo-Wilson E, Dennis JA. Personal assistance for children and adolescents (0-18) with intellectual impairments. Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.: CD006858. DOI: 10.1007/14651858.CD006858. pub2. AND Mayo-Wilson E, Montgomery P, Dennis JA. Personal assistance for children and adolescents (0-18) with physical impairments. Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.: CD00677. DOI: 10.1002/14651858.CD006277. pub2. |      | none  | Service delivery                         | School attendance;<br>Hospital admissions;<br>Parent satisfaction<br>with care             |
| speed up the achievement of continence (either/or faecal or<br>urinary) for children and young people with neurodisability? (JLA<br>PSP Priority 7)  |   | x parent   |  |                       | JILA Survey none  | none   | none   | none | none  | Education and training  Service delivery | Continence;<br>Management or<br>change in symptoms   |
| Priority Are interventions to improve consistency of approach between health and education agencies (e.g. keyworkers) effective to improve behavioural problems in children with Autistic Spectrum Disorder (ASD)? (JLA PSP Priority 22)                   | Autistic pupils should have a multi agency approach to their assessment. Speech Therapy and Occupational Therapy should be key to guiding teachers in how to teach and support autistic pupils and their familles. Teachers are so focused on targets and curriculum that they fall to see the needs of the child. e.g. punishing an autistic child by removing his play time when he may desperately need to have time outside in order to be calm and alert, still believing in age apprpriate instead of stage apprpriate.   | . A potent   |  |                       | JIA Survey none   | THOME  | THOSE  | none | none  | service delivery                         | Management or<br>change in symptoms  |

|                | is there a group of children and young people with neurodisability<br>for whom a low struulation ward environment would substantially<br>reduce the duration of inpatient episodes?  | Providing an appropriate environment in Hospital to help aid speed of recovery, calm, quieter, less busy<br>environment for children with sensory process disorder, epilepsy and other condition that require a less<br>stimulating environment. Basically will the special needs child get better in hospital quicker if a better   | 1 x parent  |  | JLA Survey none   | none  | none   | none | none | Service delivery                                | Duration of inpatient episodes                          |
|----------------|--|--|---|--|---|---|--|------|------|---|---|
| Priority 2     | To improve communication for children and young people with<br>neurodisability: (a) what is the best way to select the most<br>appropriate communication aids, and (b) how to encourage  | environment Is maintained.  What is the best communication/health passport format? ~  Assessment on the impact of language and cognitive growth with the provision of assistive and augmentative communication devices for those children unable to communicate orally. ~  Does the provision of an AAC system make a difference to people with severe and complex communication impairments? ~  Research into equipment and aids to daily living. This is a huge area, from use of ipad and computerised technology for children with communication difficulties, to development of wheelchairs and surfaces for improving sports for children with disabilities and aids to everyday living and promoting independence.  | 1 x parent ~ 3 x clinician  |  | JLA Survey Pennington L, Goldbart J, Marshall J. Speech and language therapy to improve the communication skills of children with cerebral palsy.  Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.:  CD003466. DOI: 10.1002/14651858.CD003466.pub2.   | o none  | Hass U, Andersson A, Brodin H, Persson J. Assessment of computer-aided assistive technology: analysis of outcomes and costs. AAC: Augmentative and Alternative Communication. 1997. 13(2): 125-135  "http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?AccessionNumber=21998007570#.U04jy15M8ds  | none | none | Assistive technology;<br>Education and training | Communication;<br>Social participation                  |
| Priority S     | most effective to promote inclusion of children and young people   | Access for children with CP attending mainstream schools to be able to meet their peer group in movement groups in the school holidays. The Physiotherapy is done in the group which is effective and fun. The children realise that they are not the only one their age with a disability. They form friendships. They work hard at improving their motor skills and are able to compete in a more realistic environment. Understanding that every one has different strengths whether it is balance or control of movement. Parents are able to support each other and encourage all the children. Are the teaching styles, social interactions and dynamics of the traditional school environment too stressful for many of these young people. My reason for asking is I know of many children with ASD/ADD (my 13 year old daughter being one) who have had breakdowns in mainstream education and have had to be removed from school and put into therapy. These are intelligent children whose greads are falling due to stress."  Does integrated goal-setting between parents, YP, Health Education result in better education attainment? S is anxiety exacerbated in children with ASD/ADD (my 13 year old daughter as a special school alongside children with BSSD? The sample school and then mentoring a young person with Asperger Syndrome more or less likely to break down their barriers to social inclusion than artificial social skills groups in school? It is their a way to determin if a child with Autsm will generally progress better in special educational needs provision than mainstream?  Our experience is that studies showed ""inclusion" in mainstream shools was beneficial for children with Down Syndrome (with the rightly of the Astional Curriculum than about the rightly of the takional Curriculum than about the rightly of the takional Curriculum than a some in since these studies has made the teas of schools including our kids pretty much impossible. Maybe this view of inclusion needs revaluating to take into account the changes in schools in the UK since the | 5 x parent ~ 2 x clinician  |  | JLA Survey none   | Mayo-Wilson E, Montgomery P, Dennis J. Personal assistance for children and adolesents (0-18) with intellectual impairments. Campbell Systematic Reviews 2008:4 DOI: 10.4073/csr.2008.4 "PMID: 18646172   | none   | none | none | Service delivery                                | Social participation;<br>Quality of Life                |
|                | The effectiveness and cost effectiveness of housing adaptations in terms of improving health and social outcomes for disabled children and families.   | The effectiveness and cost effectiveness of housing adaptations in terms of improving health and social outcomes for disabled children and families.   | 1 x parent  |  | JLA Survey none   | none  | Beresford, B. (2006) Housing and disabled children: a review of policy levers and opportunities, Social Policy Research Unit, University of York, York "www.york.ac.uk/inst/spru/research/pdf/JRFNov06Housing.pdf AND Heywood F. (2001) Money well spent: The effectiveness and value of housing adaptations, The Policy Press and the Joseph Rowntree Foundation "www.jf-org.uk/system/files/jr100-effectiveness-housing-adaptations, through the property of | none | none | Assistive technology                            | Quality of life   |
|                |  | Self-management in creebral palsy: at the time of transition to adult services, would education in self- management of physical problems associated with creebral palsy improve the quality of life and socio-economic independence of young adults with creebral palsy? Transition from children's to adult services. My undergrad thesis looked at this in 1975. Although the problem is more widely recognised, if mo to sure much has changed in practice. Poor employment prospects for all young people have intensified the problems.   | 1 x parent ~ 1 x other  |  | JILA Survey Lindsay S, Kingsnorth S, Mcdougall C, Keating H. A systematic review of self-management interventions for children and youth with physical disabilities. Disability and Rehabilitation. 2014. 36 (4): 276-288 (doi:10.3109/09638288.2013.785605/PMID:23614359 AND Lindsay S, Kingsnorth S, McDuagll C, Keating H. A systematic review of self-management interventions for children and youth with physical disabilities. Disability and Rehabilitation. 2014;36(4):276-88. doi: 10.3109/09638288.2013.785605-PMID:23614359   |   | none   | none | none | Education and training                          | Social participation;<br>Quality of Life                |
