

Neurodevelopmental Disorders (Canada) JLA PSP - Further details of questions discussed at the priority setting workshop on 28 September 2017

Uncertainty	Explanatory note	Rank of the uncertainty at the final workshop	Evidence
What are the most effective treatment options/plans (e.g., timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?	This question is aimed at understanding the what combination of treatments are best for achieving short-term outcomes vs. long-term outcomes, but also goes beyond this by determining when to take certain treatments, at what intensity or dosage and for how long and how often.	1	
How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?	This question speaks to how to improve the current supports and services so that they are coordinated (across different service providers), that each person has access and there is a consistent level of support to meet the needs of individuals with neurodevelopmental disorders throughout their life. Traditionally, there have been more services and supports available in early years and not during difficult transitions to adulthood, thus there appears to be gaps in the system and it is not easy for individuals and families to get the resources and services what they need.	2	Systematic review - Balogh R, McMorris CA, Lunsky Y, Ouellette-Kuntz H, Bourne L, Colantonio A, Gonçalves-Bradley DC. Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2016, Issue 4. Art.No
Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?	This question encompasses what treatments such as medication as well as less traditional treatments such as gene therapy, stem cell therapy, fecal transplant, or hormonal supplements, are effective for individuals, and for improving symptoms. This question also includes determining what group of individuals may benefit most from a particular biological treatment. *Note: in the final workshop, it was discussed that cannabis products could be investigated as part of this question	3	Systematic reviews: 1) James S, Stevenson SW, Silove N, Williams K. Chelation for autism spectrum disorder (ASD). Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD010766. DOI: 10.1002/14651858.CD010766.pub2.; 2) Xiong T, Chen H, Luo R, Mu D. Hyperbaric oxygen therapy for people with autism spectrum disorder (ASD). Cochrane Database of Systematic Reviews 2016, Issue 10. Art. No.: CD010922. DOI: 10.1002/14651858.CD010922.pub2.; 3) Rueda JR, Guillén V, Ballesteros J, Tejada MI, Solà I. L-acetylcarnitine for treating fragile X syndrome. Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD010012. DOI: 10.1002/14651858.CD010012.pub2.;
Which child and family-centered interventions or approaches promote optimal individual and family functioning?	This question arose from the need to think beyond the biology and to determine the best approach to focusing on the child or family unit as a whole, in a way that will improve their day-to-day function. At home, in the absence of healthcare and service providers, families want to be better able to implement a strategy to improve the overall wellness of their child(ren) and the family unit. This 'wellness' may include reduced stress, better management of challenging behaviours, improving socialability, and parenting strategies to promote independence of their child(ren).	4	Systematic review: Spain D, Sin J, Paliokosta E, FurutaM, Prunty JE, Chalder T, Murphy DG, Happé FG. Family therapy for autism spectrum disorders. Cochrane Database of Systematic Reviews 2017, Issue 5. Art. No.: CD011894. DOI:10.1002/14651858.CD011894.pub2
Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?	This question will help individuals with neurodevelopmental disorders and their families know which interventions are most likely to help control impulses, behaviour and emotions so that they can be brought back to a more relaxed and balanced state. This encompasses approaches for recognizing "warning signs" and regulating emotions and behaviour in different settings such as home, school, or work. Interventions may range from medication to cognitive behavioural therapy to mindfulness. There is an interest in understanding how this question can be applied by individuals (self-regulation), by parents and at school.	5	Systematic review: Hirsch LE, Pringsheim T, Aripiprazole for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2016, Issue 6. Art. No.: CD009043. DOI: 10.1002/14651858.CD009043.pub3.
Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?	The importance of supports for those who care for individuals with neurodevelopmental disorders (parents, siblings, other relatives, or caregivers) is raised through this priority. The question aims to address what resources are needed to ensure that families and caregivers of individuals with neurodevelopmental disorders are sufficiently supported in terms of their physical and emotional wellness, at all stages of the lifespan of the individual with a neurodevelopmental disorder. The supports may be community-based or formalized support (e.g. intensive training). Accessibility and financial burden are important factors in answering this question.	6	
How can treatment decisions for individuals with neurodevelopmental disorders be more precise (i.e., based on the diagnosis, age, functional need of the individual)?	As the saying goes "if you know one person with autism, you know one person with autism". Each person with a neurodevelopmental disorder may have a unique set of symptoms, needs and abilities. This question raises the importance of how to tailor treatment decisions to the individual - based on diagnosis, age, or functional need. This question also encompasses whether groups of individuals are more likely to respond to a certain treatment or what variables would affect the progress made using a particular intervention (e.g. early intervention, quality of intervention, whether medications are involved).	7	
Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?	This question is aimed at identifying which treatments are best to improve aggressive or self-injurious behaviour. There is interest in knowing which medication-based treatments are best and which non-medication options (e.g. cognitive behavioural therapy) work best.	8	Systematic review: Ali A, Hall I, Blickwedel J, Hassiotis A. Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 4. Art
Which are the most effective pharmacological and non-pharmacological intervention(s) to reduce anxiety in individuals with neurodevelopmental disorders?	This question is aimed at identifying which treatments are best to improve anxiety. This question encompasses identifying which medication-based treatments and which non-medication options (e.g. cognitive behavioural therapy) work best. There was also an interest in how this applies to individuals of different ages and effective options for those in rural communities.	9	Systematic reviews: 1) Therapist-supported Internet cognitive behavioural therapy for anxiety disorders in adults. Cochrane Database of Systematic Reviews 2016, Issue 3. Art. No.: CD011565. DOI: 10.1002/14651858.CD011565.pub2.; 2) Ipsier JC, Wilson D, Akindipe TO, Sager C, Stein DJ. Pharmacotherapy for anxiety and comorbid alcohol use disorders. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD007505. DOI: 10.1002/14651858.CD007505.pub2.; 3) Wu H, Yu D, He Y, Wang J, Xiao Z, Li C. Morita therapy for anxiety disorders in adults. Cochrane Database of Systematic Reviews 2015, Issue 2. Art. No.: CD008619. DOI: 10.1002/14651858.CD008619.pub2.; 4) James AC, James G, Cowdrey FA, Soler A, Choke A. Cognitive behavioural therapy for anxiety disorders in children and adolescents. Cochrane Database of Systematic Reviews 2015, Issue 2. Art.No.: CD004690. DOI: 10.1002/14651858.CD004690.pub4.; 5) Jori R, Amos T, Bergman H, Soares-Weiser K, Ipsier JC, Stein DJ. Augmentation of cognitive and behavioural therapies (CBT) with d-cycloserine for anxiety and related disorders. Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD007803. DOI: 10.1002/14651858.CD007803.pub2.
Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?	This question aims to identify which interventions are best for improving social skills and helping individuals with neurodevelopmental disorders maintain a satisfying social life at various stages of life (childhood, adolescence, adulthood). Interventions may include anything from medical interventions to approaches for making friends in a natural way. There is also an interest on new innovative interventions.	10	
How can educators and multi-disciplinary teams be better trained to provide individualized education for and accommodate children with neurodevelopmental disorders to ensure optimal outcomes?	This question aims to address what are the most effective strategies or best practices for teaching students with neurodevelopmental disorders that can be implemented. More training, time, sensitivity, understanding, and expertise on how to approach working with students with neurodevelopmental disorders is needed to ensure educational supports are meeting the learning needs of all their students.	11	
Which supports are most effective to protect individuals with neurodevelopmental disorders from abuse (e.g. physical, sexual, bullying) and other threats to their wellbeing?	This question arose from concerns about the physical and mental wellbeing of children and adults with neurodevelopmental disorders as members of a broader community. Specifically, how do we prevent and protect this more vulnerable population from negative outcomes such as bullying, preventable hospitalizations, identity fraud, inappropriate sexual interference, and abuse.	12	

Which intervention(s) are the most effective for improving executive functioning (e.g. rigid thinking, planning, organizing, sustaining attention, working memory, etc.) in individuals with neurodevelopmental disorders?	This question asks which interventions are best for improving executive function in individuals with neurodevelopmental disorders. Cognitive concepts including rigid thinking, planning, organizing, sustaining attention, and working memory fall under the executive functions umbrella term. This priority was raised to address the need to help individuals with neurodevelopmental disorders strengthen the skills needed to achieve their goals.	13	
How can barriers be reduced to ensure timely access of services, treatments and supports for neurodevelopmental disorders?	Poor access or awareness of services, treatments and supports for neurodevelopmental disorders is a huge challenge for families. Barriers to accessing services include prohibitive costs, geographical barriers, lack of transportation, years-long wait lists, and inconsistent support and information. The inequality of access and support for those in rural settings and northern communities is an especially important geographical barrier.	14	
How can access to coordinated care (including diagnosis and treatment) for individuals with multiple neurodevelopmental disorders be improved?	This priority focuses specifically on individuals with multiple diagnoses of neurodevelopmental disorders. There is difficulty accessing and receiving services that meet their needs, as diagnoses and professions are often siloed. This question asks how multiple diagnoses and treatments can be more coordinated and better supported in order to deliver quality care and address all areas of need for these individuals.	15	
How can families and caregivers be more involved and supported to make informed decisions that address their needs, preferences and priorities?	This question arose from families and caregivers wanting to be more informed and involved in making treatment decisions for their children and those they care for. In other words, how can researchers and healthcare providers work more collaboratively with families and caregivers to equip them with the information and support needed to make treatment decisions? Family and caregiver perspectives are often excluded from research design and the assessment of interventions. This question also asks how we can support their participation in these other important decisions.	16	
Which are the most effective interventions to improve cognition and address learning deficits in individuals with neurodevelopmental disorders?	This question addresses the need to help improve the learning abilities of individuals with neurodevelopmental disorders at all ages. What interventions and approaches can support learning difficulties, improve cognitive functioning, mitigate the negative impact of lower cognitive functioning, and generally help individuals with neurodevelopmental disorders learn and develop, and are there approaches that are age- or life stage-specific?	17	
How do co-occurring disorders impact treatment decisions for individuals with a neurodevelopmental disorder?	Neurodevelopmental disorders often co-occur with other conditions or diagnoses, for example epilepsy, addiction, psychosis, anxiety, depression or another neurodevelopmental disorder. This question aims to understand what treatments and approaches are most effective when an individual who has multiple conditions, and what impact co-occurring disorders have on treatment effectiveness. This question also pushes researchers to explore whether current treatments should be adapted to consider co-occurring conditions or whether similar treatment approaches are applicable across multiple disorders.	18	Systematic reviews: 1) Jackson CF, Makin SM, Marson AG, Kerr M. Pharmacological interventions for epilepsy in people with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005399. DOI: 10.1002/14651858.CD005399.pub3.; 2) Jackson CF, Makin SM, Marson AG, Kerr M. Non-pharmacological interventions for people with epilepsy and intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005502. DOI:10.1002/14651858.CD005502.pub3.; 3) Ayub M, Saeed K, Munshi TA, Naeem F. Clozapine for psychotic disorders in adults with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD010625. DOI: 10.1002/14651858.CD010625.pub2.