| Priority<br>12 | Are any types of physical therapy (e.g. Bobath, Neuro-<br>Developmental Therapy, Conductive Education, hydro, constraint, strength-training etc) more or less effective to promote motor functioning in children and young people with neurodisability (e.g. cerebral palsy, acquired brain injury)? (JLA PSP Priority 12) | Are core stability exercises effective in children with developmental coordination disorder? ~  Can physiotherapy help relieve pain and muscle tightness in the short term for people with hemiplegia? ~  Conductive therapy against bobath therapy and biamaule therapy for children with hemiplegia. ~  Conductive therapy against bobath therapy for children with cerebral palsy. ~  Conductive therapy against bobath therapy for children with cerebral palsy. ~  Conductive therapy against bobath therapy for children with cerebral palsy. ~  Conductive therapy against bobath therapy for children with cerebral palsy. ~  Conductive therapy against bobath therapy for children with cerebral palsy. ~  Definitively, what is the effect of Bobath/NDT treatment of cerebral palsy in GMRCS Level V children (Studies have been done, but the final statement is always, "there's not enough evidence." I want to know, is I worth it. do the movement patterns change? do they gain functional skills? -and at what intensity the treatment needs to be applied.) ~  Do a longitudinal study on the effectiveness of OT assessment to identify motor difficulties, including proprioception, and consequent individual therapy. Small group work to mitigated the impact of poor small / gross motor skills on a child's ability to be successfully included in a mainstream education setting: such the EYS profile to identified but not given access to therapy with those identified and given access to therapy. ~  Do exercises to stretch overly tight muscles in the legs have any joint perm benefits? ~  Do be exercise to stretch overly tight muscles in the legs have any joint perm benefits? ~  Do be conductive education improve gross and fine motor skills for children with hemiplegia? & if so, how long does the improvement last? ~  Does constraint induced movement therapy (CIMT) improve gross and fine motor skills for for children with hemiplegia? & if so, how long does the improvement last? ~  Does intermitten intensive provision of sobath/NDT therapy in addition to usua | 1 x young person 15 x parent ~ 21 x clinician ~ 2 x research recommendation | What is the clinical and cost effectiveness of activity-based context focused physical therapy compared with child-focused physical therapy in children and young people who are at GMFCS level I, II or III 7" How much difference does intensive Bobath-type physical therapy improve motor function in babies that have sustained brain injury a) as premature babies with periventricular leukomalacia or intraventricular hemorrhage or b) as full term babies with hypoxic injury? | ILA Survey Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, SA. and Soldsmith, S. A systematic review of Interventions for children with cerebral paley state of the evidence. Developmental Medicine & Child Neurology. 2013. 55: 885–910. doi: 10.1111/jmcn.12246-PMID:2396255 AND Huang HH, Fetters L, Hale J, McBride A. Bound for success: a systematic review of constrain-induced movement therapy in children with cerebral paley supports improved arm and hand use. Physical Therapy 2009; 89(11): 1126-1141-PMID:19729391 AND Grunt S, Becher JG, Vermeulen RJ. Long-term outcome and adverse effects of selective dorsal rhizotomy in children with cerebral palsy: a systematic review. Developmental Medicine and Child Neurology. 2011. 53(6): 490-498-PMID:21518341 | with cerebral palsy: systematic review of the current literature. Journal of Aquatic Physical Therapy 2011. 19(1): 19-29. https://doi.org/10.1016/j.j.19.19.19.19.19.19.19.19.19.19.19.19.19.   | A. Effectiveness of physical therapy interventions for children with cerebral palys; a systematic review. BMC Pediatrics. 2008. 24;8:14. doi: 10.1186/1471-2431-8-14. "PMCID: PMC2390545 AND Sakzewski L, Ziviani J, Boyd R. Systematic Review and Meta analysis of Therapeutic Management of Upper-Limb   |      | none | Physical therapies                              | Physical functioning;<br>Social participation           |
|                |  | Does respiratory physiotherapy help clear secretions from children with severe cerebral palsy " Does routine PEP (positive expiratory pressure) improve or maintain respiratory health for children with complex needs who are non-mobile?" I would like to know whether cpap at night (like Martin Samuels at UHNS does for motor neurone disease) would improve the respiratory prognosis and quality of life for children with ataxia-telangiectasia, whose life is often threatened by respiratory infections but also their quality of life (because of broken sleep and inadequate oxygenation) " I would like to see if airway clearance technique or chest physiotherapy as it is also refered to is beneficial ie, to quality of life, frequency of respiratory illness or other outcome eg. life expectancy in children affected by Complex neurodisability. " What interventions reduce the frequency and impact of chest infections of children with severe Cerebral Palsy.  | 4 x clinician ~ 1 x other   |  | JLA Survey none   | Chaves GSS, Fregonezi GAF, Dias FAL, Ribeiro CTD, Guerra RO, Freitas DA, Parreira VF, Mendonca KMPP. Chest physiotherapy for pneumonia in children. Cochrane Database of Systematic Reviews 2013, Issue 9. Art. No.: CD010277. DOI: 10.1002/14651858.CD010277.pub2. | none   | none | none | Therapy"Assistive technology                    | Survival; Quality of<br>life                            |
| Priority<br>16 | Are child-focused strategies (e.g. one-to-one or group social and skills training) effective to improve confidence, self-esteem and promote participation in recreation and leisure activities for children and young people with neurodisability? (JLA PSP Priority 16)   | Does provision of social skills training to child with disability result in improved peer relationships? Interpersonal interaction and relationships in general? ~ How can recreation and leisure participation be increased in children with communication and mobility limitations? ~ What are the effective interventions to increase children's condifence, and what effects do they have on the child's participation and well-being? ~ What are the most effective ways to improve self esteem with children who have a neurodisability? ~ What is the effectiveness of group intervention for 4-6 year olds with co-ordination difficulties/learning difficulty/global delay/cerebral palsy to address cutlery and dressing skills?   | 5 x clinician   |  | ILA Survey Storebø OJ, Skoog M, Damm D, Thomsen PH, Simonsen E, Gluud C. Social skills training for Attention Deflicit Hyperactivity Disorder (ADHD) in children aged 5 to 18 years. Cochrane Database of Systematic Reviews 2011, Issue 12. Art. No.: CD008223. DOI: 10.1002/14651858.CD008223.pub2. AND Grunt S, Becher JG, Vermeulen RJ. Long-term outcome and adverse effects of selective dorsal rhizotomy in children with cerebral palsy: systematic review. Developmental Medicine and Child Neurology 2011; 53(6): 490-498 "http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?AccessionNimber=12011003446&UserID=0   | 3   | none   | none | none | Therapy   | Social participation;<br>Confidence and self-<br>esteem |

| young people with neurodisability to improve physical and/or social functioning?  | does the use of interactive video games eg wifit help in children with DCD ~  Does the Use of social media and technology in therapy intervention improve therapy outcomes/goals. ~  How can parents evaluate the impact of computer games on children with ASD. Does Call of Duty increase the level of aggression in teenage boys with ASD ~  How can parents with teenage boys with ASD reduce the level of addiction to computer games, phones and other electronic devices without having to experience meltdowns ~  Investigation of the potential for computer gaming to encourage affected limb improvement in patients with hemiplegia. Hemiplegic children neglect and are disinclined to use their affected hand - and finding tasks that provide reward for hand use is difficult. Computer gaming seems a very good way to do this but studies are needed to develop glove-based methods to encourage finger/wrist/supination movements alongside simple but entertaining games which contain reward system for use.) ~  Is there role for virtual therapy Eg using Wii/Wii Fit, Xbox kinect for children with motor disorders, or equally to aid social communication (some games set up for cooperative play) ~  What effects do p. Wii games etc., have on children who have visual processing difficulties?   | 4 x parent ~ 3 x clinician   |  | JI . | A Survey none  | Biddiss E, Irwin J. Active Video Games to Promote Physical<br>Activity in Children and Youth: A Systematic Review, Arch<br>Pediatr Adoles Med. 2010. 64(7): 664-672.<br>doi:10.1001/archpediatrics.2010.104. ~PMID: 20603468  | none   | none   | none   | Physical therapies; Assistive technology        | ive Physical functioning;<br>Social participation    |
|---|--|--|--|------|--|---|--|--|--|---|--|
| more or less effective to promote functioning and prevent deformity for children and young people with neurodisability? (JLA PSP Priority 21)                                     | A comprehensive scientific study on the benefits of tycra garments in use with children with cerebral palsy would be useful. currently little conclusive evidence is available. "Are lycra garments effective at improving functioning and participation for children and young people with cerebral palsy?"  Are there any short term and long term outcomes of using dynamic lycra orthoses in children with hemiplegia? Can foot deformities really be prevented by early and ongoing use of orthtoics. Many children give up on using them in early teenage years and end up with breach of the foot but would this happen anyway as too much is asked of orhotics?"  Can functional hand/wrist splints improve a child's ability to use their hemiplegic hand in their everyday occupations?"   | 1.x young person ~ 6 x parent ~ 20 x clinician ~ 4 x research recommendation | What is the clinical and cost effectiveness of a prolonged stretch of the calf muscles with a hinged ankle-foot orthosis compared to orthosis compared nankle-foot orthosis worn for a shorter time in children an young people with unilateral spasticity affecting the leg? "What is the clinical and cost linical and cost  |      | A Survey  Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, SA. and Goldsmith, S. A systematic review of interventions for children with cerebral palsy: state of the evidence. Developmental Medicine & Child Neurology. 2013. 55: 885–910. doi: 10.1111/dmcn.12246-PMID:238496330  AND Jackman, M., Novak, I. and Lannin, N. Effectiveness of hand splints in children with cerebral palsy: a systematic review with meta-analysis. Developmental Medicine & Child Neurology. 2014. 56: 138–147. doi: 10.1111/jdmcn.12205-PMID:23844961 | Healthcare for Cerebral Palsy: Implications and Opportunities for Orthotics Report of a meeting held at : Wolfson College, Oxford, 8-11 September 2008 - Wolfson College, Oxford, 8-11 September 2008 - Preport_oxford_2008.pdf   | Figueiredo EM, Ferreira GB, Maia Moreira RC, Kirkwood<br>RN, Fetters L Efficacy of ankle-foot orthoses on gait of<br>children with cerebral palsy: systematic review of<br>literature. Pediatr Phys Ther. 2008 Fall;20(3):207-23. doi: | none   | none   | Assistive technology                            | Physical functioning;<br>Prevent deformity           |
|   | Occupations:  Can the use of Carbon finer splints aid miscle development of affected limbs when compared to traditional fixed AFOs  Can the use of Carbon finer splints aid miscle development of affected limbs when compared to traditional fixed AFOs  Do dynamic ankle foot orthoses (DAFOS) have a beneficial functional impact on children with hypertonicity of plantarfizeous? -  Oo lycra upper limb splints/garments provide any functional benefit for children with cerebral palsy? ~  effect of supportive footwear versus bare feet on rate of motor development in children with ligamentous laxity Also effect on ankle posture. ~  for children with cerebral palsy , how can splinting be used to help relieve tightness without causing weaknesses? -  How offective are Dynamic Ankle Foot Orthoses with neurological inlays at altering muscle tone and improving movement patterns? -  Now long does a passive stretch need to be done for ~  How to engage families to improve participation with ongoing physical activity/sport? ~  In a child with spastic CP, how long should a muscle be stretched and how often, to prevent loss of muscle length? -  Is providing only one pair of piedro boots at any one time and then waiting for another 3-4 weeks for delivery justified? Should thuse children be not supplied with two pairs at a time so that they dont have to go without an  |  | what is the clinical and to's effectiveness of wearing a hinged ankle-foot orthosis to prevent an equinus foot posture compared to an ankle-foot orthosis or solid ankle-foot orthosis or solid ankle-foot orthosis or solid ankle-foot orthosis after surgery compared to not wearing an ankle-foot orthosis in children and young people with lower limb spasticity? ~ |      | 10:1111/umin.1.12203 rmiD.2.5040460  | Cinicire and your physical osationities. Disability and<br>Rehabilitation 2014;36(4):276-88. doi:<br>10.3109/09638288.2013.785605 "PMID: 23614359   | 10.107/FFF.00013651618.1U34. FMIU. 10/05236  |  |  |   |  |
| resources) to educate family/staff/carers about correct fitting of  | Could Hydrocolloid patches be efficably used in the treatment of blisters, sores, and ""hot spots" for children<br>who have problems wearing their lower limb orthoses? Personal experience has shown that minor injuries<br>caused by the orthoses can cause compliance issues with the wearing of the orthoses. Hydrocolloid patches<br>could be advocated or even prescribed by orthotists and physiotherapists for the simplest of minor wounds with   | 1 x clinician  |  | JI.  | A Survey none  | none  | none   | none   | none   | Assistive technology;<br>Education and training | Adherence to treatment                               |
|   | appropriate training.  Do exercises targeted at strengthening the tongue, jaw and face muscles and joints improve the clarity of speech?  Do oral motor exercises improve functional eating in children with CP?   | 1 x parent ~ 1 x clinician   |  | II.  | A Survey Pennington L, Goldbart J, Marshall J. Speech and language therapy to improve the communication skills of children with cerebral palsy. Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.: CD03466. DDI: 3.1002/14651885. CD03466, pbub. 2.7AND ARVEDSON, J., CLARK, H., LAZARUS, C., SCHOOLING, T. and FRYMARK, T. (2010). The effects of oral-motor exercises on swallowing in children: an evidence-based systematic review. Developmental Medicine & Child Neurology, 52: 1000–1013. doi: 10.1111/j.1469-8749.2010.03707.x                                   | o inone   | none   | none   | none   | Physical therapies                              | Communication;<br>Eating                             |