Which teaching strategies, classroom approaches and supports/services work best to meet the academic needs of students with neurodevelopmental disorders?	Individuals with neurodevelopmental disorders are often in challenging school placements and/or lack proper educational supports. This question aims to better understand the most effective educational practices to meet the academic needs and improve the educational experience and outcomes of students with neurodevelopmental disorders in various school settings. This uncertainty includes investigating the effectiveness and impact of already existing interventions such as inclusive education and modifications/accommodations, and also questions what other strategies and approaches can be used to support students with neurodevelopmental disorders. *Note: there was a specific interest in promoting social connection, learning/development, as well as improving performance in reading and algebra.	19	
What are the beneficial effects of cannabis products and/or medicinal marijuana for individuals with neurodevelopmental disorders?	Individuals with neurodevelopmental disorders are often in challenging school placements and/or lack proper educational supports. This question aims to better understand the most effective educational practices to meet the academic needs and improve the educational experience and outcomes of students with neurodevelopmental disorders in various school settings. This uncertainty includes investigating the effectiveness and impact of already existing interventions such as inclusive education and modifications/accommodations, and also questions what other strategies and approaches can be used to support students with neurodevelopmental disorders. *Note: there was a specific interest in promoting social connection, learning/development, as well as improving performance in reading and algebra.	20	

Neurodevelopmental Disorders (Canada) JLA PSP - ALL questions received

ID	Uncertainty	Original uncertainty	Evidence	Source of Uncertainty
A1	How can families and caregivers be more involved and supported to make informed decisions that address their needs, preferences and priorities?	Are persons with autism served better if parents are allowed more freedom over the choice of therapies they want to pursue?; How can people with neurodevelopmental disorders and their families be involved directly in setting objectives for services provided?; How to sufficiently get parents to understand the options available to them such that they can make informed decisions?	None.	mostly family members/carers, also a few clinicians
A2	Which child and family-centered interventions or approaches promote optimal individual and family functioning?	Can we shift the focus of our interest from 'child' to child-and-family?; What aspects of what we do promote optimal child and family functioning [considered together] and development?; How can we work with individuals with ND in a way that makes them and their caregivers feel encouraged, supported, and empowered?; What interventions exist for families affected by NDD?	Systematic review: Spain D, Sin J, Palokosta E, FurutaM, Prunty JE, Chalder T, Murphy DG, Happé FG. Family therapy for autism spectrum disorders. Cochrane Database of Systematic Reviews 2017, Issue 5. Art. No.: CD011894. doi:10.1002/14651858.CD011894.pub2	mostly family members/carers, also clinicians and patients
A3	Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?	How can we better support families caring for a child with neurodevelopmental conditions across the lifespan?; How can we best support caregivers' health and mental health? That is, what are ways that we can maximize the health of caregivers (family) so that they can provide support and not feel isolated.; What are the health, social and emotional needs of families caring for an individual with a neurodevelopmental disorder?; How to manage daily life with NDDs?	None.	mostly family members/carers, also clinicians, service providers and patients
AAA1	Which supports are most effective to protect individuals with neurodevelopmental disorders from abuse (e.g. physical, sexual, bullying) and other threats to their wellbeing?	How do I help a child with and understand what abuse and bullying is from their peers and strangers when it's happened their whole lives to the point that they think those behaviours are acceptable?; What are we doing to prevent abuse (e.g., physical, sexual and emotional) of children and adults?; Personal safety out in the community	None.	mostly family members/carers, also a few patients and clinicians
B1	How can biomarkers help to influence treatment options/plans for individuals with neurodevelopmental disorders?	Are there genetic markers that can help doctors choose drugs for ADHD and autism?; What clues are there in the brain that might help us decide who is a good candidate for medical (medication) management?	None.	mostly family members/carers
B3	How can treatment decisions for individuals with neurodevelopmental disorders be more precise (i.e., based on the diagnosis, age, functional need of the individual)?	Are we able to more precisely determine which approach might work for which person?; Can symptoms be addressed individually, as opposed to dismissed as just part of the disorder?; Improve the form of therapies to better fit the individual; Which factors affect how receptive an individual will be to different types of interventions?	None.	family members/carers, clinicians, service providers
B4	What are the comparative benefits and weaknesses of different treatments for individuals with neurodevelopmental disorders?	I feel as though not enough research has been done to fully understand the effects of different therapies on different people. There are a lot of blogs that state personal opinions. What are the positive and negative outcomes from different therapies?; What are the main differences, and benefits of one treatment versus another?; What is more effective long-term for treating ADHD, medication or behavioural therapy?; What interventions are most effective and have most tolerability?	None.	family members/carers, clinicians