| effective in improving behaviour and/or increasing<br>play/participation for children and young people with<br>neurodisability? (JLA PSP Priority 13)                             | Does sensory integration occupational therapy add value to outcomes for children with processing difficulties that it should warrant inclusion at the same level as traditional therapies (Physio, 5.8.7 etc) in treatment plans? *Does Sensory integration therapy/techniques make neurological changes to the brain? *Is there any evidence for the use of occupational therapy for sensory sensitivities in autism spectrum disorder? *Sensory integration Therapy impact on play and participation in preschool children with sensory processing difficulties. *Should we be doing sensory integration? Does it make a difference? ** Should we be doing sensory integration? Does it make a difference? ** What effect does properly applied, *Sensory Integration Therapy /have on motor and sensory development ** What impact does sensory integration treatment have on children with ASD? ** What is the evidence for the use of *Sensory Diets' for children with sensory sensitivities? ** What is the most effective way to address sensory processing difficulties in children with an autism spectrum disorder? ** Does speech therapy sustainably improve communication skills in children with intellectual disability  | 1 x parent ~ 9 x clinician   |  | J    | A Survey  Sinha Y, Silove N, Hayen A, Williams K. Auditory integration training and other sound therapies for autism spectrum disorders (ASD).  Cochrane Database of Systematic Reviews 2011, Issue 12. Art. No.: CD03681. DOI: 10.1002/14651858.CD03681.pub3.  AND  Lang R, O'Reilly M, Healy O, Rispoil M, Lydon H, Streusand W, et al. Sensory integration therapy for autism spectrum disorders: a systematic review. Research in Autism Spectrum Disorders. 2012.  6(3): 1004-1018  http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?AccessionNumber=120120268268UserID=0.         | none  | none   | none   | none   | Physical therapies;<br>Psychological therapy    | Social participation;<br>Behaviour                   |
| PSP Priority 4)   | Does early powered mobility lead to increased self-efficacy? ~  Does the provision of active user wheelchair stogether with wheelchair skills training give children and young people affected by neurodisability increased opportunities to socialise with their peer-group in the community and school environments? ~  Does wheelchair skills training for children and young people affected by neurodisability increase opportunities for further deucation and employment in adulthood, resulting in greater economic achievement? ~  Is wheelchair skills training beneficial, does in improve independence, fitness, self-esteem ~  What are the benefits of early powered mobility for children under 1 year old with mobility limitations? ~  What are the benefits of early powered mobility of children under 1 year old with mobility limitations? a family life (eg parks, zoo, family outings) increased participation/interaction with peers (eg play, pre-school)   | 1 x parent ~ 2 x clinician ~ 2 x other                                       |  | J    | A Survey none  | Bray N, Tudor Edwards R, Noyes J, Harris N. Exploring costs<br>and effectiveness in assistive mobility technology for<br>disabled children: a systematic review of economic<br>literature. PROSPERO 2012:CRD42012001988   | none   | Casey J, McKeown L,<br>McDonald R, Martin S.<br>Wheelchairs for children<br>under 12 with physical<br>impairments (Protocol).<br>Cochrane Database of<br>Systematic Reviews 2012,<br>Issue 10. Art. No.: CD010154.<br>DOI:<br>10.1002/14651858.CD01015 | Mobility on the<br>Development of Young<br>Children With Severe<br>Motor<br>Impairments~NCT01115 | Education and training                          | Self-efficacy  |
| Are any designs of hearing aids (e.g. Edulink and others) more or<br>less effective in children and young people with auditory<br>neuropathy and/or auditory processing disorder? | How effective is the use of hearing aids or Edulink type devices in children and young people with auditory neuropathy and/or auditory processing disorder.  | 1 x parent   |  | 11   | A Survey Roush P, Frymark T, Venediktov R, Wang B. Audiologic Management<br>of Auditory Neuropathy Spectrum Disorder in Children: A Systematic<br>Review of the Literature. American Journal of Audiology. December<br>2011. 20. 159-170. doi:10.1044/1059-0889(2011/10-0032)  | :   | none   | none   | none   | Assistive technology                            | Social participation;<br>Confidence, self-<br>esteem |
| people with neurodisability? (JLA PSP Priority 5)   | Counselling for children & families linked to above key worker role. I have in 20 + years work in paediatrics come across less than 20 children who had been offered counselling & only then CAMHS involved at absolute crisis point (following a long wait) " Do interventions from specialist learning disability health teams (psychiatry, psychology, community nurses, SALT and 07s) make a real difference in improving the health and well being of children with intellectual disabilities and their families? " Does the intervention of Camhs to treat Social Anxiety in Asperger Syndrome have a positive effect on the anxiety? Would the anxiety, and therefore the therapy, be more successful delivered in the home rather than a clinical setting?" How will IAPT be adapted by CAMHS for children with a earning disability. How can talking therapy s be adapted for this group. What other therapys support this group and can this be included in the IAPT rollout programme Outcomes - are interventions designed to address mental health or behavioural issues alone, as effective when given to children with neurodisability? " Psychological support, its role in supporting young people with disability but also parents in positive parenting of holdren with inapriments, and how to maximise their participation and potential in every sphere. I feel we look at specific therapy approaches, management of physical manifestations of neurological impairments, but less the proposed as specific therapy approaches, management of physical manifestations of neurological impairments, but less with disability. Hase |  |  | Л    | ~PMI0:21940978 A Survey none   | Glasscoe CA, Quittner AL. Psychological interventions for people with cystic fibrosis and their families. Cochrane Database of Systematic Review 2008, Issue 3. Art. No.: CD003148. DOI: 10.1002/14651858.CD003148.pub2 AND  No BP, Carter M, Stephenson J. Anger management using a cognitive-behavioural approach for children with special education needs: a literature review and meta-analysis. International Journal of Disability Development and Education 2015. 73(3): 245-265.  http://www.tandfonline.com/do/abs/10.1080/1034912X. 2010.5011689. U044uy5/MS88.  http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH003045.8/ |  | none   | none   | Psychological therapy                           | Mental health;<br>Wellbeing                          |
|   | seen owrk on motivational interviewing for children with diabetes, why not with other conditions? Why do some<br>children with disability flourish and others less so. What are the hidden factors?  |  |  |      |  |   |  |  |  |   |  |

| sleep systems etc) effective and cost effective to prevent deformity   |  | 1 x parent ~ 29 x clinician  | What is the optimal postural<br>management programme  | NICE CG 145 JLA Survey | none  | none  | Morris C, Condie D, editors. Recent Developments in<br>Healthcare for Cerebral Palsy: Implications and   | Lloyd C, Logan S, McHugh C,<br>Humphreys G, Parker S,          | none Assistive techno                     | Prevent defor  |
|--|--|--|---|------------------------|---|---|--|--|---|--|
| (hip and/or spine) and improve function in children and young  | Can appropriate seating/sleeping systems delay/prevent hip dislocation ~   |  | using a standing frame in   |                        |   |   | Opportunities for Orthotics Report of a meeting held at<br>Wolfson College, Oxford, 8-11 September   | Beswick D, et al. Sleep  |   | Pain; Sleep;   |
| people with neurodisability? What is the incidence of adverse<br>effects e.g. pain, sleep problems etc? (JLA PSP Priority 15)  | Can night time positioning (sleep system) minimise the progression of scoliosis or improve a scoliosis in children and young people with a movement disorder and/ or learning difficulties. ~  |  | children aged 1–3 years? ~<br>What is the clinical and cost   |                        |   |   | Wolfson College, Oxford, 8-11 September<br>2008~http://www.ispoint.org/sites/default/files/archives/   | positioning for children with<br>is cerebral palsy (Protocol). |   | Management<br>change in                                    |
|  | Comparison of Specialised Static seating systems versus wheelchairs for postural seating solutions for young   |  | effectiveness of 24-hour  |                        |   |   | po_cp_report_oxford_2008.pdf   | Cochrane Database of   |   | symptoms; a  |