B4-2	What are the benefits of technology-enhanced treatments for individuals with neurodevelopmental disorders?	Are iPads and other tech gadgets more helpful or harmful to those with neurodevelopmental disorders?; What new evidence-based approaches (e.g., technology-based) are there that enhance the quality of life of individuals with neurodevelopmental disorders (e.g., increasing levels of independence, self-determination, participation in their home communities)?	None.	mostly family members/carers
B5+F1+F2	What are the most effective treatment options/plans (e.g., timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?	What are the best ages or developmental stages for treatment to begin?; What are the best treatments (both medication and behavioural) for these disorders?; What is the level of intensity required for different therapies in order to maximize effectiveness?; How long is the intervention supposed to be effective before it plateaus?; What are the most effective, least-intrusive interventions for persons with different kinds of neurodevelopmental disorders?	None.	mostly family members/carers and clinicians, also some service providers and members of organizations
BB1	Which pharmacological and non-pharmacological interventions help to optimize brain/nevous system biological functioning in individuals with neurodevelopmental disorders?	Can interventions change neuronal connections?; What does (emerging) evidence suggest about ways to optimize brain, cognitive development (and health, in general) of a child/adult with Down syndrome?	None.	family members/carers, service providers
BBB1	Which education and/or treatment decision-making tools increase individuals with neurodevelopmental disorders' understanding of and involvement in their own care?	How can you educate individuals to be more actively involved in their health care as they reach adulthood?; What kind of decision-making tools support individual decisions related to risks/benefits of various interventions?	None.	mostly family members/carers
C3+E2	How can educators and multi-disciplinary teams be better trained to provide individualized education for and accommodate children with neurodevelopmental disorders to ensure optimal outcomes?	Can we develop a programme for education of educators about best practices for educating children with neurodevelopmental conditions?; How the school system can provide better access to intervention that is more tailored to individual needs?; Why isn't there more expertise and awareness in the school system on neurodevelopmental disorders?; What can be done to better support teachers in schools? There is a glaring lack of understanding in general; teaching strategies tend to be cookie cutter solutions that do not address individual needs. This leads to anxiety, depression and failure.	None.	mostly family members/carers, also clinicians and service providers
C5	How can family doctors and other healthcare professionals be better trained to treat children with neurodevelopmental disorders to ensure optimal outcomes?	Family practitioners are certainly helpful but lack the expertise needed to provide the help needed for these specific disorders.; What training needs are needed for front-line persons supporting persons with neurodevelopmental disabilities?; How well-acquainted with specialized interventions are paediatricians and developmental paediatricians?	None.	mostly family members/carers, some clinicians
D1+D2	How can barriers be reduced to ensure timely access of services, treatments and supports for neurodevelopmental disorders?	How accessible are the services for individuals with neurodevelopmental developmental disorders?; How can people who are in need get access to the help they need much faster and easier?; how to access care, especially crisis care?; How can we be consistent with support to people diagnosed so as to achieve better responses?; What interferes with implementation of structural supports (i.e. school/occupational resources) and what are some ways around those barriers?; How to help areas with few supports?; is there a way to supplement costs of specialized therapies that may not be covered?	None.	family members/carers, patients, clinicians, service providers, members of organizations
DD1	How are interventions for neurodevelopmental disorders evaluated for cost effectiveness and resource allocation?	Would increased financial support make a difference in prognosis and treatments for individuals living with a neurodevelopmental disorder?; What interventions are cost effective?; Health economics (cost) analysis of mental health interventions for people with neurodevelopmental disabilities; How do we provide the best combination of treatments at a reasonable costs that would allow governments and medical facilities to implement them?	None.	family members/carers, clinicians, service providers

DDD1	What end-of-life planning interventions can be implemented to improve outcomes and ensure the necessary care of individuals with neurodevelopmental disorders following the loss of a caregiver?	What can individuals/families expect as the individual reaches their senior years, and what additional supports may need to be created? Who will look after my child/children when we pass on? ie. living situation; End of life care for people with neurodevelopmental disorders. Huge issue for families and caregivers.	None.	family members/carers, patients
E1	Which teaching strategies, classroom approaches and supports/services work best to meet the academic needs of students with neurodevelopmental disorders?	Analysis of school-based supports and services for students with neurodevelopmental disorders - (i.e.) can people access supports/services and do the available services improve outcomes? How best to service children with ASD within public school settings, where resources may be limited and regular classroom placement can be challenging? Which classroom teaching strategies and accommodations assist children with neurodevelopmental disabilities achieve better academic outcomes? How to support kids to get the proper educational supports?	None.	family members/carers, clinicians, service providers