|  | people with physical disabilities in mainstream secondary schools. Children transition to secondary school and have to move around a large campus and multiple classrooms addressing postural needs for these young people   | 1  | postural management<br>programmes in non-   |                        |   |   |  | Systematic Reviews 2011,<br>Issue 7. Art. No.: CD009257.       |   | effects or<br>complication                                 |
|  | is a challenge. ~  |  | ambulatory children and   |                        |   |   |  | DOI:   |   | complication   |
|  | Do knee blocks/sacra pads work to control pelvic tilt? ~   |  | young people with bilateral   |                        |   |   |  | 10.1002/14651858.CD009257.                                     |   |  |
|  | Does 24 hour postural management prevent deformity and deterioration in function? ~  Does dynamic seating work to reduce extensor spasms and are there any contradictions in its use? ~  |  | spasticity affecting all four<br>limbs?   |                        |   |   |  |  |   |  |
|  | Does postural management really reduce hip migration in none amublent disabled children? ~   |  |   |                        |   |   |  |  |   |  |
|  | Does standing daily in a standing frame prevents from secondary musckuloskeletal deformities to occur ~  Does standing in a standing frame improve bone mineral density, bladder and bowel effeciency, prevent   |  |   |                        |   |   |  |  |   |  |
|  | contracture, improve hip integrity, improve psychosocial wellbeing? these claims are all made but there is very  | 1  |   |                        |   |   |  |  |   |  |
|  | little research to support them. ~  Effectiveness of postural management in yielding better outcomes for the PMLD client group ~   | 1  |   |                        |   |   |  |  |   |  |
|  | How long should non walking children stand in standing frames to effect an improvement in bone mineral   | 1  |   |                        |   |   |  |  |   |  |
|  | density and / or to reduce risk of hip joint subluxation. ~  | 1  |   |                        |   |   |  |  |   |  |
|  | how long should children who use standing frames, stand for ~<br>Parent workshops to explain how 24 hour postural care helps their child. To emphasise their child spends more   | 1  |   |                        |   |   |  |  |   |  |
|  | time at home than anywhere else ~  |  |   |                        |   |   |  |  |   |  |
|  | Postural care - protecting the body shape of children who have mobility problems by using night time sleep   | 1  |   |                        |   |   |  |  |   |  |
|  | systems and body shape measurments alongside traditional postural care inputs. see<br>www.posturalcareskills.com and http://www.mencap.org.uk/posturalcare ~   | 1  |   |                        |   |   |  |  |   |  |
|  | Seating: Is there evidence for or against the use of knee blocks compared to using a good pelvic positioning beltin  |  |   |                        |   |   |  |  |   |  |
| Is provision of special glasses (e.g. with tinted, ambient prism<br>lenses) and 'vision therapy' effective to improve functioning in   | Do coloured overlays/ glasses improve the visual perception of children and have a functional impact e.g. better able to catch a ball, neater writing etc.   | 1 x parent   |   | JLA Survey             | none  | none  | none   | none   | none Assistive technol<br>Physical therap |  |
| children and young people with neurodisability?  | and to date a bully nearer writing etc.  |  |   |                        |   |   |  |  | Thysical dicrap                           | .s Social particip   |
| What is the long term comparative safety and effectiveness of  | What are the advantages and/or disadvantages of fixed spinal bracing and dynamic spinal bracing on children  | 1 x parent ~ 2 x clincian ~ 12 x research  | What is the clinical and cost   | NICE CG 145            | Novak I, Mcintyre S, Morgan C, Campbell L, Dark L., Morton N, et al.  | none  | Morris C, Condie D, editors. Recent Developments in  | none   | none Drugs; Physical                      | herapies: Physical funct                                   |
|  | with postural curves. Considerations around maiantainace of curve in and out of bracing and and muscle   | recommendation   | effectiveness of botulinum  | NICE CG 143            | A systematic review of interventions for children with cerebral palsy:  | none  | Healthcare for Cerebral Palsy: Implications and  | none   | Surgery; Assisti                          |  |
| neurotoxin A (BoNT-A), Selective Dorsal Rhizotomy (SDR),   | strength shpould be included. ~  | 1  | toxin type A when used  |                        | state of the evidence. Developmental Medicine & Child Neurology.  |   | Opportunities for Orthotics Report of a meeting held at  |  | technology                                | Management   |
| Intrathecal Baclofen (ITB), orally administered medicines) in<br>children and young people with neurodisability? (ILA PSP Priority 6)  | What is the role for botox assisted physiotherapy in neurodisability ~  Also, in the era of pharmacotherapy and advents in orthopaedic and other surgical procedures, is there any real  | 1  | routinely or according to<br>clinical need in children and  |                        | 2013. 55: 885-910. doi: 10.1111/dmcn.12246<br>AND   |   | Wolfson College, Oxford, 8-11 September<br>2008~http://www.ispoint.org/sites/default/files/archives/   | is   |   | change in<br>symptoms; ad                                  |
| ,,   | evidence that incessant physiotherapy/treacherous exercises improve functional outcome in children with  | 1  | young people who are at   |                        | Huang HH, Fetters L, Hale J, McBride A. Bound for success: a  |   | po_cp_report_oxford_2008.pdf   |  |   | effects or   |
|  | cerebral palsy? If yes, then is it significant enough to be worth at the expense of how exercises and appointments take over family's life?  |  | GMFCS level I, II or III? ~<br>What is the clinical and cost  |                        | systematic review of constraint-induced movement therapy in<br>children with cerebral palsy supports improved arm and hand use.   |   | AND<br>Butler C, Campbell S. Evidence of the effects of intrathecal  |  |   | complication   |
|  | appointments take over raining sine:   |  | effectiveness of treatment  |                        | Physical Therapy. 2009. 89(11): 1126-1141~PMID:23962350   |   | baclofen for spastic and dystonic cerebral palsy.  |  |   |  |
|  |  |  | with botulinum toxin type A   |                        | AND   |   | Developmental Medicine and Child Neurology. 2000. 42(9   | :  |   |  |
|  |  |  | combined with a 6-week<br>targeted strengthening  |                        | Grunt S, Becher JG, Vermeulen RJ. Long-term outcome and adverse<br>effects of selective dorsal rhizotomy in children with cerebral palsy: a   |   | 634-645~PMID: 11034458<br>AND  |  |   |  |
|  |  |  | programme compared to a 6-  |                        | systematic review. Developmental Medicine and Child Neurology.  |   | Mulligan H, Borkin H, Chaplin K, Croft N, Scherp A. The  |  |   |  |
|  |  |  | week targeted strength<br>training programme only in  |                        | 2011. 53(6): 490-498 ~http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?AccessionNu   |   | efficacy of botulinum toxin A in the treatment of spasticity<br>in ambulant children with cerebral palsy: a structured   |  |   |  |
|  |  |  | training programme only in<br>school-aged children and  |                        | "http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?AccessionNu<br>mber=12011003446&UserID=0   |   | in ambulant children with cerebral palsy: a structured<br>review. New Zealand Journal of Physiotherapy. 2001. 29(3   | :  |   |  |
|  |  |  | young people with lower   |                        |   |   | 18-  |  |   |  |
|  |  | 1  | limb spasticity who are at<br>GMFCS level I, II or III? ~   |                        |   |   | 28~http://www.crd.york.ac.uk/crdweb/ShowRecord.asp?lnkFrom=OAI&ID=12002005375#.U04zBV5M8ds   | ı  |   |  |
|  |  | 1  | What is the clinical and cost   |                        |   |   | AND  |  |   |  |
|  |  | 1  | effectiveness of botulinum<br>toxin type A for reducing   |                        |   |   | Sampson F, Hayward A, Evans G, Morton R, Collett B.<br>Functional benefits and cost/benefit analysis of continuou  |  |   |  |
|  |  | 1  | muscle pain? ~  |                        |   |   | intrathecal baclofen infusion for the management of  | 1  |   |  |
|  |  | 1  | What is the clinical and cost   |                        |   |   | severe spasticity. Journal of Neurosurgery. 2002. 96(6):   |  |   |  |
|  |  | 1  | effectiveness of botulinum<br>toxin type A compared to  |                        |   |   | 1052-1057~PMID: 12066906   |  |   |  |
|  |  | 1  | botulinum toxin type B for  |                        |   |   | Morris C. A review of the efficacy of lower-limb orthoses  |  |   |  |
|  |  | 4 x clinician  |   | JLA Surve              | Reinehr T, Dobe M, Winkel K, Schaefer A, Hoffmann D. Obesity in   |   | Verschuren O, Ketelaar M, Takken T, Helders PJ, Gorter JW  | . none n   | none Education and                        |  |
| activity (to improve fitness, reduce obesity etc.) for children and<br>young people with neurodisability? (JLA PSP Priority 8)   | education? ~ Promotion of Physical fitness and activity for children and young adults with cerebral palsy and neurodisability  |  |   |                        | Disabled Children and Adolescents. Dtsch Arztebl Int. 2010; 107(15):<br>268–275. doi: 10.3238/arztebl.2010.0268~PMID:20406413   |   | Exercise programs for children with cerebral palsy: a<br>systematic review of the literature. American Journal of  |  |   | Fitness; Bood  |
| ,8,,-,-,-,-,-,-,-,-,-,-,-,-,-,-,   | promotion of activity is a key public health issues that physotherapists have a key role in addressing. The lack of  | 1  |   |                        | AND   |   | Physical Medicine and Rehabilitation. 2008. 87(5): 404-  |  |   |  |
|  | these opportunities result in adverse affects to health. ~   | 1  |   |                        | Sterba J A. Does horseback riding therapy or therapist-directed   |   | 417~PMID:17993987  |  |   |  |
|  | The value of adapted trikes in providing cardio vascular exercise in children with neurodisability ~ What is most effective way to improve the fitness of ambulant children with cerebral palsy?   | 1  |   |                        | hippotherapy rehabilitate children with cerebral palsy?<br>Developmental Medicine and Child Neurology. 2007. 49(1): 68-   |   | Mutlu A, Krosschell K, Gaebler Spira D. Treadmill training   |  |   |  |
|  | White is most effective way to improve the military of ambalant children with except at parsy.   | 1  |   |                        | 73~PMID:17209981  |   | with partial body-weight support in children with cerebral   |  |   |  |
|  |  | 1  |   |                        | AND   |   | palsy: a systematic review. Developmental Medicine and   |  |   |  |
|  |  | 1  |   |                        | Noorduyn S, Mbuagbaw L, Ross S, Gorter JW. Disability and<br>rehabilitation in pediatric cerebral palsy: a meta-analysis of the   |   | Child Neurology. 2009. 51(4): 268-275~PMID:19207302  |  |   |  |
|  |  | 1  |   |                        | impact of exercise training programs upon hr-qol, body  |   |  |  |   |  |
|  |  |  |   |                        | function,activity, and participation. PROSPERO<br>2012:CRD42012002771   |   |  |  |   |  |
|  |  |  |   |                        |   |   |  |  |   |  |
| Does using instrumented gait analysis improve decision-making  | Do surgical interventions identified by gait analysis give better functional outcomes than those identified by   | 1 x clinician ~ 1 x research   | What is the clinical and cost   | NICE CG 145 JLA Survey | none  | Narayanan UG. Management of Children With Ambulatory  | none   | none n   | none Assistive techno                     | logy Clinical decision                                     |
| about treatments compared to clinical assessment alone for   | clinical examination in cerebral palsy (We know from previous research that gait analysis alters the surgical plan   |  | effectiveness of gait analysis  |                        |   | Cerebral Palsy: An Evidence-based Review, Journal of  |  |  |   | making   |
| children and young people with cerebral palsy? (JLA PSP Priority 24  | ) but do not know if it is for the better).  | 1  | as an assessment tool in<br>studies to evaluate   |                        |   | Pediatric Orthopaedics. September 2012. 32 (Supplement 2): S172–S181  |  |  |   |  |
|  |  | 1  | interventions such as   |                        |   | doi: 10.1097/BPO.0b013e31825eb2a6~PMID: 22890458  |  |  |   |  |
|  |  | Į.   |   |                        |   |   |  |  |   |  |
| Î.   |  |  | continuous pump-<br>administered intrathecal  |                        |   |   |  |  |   |  |
|  |  |  | administered intrathecal<br>baclofen?   |                        |   |   |  |  |   |  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  | 1 x clinician ~ 1 x research   | administered intrathecal<br>baclofen?<br>What is the clinical and cost  | NICE CG 145 JLA Survey | McGinley JL, Dobson F, Ganeshalingam R, Shore B J, Rutz E, Graham   |   | none   | none n   | none Surgery                              | Quality of life  |
| Does multilevel surgery improve Quality of Life of children with cerebral palsy?   | Does multi-level surgery improve the long-term quality of life in children with CP?  | 1 x cliniclan ~ 1 x research recommendation  | administered intrathecal<br>baclofen?   |                        | McGinley JL, Dobson F, Ganeshalingam R, Shore B J, Rutz E, Graham HK. Single-event multilevel surgery for children with cerebral palsy: a systematic review. Developmental Medicine & Child Neurology.                | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics. September 2012. 32 (Supplement   |  | none n   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that  |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics. September 2012. 32 (Supplement<br>2): S83–S90. doi:10.1097/BPO.0b013e3182519a0e. ~PMID:  |  | none n   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.   | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics. September 2012. 32 (Supplement<br>2): S83–S90. doi:10.1097/BPO.0b013e3182519a0e. ~PMID:<br>22890464  |  | none r   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that  |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics. September 2012. 32 (Supplement<br>2): 833–590. doi:10.1097/BPO.0b013e3182519a0e. "PMID:<br>22890464<br>Wright 1G, Kocher MS, Sanders JO. Evidence-based<br>Pediatric Orthopaedics: An Introduction, Part 2. Journal of   |  | none n   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics September 2012 2.3 (Supplement<br>2): S83-590. doi:10.1097/BPO.0b013e3182519a0e. ~PMID:<br>22890464<br>Wright 1G, Kocher MS, Sanders JO. Evidence-based<br>Pediatric Orthopaedics: Apreher 2012. 32 (Supplement<br>Pediatric Orthopaedics. September 2012. 32 (Supplement   |  | none r   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of<br>Pediatric Orthopaedics. September 2012. 32 (Supplement<br>2): 833–590. doi:10.1097/BPO.0b013e3182519a0e. "PMID:<br>22890464<br>Wright 1G, Kocher MS, Sanders JO. Evidence-based<br>Pediatric Orthopaedics: An Introduction, Part 2. Journal of   |  | none n   | Surgery Surgery                           | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 583–590. doi:10.1097/BPO.0b01328138251990e. "PMID: 22890464 Wright I.G. Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID: 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID:   |  | none n   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  |  | administered intrathecal<br>baclofen?<br>What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-                                    | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 583–590. doi:10.1097/BPO.0b01328138251990e. "PMID: 22890464 Wright I.G. Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID: 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID:   |  | none   | none Surgery                              | Quality of life  |