EE1 + EE2	Which intervention(s) are the most effective for improving executive functioning (e.g. rigid thinking, planning, organizing, sustaining attention, working memory, etc) in individuals with neurodevelopmental disorders?	How can we effectively help those with asd, ocd or adhd become unstuck from the things they seem to perseverate on that seem to get in the way in their life? What are specific targeted and evidence based therapies that can be used to strengthen executive functioning? What are the best strategies to help and ASD child/teen with rigid thinking learn to have more flexible thinking?	None.	mostly family members/carers
F2-Z	Which interventions have the most impact on development (including prenatal interventions, interventions before diagnosis, early interventions relative to the timing of diagnosis) in individuals with neurodevelopmental disorders?	Role of early intervention in addressing neurodevelopmental challenges? What should early intervention services include and look like? What interventions would you suggest to more generalist providers while patients await specialist interventions (eg if I do an assessment and diagnose, and offer part time services to bridge the wait)? What is an effective and appropriate early intervention for kids with neurodevelopmental challenges?	None.	mostly family members/carers, also clinicians and service providers
FF1	Which vitamin, mineral and supplement treatments best promote symptom relief in individuals with neurodevelopmental disorders?	[Does the] use of vitamins and minerals really make a difference in the prognosis of people with autism?; Are there any alternative methods (naturopathic medicines, vitamins, diets, etc.) that can be proven to improve the quality of life and learning for a person with a neurodevelopmental disorder?; Could herbs assist in treating OCD? (re: homeopathy?)	Systematic review - Tan ML, Ho JJ, Teh KH. Polyunsaturated fatty acids (PUFAs) for children with specific learning disorders. Cochrane Database of Systematic Reviews 2016, Issue 3. Art. No.: CD009398. DOI: 10.1002/14651858.CD009398.pub3.	mostly family members/carers, a few patients
FFF1	Which supports are needed to improve enrollment and success in post-secondary education for individuals with neurodevelopmental disorders?	What kind of different support services could be offered to high school students to ease their transition to post secondary education? How can we improve college/university/post-secondary enrollment for people with NDDs?	None.	mostly family members/carers
G1	What are the most effective strategies to improve understanding of neurodevelopmental disorders and reduce stigma?	Ways to reduce stigma and increase public awareness; How can societal barriers be reduced?; What would an effective sustained social marketing campaign include whose goal is to promote the social model of full inclusion in society for those with NDD?	None.	family members/carers, clinicians, patients
H1	How is the safety of medical and non-medical interventions assessed and optimized?	For non-drug therapies, what kind of testing is required to know if they are effective and safe for children?; How can it be determined if an intervention is effective, safe and ethical?; How can unwanted side-effects of medications be mitigated or reduced?	None.	family members/carers, service providers, members of organizations
H2+H2-2+H3	Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?	Research into genetic therapies?; What are effective biological treatments for autism?; What is the role of stem research for Down syndrome?	Systematic reviews: 1) James S, Stevenson SW, Silove N, Williams K. Chelation for autism spectrum disorder (ASD). Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD010766. DOI: 10.1002/14651858.CD010766.pub2.; 2) Xiong T, Chen H, Luo R, Mu D. Hyperbaric oxygen therapy for people with autism spectrum disorder (ASD). Cochrane Database of Systematic Reviews 2016, Issue 10. Art. No.: CD010922. DOI: 10.1002/14651858.CD010922.pub2.; 3) Rueda JR, Guillén V, Ballesteros J, Tejada MI, Solà L. L-acetylcarnitine for treating fragile X syndrome. Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD010012. DOI: 10.1002/14651858.CD010012.pub2.;	mostly family members/carers
I1	How can the adaptive skills (e.g. independence, self-efficacy and self-determination) of individuals with neurodevelopmental disorders be enhanced?	Can interventions increase adaptive skills?; How can we ensure people with ND become as independent and self-determining as possible?; Which interventions best impact quality of life/adaptive functioning even if not necessarily addressing 'core symptoms'?	None.	mostly clinicians, family members/carers
I1-2	How can the quality of life of individuals with neurodevelopmental disorders be measured and enhanced?	How can we improve the quality of life of individuals with ND?; Metrics on quality of life goals and preferences of the individual; How do we better assist these individuals to define what quality of life is to them? (i.e. is it being independent in eating, living on their own, having a job, etc)	None.	clinicians, family members/carers, service providers
I1 + I12	Which interventions are most effective for treating sensory issues in individuals with neurodevelopmental disorders?	What are effective behavioural interventions to improve the sensory processing impairments in autism?; What approaches are good for improving sensory issues in autism and related NDDs?; The efficacy of sensory-based interventions or sensory diets on persons with neurodevelopmental disorders.	None.	mostly family members/carers