|  | Does multi-level surgery improve the long-term quality of life in children with CP?  In children with spasticity does orthopaedic surgery: 1. improve functional ability 2. prevent deterioration in   | recommendation   | administered intrathecal<br>backofen? What is the clinical and cost<br>effectiveness of single-event<br>multilevel surgery in terms of<br>producing benefits that<br>continue after skeletal<br>maturity has been achieved?   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-<br>8749.2011.04143.x°PMID:22111994 | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 583–590. doi:10.1097/BPO.0b01328138251990e. "PMID: 22890464 Wright I.G. Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID: 2): 591–594. doi:10.1097/BPO.0b0132813825199fa. "PMID:   |  | none n   | Surgery  Tone Assistive technique         |  |
| cerebral palsy?  Does screening and following recommended best practice (e.g. orthotics, postural management, and surgery) reduce hip  | in children with spasticity does orthopaedic surgery:- 1. improve functional ability 2. prevent deterioration in ability 3. prevent deformity  | recommendation   | administered intrathecal backdoen? What is the clinical and cost effectiveness of single-event multilevel surgery in terms of producing benefits that continue after selectal maturity has been achieved?  What is the clinical and cost effectiveness of a spinal  |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-<br>8749.2011.04143.x°PMID:22111994 | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics September 2012. 23 (Supplement 2): S83-590. doi:10.1097/BPO.0b013e3182519a0e. ~PMID: 2289064b "Wight 16, Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): 591-594. doi:10.1097/BPO.0b013e31825199fa. ~PMID: 22890465   | Morris C, Condie D, editors. Recent Developments in<br>Healthcare for Cerebral Palsy: implications and   | none n   |   |  |
| cerebral palsy?  Does screening and following recommended best practice (e.g.  | in children with spasticity does orthopaedic surgery: 1. improve functional ability 2. prevent deterioration in ability 3. prevent deformity " Is hip reconstruction or leaving alone, then proximal femoral resection if symptomatic better for older children  | recommendation  3 x parent ~ 3 x clinician ~ 2 x research                            | administered intrathecal bacdofen? What is the clinical and cost effectiveness of single-event multilevel surgery in terms of producing benefits that continue after skeletal maturity has been achieved?  What is the clinical and cost effectiveness of a spinal orthosis compared to no  |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-<br>8749.2011.04143.x°PMID:22111994 | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics: September 2012. 32 (Supplement 2): S83–S90. doi:10.1097/BPO.0b013e3182519940. "PMID: 23890464 "Wright Life, Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics September 2012. 32 (Supplement 2): S91–S94. doi:10.1097/BPO.0b013e31825199fa. "PMID: 22890465 "An Evidence-based Review, Journal of Cerebral Palsy: An Evidence-based Review, Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): S91–S94. doi:10.1097/BPO.0b013e31825199fa. "PMID: 22890465 "An Evidence-based Review, Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2012. 32)  | Morris C, Condie D, editors. Recent Developments in<br>Healthcare for Cerebral Palsy: implications and<br>Opportunities for Orthotics Report of a meeting held at  | none n   |   |  |
| cerebral palsy?  Does screening and following recommended best practice (e.g. orthotics, postural management, and surgery) reduce hip  | in children with spasticity does orthopaedic surgery. 1. improve functional ability 2. prevent deterioration in ability 3. prevent deformity ~ is hip reconstruction or leaving alone, then proximal femoral resection if symptomatic better for older children with hip dislocation and without degenerative change in cerebral palsy. ~ is relocating dysplastic hips in on ambulant children effective?   | ax parent ~ 3 x clinician ~ 2 x research recommendation                              | administered intrathecal baciofen?  What is the clinical and cost effectiveness of single-event multilevel surgery in terms of producing benefits that continue after skeletal maturity has been achieved?  What is the clinical and cost effectiveness of a spinal orthosis compared to no orthosis when not in a supportive chair in children   |                        | HK. Single-event multilevel surgery for children with cerebral palsy: a<br>systematic review. Developmental Medicine & Child Neurology.<br>2010. 54: 117–128. doi: 10.1111/j.1469-<br>8749.2011.04143.x°PMID:22111994 | Pediatric Orthopaedics: An Introduction, Part 1. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): \$383–\$90. doi:10.1097/BPO.00132e318251998c. "PMID: 2289046 Wright IG, Kocher MS, Sanders JO. Evidence-based Pediatric Orthopaedics: An Introduction, Part 2. Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): \$91–\$94. doi:10.1097/BPO.0b013e31825199fa. "PMID: 22890465  Narayanan UG. Management of Children With Ambulatory Cerebral Palsy: An Evidence-based Review, Journal of Pediatric Orthopaedics. September 2012. 32 (Supplement 2): \$17–5181 doi:   | Morris C, Condie D, editors. Recent Developments in Healthcare for Cerebral Palsy: implications and Opportunities for Orthotics Report of a meeting held at Wolfson College, Oxford, 8-11 September 2008-http://www.ispoint.org/sirkes/default/files/archives,                               | none n   |   |  |
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| Is joint fusion more effective than joint preserving approaches in<br>managing ankle foot deformities in children and young people with | Is joint-preserving foot surgery any better than fusion stabilisation  | 1 x clinician  |                               |                       | JLA Survey | none  | none  | none  | none                          | none | Surgery                | Prevent deformity;<br>Management or |
|---|--|----------------|-------------------------------|-----------------------|------------|---|---|---|-------------------------------|------|------------------------|-------------------------------------|
| neurodisability?  |  |                |                               |                       |            |   |   |   |                               |      |                        | change in                           |
|   |  |                |                               |                       |            |   |   |   |                               |      |                        | symptoms; adverse                   |
|   |  |                |                               |                       |            |   |   |   |                               |      |                        | effects or                          |
|   |  |                |                               |                       |            |   |   |   |                               |      |                        | complications                       |
|   | what is the most effective way to brush someone with a neurodisability's teeth?                                    | 1 x clinician  |                               |                       | JLA Survey | none  | none  | none  | none                          | none | Education and training | Oral health;                        |
| swilling etc) should be given to families of children and young   |  |                |                               |                       |            |   |   |   |                               |      |                        | Management or                       |
| people with neurodisability to maintain oral health?  |  |                |                               |                       |            |   |   |   |                               |      |                        | change in symptoms                  |
|   | Are outcomes affected by the level of physiotherapy input provided, e.g. intensive input (once a week), or blocks  |                |                               | NICE CG 145 ~ SIGN 98 |            | Martin L, Baker R, Harvey A. A Systematic Review of Common            | Reichow B, Servili C, Barbui C, Taghi Yasamy M, Saxena S, | Boyd RN, Morris ME, Graham HK. Management of upper        | Tatla S, Sauve K. The effects |      | Physical therapies;    | Physical functioning                |