J1	How can inter-professional collaboration and the use of multi-disciplinary teams be promoted in the care of individuals with neurodevelopmental disorders?	What factors make interprofessional collaboration possible and how can that be generalized across different (urban and rural) communities?; How can we open the minds of medical professionals to accept broader ideas of what NDDs are and take a more collaborative approach?	None.	family members/carers, service providers, clinicians
J2	How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?	How can services work together more effectively to support children and their families?; How can we better provide long term, coordinated care for these individuals across systems (such as schools, hospitals, private practices)?; How can we design a system of care that transitions from preschool to school and meets the child and family's needs across the lifespan (incorporating health education and social supports)?; How do we better organize service delivery such that families and clinicians have clear pathways for a given problem/disorder?	Systematic review - Balogh R, McMorris CA, Lunskey V, Quillette-Kuntz H, Bourne L, Colantonio A, Gonçalves-Bradley BC. Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2016, Issue 4. Art.No	mostly family members/carers, clinicians
J11	How can the outcome or outlook for an individual with a neurodevelopmental disorder be predicted and monitored throughout the lifespan?	There is really such a broad range of abilities/disabilities within the group under discussion. Is it possible to develop more precise developmental trajectories within disorders and ability/disability levels?; How can you monitor improvement- no improvement--making matters worse?	None.	clinicians, service providers
J11-0	Which quantitative outcome measures are optimal to evaluate interventions for neurodevelopmental disorders?	Can we use imaging to monitor progress objectively?; published studies on quantitative, objective (non 'expert' judgement) treatment methods.	None.	clinicians, members of organizations

J1-2	Can interventions that work with one neurodevelopmental disorder generalize to others and how can this be implemented?	How does generalization from the intervention setting to the natural environment work? Is the intervention sustainable and scalable?	None.	mostly clinicians
K1 + A1	How do we construct our social system to optimally support adolescents/adults with neurodevelopmental disorders?	Are there enough resources/supports in place for the growing population of young adults with a neurodevelopmental disorder and can our health care system adequately support their needs? What are the critical facilitators that need to be in place to ensure young adults with 'invisible disabilities/NDs' are fully included in society (social model)? What are the most important strategies and supports for adults with ASD? Why aren't there programs available for teens and young adults to help them integrate into society?	None.	family members/carers, service providers, patients
KK1	What is needed to best support youth with neurodevelopmental disorders and their families through the transition between pediatric and adult care?	Is there an adequate transition between pediatric and adult care? What services can be provided to help people with neurodevelopmental disorders navigate the transition to early adulthood?	None.	mostly family members/carers
L1-2	What are the beneficial effects of mindfulness or meditation for individuals with neurodevelopmental disorders?	What is being done to concentrate more on a holistic approach to people with neurological disorders opposed to medications etc.; What research is being done on the effectiveness of mindfulness in those with neurodevelopmental disorders? What role can meditation play in helping alleviate symptoms over the long term?	Systematic review - Hwang, Y.-S., & Kearney, P. (2013a). A systematic review of mindfulness intervention for individuals with developmental disabilities: long-term practice and long-lasting effects. Research in Developmental Disabilities, 34(1), 314-326.	mostly family members/carers
L1-3	What are the beneficial effects of cannabis products and/or medicinal marijuana for individuals with neurodevelopmental disorders?	How CBD hemp and medicinal marijuana can treat autism? How effective is cannabis oil in the treatment of neurodevelopmental disorders?	None.	family members/carers
L1	Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?	Are there ways to prevent aggression from developing in individuals with neurodevelopmental disorders (specifically in the autism population)? How can aggressive and self-harm symptoms be mitigated? What are the most effective non-medication treatments for reducing aggression in children with ADHD?	Systematic review: Ali A Hall J, Bickwedel J, Hassiotis A. Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 4. Art.	mostly family members/carers
M1	What are the best practices and employment-related services and supports for individuals with neurodevelopmental disorders? (e.g., skills training, aptitude testing, placement programs, etc.)	What strategies can be developed to increase inclusion in the workplace for adults with developmental disabilities? How can we teach interview skills to someone on the spectrum when they are so challenged with social interactions? How can we improve job attainment for people with NDDs?	None.	family members/carers, clinicians, service providers, patients
N2	Which supports and housing options best meet the needs for individuals with neurodevelopmental disorders?	Ideal living situations for individuals with ASD? what are barriers to development of adult supported living facilities for those with neurodevelopmental disorders and how can these barriers be overcome to ensure adequate resources for families? What are we going to do for housing as the population ages for those who have neurodevelopmental disorders?	None.	family members/carers, clinicians, service providers, patients