|   | of treatment (once a week for 6 weeks) followed by no input for 6 weeks, or termly review with home                | recommendation | for the passive stretch       |                       |            | Physiotherapy Interventions in School-Aged Children with Cerebral     |   |   | of motivating interventions   |      | Psychological therapy  | Social participation;               |
|   | programme provided ~   |                | component of physical         |                       |            | Palsy. Physical & Occupational Therapy in Pediatrics. 2010. 30(4): 29 |   |   | on rehabilitation outcomes    | in   |                        | Quality of Life                     |
|   | Do short intensive periods of any typical intervention (eg speech therapy, physical exercises etc) work any better |                | therapy? ~                    |                       |            | 312 doi:10.3109/01942638.2010.500581~PMID: 20735200 ~                 | 2014:CRD42014006993                                       | 8(Supplement 5): 150-166                                  | children and adolescents      |      |                        |                                     |
|   | than regular long term ones? ~   |                | What is the clinical and cost |                       |            | Pennington L, Goldbart J, Marshall J. Speech and language therapy t   | to  | "http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?Ac       | with acquired brain injuries  | :    |                        |                                     |
| strategies / dosage / direction of therapy interventions? (JLA PSP  | Do skills deteriorate when professional input is withdrawn? How closely are programmes followed without            |                | effectiveness and optimal     |                       |            | improve the communication skills of children with cerebral palsy.     |   | cessionNumber=12002000120&UserID=0                        | a systematic review.          |      |                        |                                     |
|   | professional monitoring visits? ~  |                | age for modified constraint-  |                       |            | Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.:      |   | AND   | PROSPERO                      |      |                        |                                     |
|   | Does more intensive physiotherapy carried out by a trained paediatric physiotherapist result in greater            |                | induced movement therapy?     |                       |            | CD003466. DOI: 10.1002/14651858.CD003466.pub2. ~ Warren ZE,           |   | Anttila H, Autti-Ramo I, Suoranta J, Makela M, Malmivaara |                               |      |                        |                                     |
|   | improvements in gross motor function and/or gait parameters in children with cerebral palsy? e.g. single           |                | ~ What is the optimal timing  |                       |            | McPheeters ML, Sathe NA, et al. A systematic review of early          |   | A. Effectiveness of physical therapy interventions for    | ~www.crd.york.ac.uk/PROS      |      |                        |                                     |
|   | session monthly versus twice weekly; weekly sessions for 6 weeks versus three times per week etc. ~                |                | of interventions? Are there   |                       |            | intensive intervention for autism spectrum disorders. Pediatrics.     |   | children with cerebral palsy: a systematic review. BMC    | RO/display_record.asp?ID=0    | CR   |                        |                                     |
|   | Effectiveness of age appropriate social skills groups or sessions for small groups with Asperger Syndrome and      |                | benefits from early           |                       |            | 2011. 127 (5) e1303 -e1311 (doi: 10.1542/peds.2011-                   |   | Pediatrics. 2008. 8:14 doi: 10.1186/1471-2431-8-14        | D42013005337                  |      |                        |                                     |
|   | autism designed by speech and language specialist over time and frequency ie: the opitum frequency for these       |                | intervention?                 |                       |            | 0426)~PMID:PMID: 19143460   |   | ~PMID: 18435840 ~ McConachie, H. and Diggle, T. Parent    |                               |      |                        |                                     |
|   | kinds of interventions (eg weekly for an hour, twice weekly, monthly etc). My suspicion is that most children who  |                |                               |                       |            | AND   |   | implemented early intervention for young children with    |                               |      |                        |                                     |
|   | manage to get this interevention specificed in their statement get is infrequently (twice a term) and this is not  |                |                               |                       |            | Ziviani J, Feeney R, Rodger S, Watter P. Systematic review of early   |   | autism spectrum disorder: a systematic review. Journal of |                               |      |                        |                                     |
|   | enough for most given the way most children with autism learn (ie over learn in different settings because they    |                |                               |                       |            | intervention programmes for children from birth to nine years who     |   | Evaluation in Clinical Practice. 2007 Feb. 13(1):120-9.   |                               |      |                        |                                     |
|   | find it hard to generalise). So - the optimum number of interventions of this kind to show progress over time and  |                |                               |                       |            | have a physical disability. Australian Occupational Therapy Journal   |   | doi: 10.1111/j.1365-2753.2006.00674.x ~PMID: 17286734     |                               |      |                        |                                     |
|   | the effects of making this available early in a child's school life ~  |                |                               |                       |            | 2010; 57(4): 210-223~PMID:20854595 ~                                  |   |   |                               |      |                        |                                     |
|   | Effectiveness of continuing a physiotherapy programme at home as well as at school. ~                              |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | How much of what style of physiotherapy makes a positive functional difference to children with Cerebral Palsy     |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | at each level of the Gross Motor Function Classification System? ~   |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | How often should a child with neurodisability get therapeutic intervention from a qualified therapist to gain      |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | improvements? ~  |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | Is intensive physiotherapy with children with mulisensory impariment GMFS Iv and V , in school settings            |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | beneficial and does it mmater if exercises are delivered by qualified physiotherapist or physiotherapy assistants/ |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | classroom assistants? ~  |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | Is once a week phsylotherapy intervention (hands on) better than an intersive episode of care (for example 5       |                |                               |                       |            |   |   |   |                               |      |                        |                                     |
|   | days a week for 2 weeks) for children with GMFCS level 4 and 5 CP? ~   |                |                               |                       |            |   |   |   |                               |      | 1                      |                                     |