NN1	Which are the most effective interventions to improve muscle tone in individuals with neurodevelopmental disorders?	What can we do for low muscle tone? Children with neurodevelopmental disorders often have issues with physical strength and dexterity, what are the best approaches to help with development of core muscles, pelvic girdle muscles and shoulder girdle muscles when they have not been developing in the expected capacity range?	None.	family members/carers
NN1	Which interventions are effective for preventing obesity in individuals with neurodevelopmental disorders?	Is anyone looking at obesity and willing to look at the success of shots of HCG & acknowledge that it works?; obesity prevention for people with neurodevelopmental disorders	None.	clinician, family member/carer
O1	Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?	best interventions for social skills for children, youths, adults with ASD? How do we nurture social relationships with children who don't easily adapt to social expectations and norms? What are specific, evidence-based programs or therapies that strengthen social thinking skills?	None.	mostly family members/carers, patients
OO1	How can access to coordinated care (including diagnosis and treatment) for individuals with multiple neurodevelopmental disorders be improved?	What services are available for children with multiple diagnosis to receive quality care to address all areas of need in a more coordinated fashion?; It is very difficult to obtain access to dual diagnosis teams. Is there any guidance for parents who are in need but are challenged in [terms of access]?	None.	family members/carers
P1	Which education approaches improve families' and caregivers' knowledge of neurodevelopmental disorders to lead to better health outcomes?	What is the best approach for knowledge dissemination to families of individuals with complex and rare neurodevelopmental disorders? What education [is] available/valuable to not just the individual with a neurodevelopmental disorder, but to their caregivers (families, support staff etc)?; How is caregiver education related to outcomes for individuals with neurodevelopmental disorders?	None.	family members/carers, clinicians
Q1	Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?	Do social skills training programs really work for children with impulse control issues?; How can we best help people with ND become better able to self-regulate their behavior, thinking, and emotions?; Which therapies can be developed for children who struggle with self-regulation, and haven't responded well to existing strategies (e.g. mindfulness, CBT, DBT)?	Systematic review: Hirsch LE, Pringsheim T, Arripazole for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews 2016, Issue 6. Art. No.: CD009043. DOI: 10.1002/14651858.CD009043.pub3.	family members/carers, clinicians
QQ1 + SS2 + X1	How can combining interventions (e.g. pairing ABA (applied behavioural analysis) with physiotherapy) be optimized for individuals with neurodevelopmental disorders?	How can we better support NDD (neurodevelopment disorder) patients with combined therapies?; There are so many approaches, and obviously some approaches work better for some people than others, but has a comparison been done about the effectiveness of a singular approach, or a particular combination of approaches?; More specialized services - programs or therapies such as ot, pt.	None.	family members/carers, members of organizations
R1	What is the frequency and types of supports needed to most effectively address the mental health needs of individuals with neurodevelopmental disorders?	How can we ensure that mental health needs are being appropriately made available before the need becomes chronic and difficult to treat?; What mental health interventions should be made available?; Which interventions can prevent or ameliorate mental health problems for individuals with neurodevelopmental disorders?	None.	mostly clinicians and family members/carers
RR1	What are the benefits associated with participation in sports, recreational and leisure activities for individuals with neurodevelopmental disorders?	What are the benefits of physical activity for people with neurodevelopmental disorders? (Not just the physical benefits). What are the sport, recreation and leisure activities most valued by people with neurodevelopmental disorders, and their families?	None.	service providers, clinicians
RR1-2	What are the benefits associated with arts-related therapies (e.g., art therapy, music therapy) for individuals with neurodevelopmental disorders?	How successful are the alternative therapies (e.g., art, music, dance) in contributing to behavioural stability/wellness?; More research into the effects of 'alternative' therapies; for example, music therapy, laser therapy to help	Systematic review - Geretschager M, Elefant C, Mössler KA, Gold C. Music therapy for people with autism spectrum disorder. Cochrane Database of Systematic Reviews 2014, Issue 6. Art. No.: CD004381. DOI: 10.1002/14651858.CD004381.pub3.	family members/carers, service providers
S1 + S1-2	Which are the most effective interventions to improve cognition and address learning deficits in individuals with neurodevelopmental disorders?	How can we better support the learning of children with learning disabilities or an intellectual deficit who also have complex medical issues?; Implications of cognitive deficits and whether there are ways to circumvent or mitigate the negative impact of lower cognitive functioning; What are the most effective interventions for learning at various ages/grade levels?	None.	mostly family members/carers
SS1	What are the most effective ABA-based (applied behavioural analysis-based) interventions for individuals with neurodevelopmental disorders at various age ranges?	Can ABA therapy be effective in children with autism over the age of 6 or for adults with autism?; The efficacy of Applied Behaviour Analysis based interventions for a person with a neurodevelopmental disorder?	None.	family members/carers, clinician

Unique - 265	How can we improve the health care of underserved populations and refugees with neurodevelopmental disorders?	How can we improve the health care of underserved populations and refugees?	None.	clinician
Unique - 300	How can empathy in individuals with neurodevelopmental disorders be promoted?	How to promote empathy in individuals with neurodevelopmental disorders?	None.	clinician
Unique - 511	What are effective ways of training law enforcement and the justice system to properly handle individuals with neurodevelopmental disorders who may be at increased risk of exhibiting behaviours that get them involved with the justice system?	What are effective ways of training law enforcement and the justice system to properly handle individuals with neurodevelopmental disorders who may be at increased risk of exhibiting behaviours that get them involved with the justice system?	None.	clinician
Unique - 791	Measures to reverse the effect caused by compounds in vaccines, the agent that carries	Measures to reverse the effect caused by compounds in vaccines, the agent that carries.	Systematic reviews: 1) Demicheli V, Rivetti A, Debalini MG, Di Pietrantonj C. Vaccines for measles, mumps and rubella in children. Cochrane Database of Systematic Reviews 2012, Issue 2. Art. No.: CD004407. DOI: 10.1002/14651858.CD004407.pub3. 2) Modabbernia, A., Velthorst, E., & Reichenberg, A. (2017). Environmental risk factors for autism: An evidence-based review of systematic reviews and meta-analyses. Molecular Autism, 8, 13–28. 3) Ng M, G. de Montigny J, Oher M, T. Docé M. Environmental factors associated with autism spectrum disorder: a scoping review for the years 2003–2013. Health Promotion and Chronic Disease Prevention in Canada : Research, Policy and Practice. 2017;37(1):1-23. 4) Taylor LE, Swerdfeger AL, Eslick GD. Vaccines are not associated with autism: an evidence-based meta-analysis of case-control and cohort studies. Vaccine 2014;32(29):3623-9.	family member/carer
V1	Which are the most effective interventions to help individuals with neurodevelopmental disorders, including those who are non-verbal, with their speech, language and communication?	What are effective behavioural interventions to improve the communication impairments in autism?; How do children with neurodevelopmental disorders fare when provided with consistent speech and language therapy intervention?; How can we improve speech and communication?	Systematic review – Lee ASY, Gibbon FE. Non-speech oral motor treatment for children with developmental speech sound disorders. Cochrane Database of Systematic Reviews 2015, Issue 3. Art. No.: CD009383. DOI: 10.1002/14651858.CD009383.pub2.	mostly family members/carers
W1	Which pharmacological and non-pharmacological treatments are effective for improving attention in individuals with neurodevelopmental disorders?	Are there non-pharmacological treatments for attention deficits that work well?; What are the best practices to reduce the impact of inattention on performance?; What are the best strategies for helping people with ADHD when medication is not an option?	Systematic reviews: 1) Punja S, Shamsseer L, Hartling L, Urichuk L, Vandermeer B, Nikles J, Vohra S. Amphetamines for attention deficit hyperactivity disorder (ADHD) in children and adolescents. Cochrane Database of Systematic Reviews 2016, Issue 2. Art.No: CD009996. DOI: 10.1002/14651858.CD009996.pub2.; 2) Storebø OJ, Ramstad E, Krogh HB, Nilausen TD, Skoog M, Holmskov M, Rosendal S, Groth C, Magnusson FL, Moreira-Maia CR, Gillies D, Buch Rasmussen K, Gauči D, Zwi M, Kirubakaran R, Forsbøl B, Simonsen E, Gluud C. Methylphenidate for children and adolescents with attention deficit hyperactivity disorder (ADHD). Cochrane Database of Systematic Reviews 2015, Issue 11. Art. No.: CD009885. DOI: 10.1002/14651858.CD009885.pub2.; 3) Jotaszowie J, Castells X, Ehimare UP, Smith CH. Tricyclic antidepressants for attention deficit hyperactivity disorder (ADHD) in children and adolescents. Cochrane Database of Systematic Reviews 2014, Issue 9. Art. No.: CD006997. DOI: 10.1002/14651858.CD006997.pub2.;	mostly family members/carers
W1	How do co-occurring disorders impact treatment decisions for individuals with a neurodevelopmental disorder?	[What is the] effect of comorbid disorders (such as anxiety, depression) on treatments?; How co-morbid disorders impact the manifestation of the disorder and its treatment; investigate multiple diagnoses interactions and relationships	Systematic reviews: 1) Jackson CF, Makin SM, Marson AG, Kerr M. Pharmacological interventions for epilepsy in people with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005399. DOI: 10.1002/14651858.CD005399.pub3.; 2) Jackson CF, Makin SM, Marson AG, Kerr M. Non-pharmacological interventions for people with epilepsy and intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD005502. DOI: 10.1002/14651858.CD005502.pub3.; 3) Ayub M, Saeed K, Munshi TA, Naeem F. Clozapine for psychotic disorders in adults with intellectual disabilities. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD010625. DOI: 10.1002/14651858.CD010625.pub2.	mostly family members/carers, some clinicians
WW1	How can the impact of social support be promoted and assessed among individuals with neurodevelopmental disorders?	How to get people with ASD to meet, support each other?; Does social support significantly affect the lived experience of symptoms?	None.	mostly family members/carers
X1	Which interventions are the most effective to improve sleep issues in individuals with neurodevelopmental disorders?	How can the quality and quantity of sleep be improved for a person living with autism?; How can we improve prevention, diagnosis and treatment (new alternatives to the CPA) for sleep apnea in those with Down syndrome?; Does 'night milk' (supposedly larger quantities of tryptophan) have any value in helping kids active brains to relax and sleep; would it create a greater quality of sleep?	Systematic review – Venekamp RP, Hearne BJ, Chandrasekharan D, Blackshaw H, Lim J, Schilder AGM, Hansell-Downing AP. Melatonin versus non-melatonin management for obstructive sleep-disordered breathing in children. Cochrane Database of Systematic Reviews 2015, Issue 9. Art. No.: CD010625. DOI: 10.1002/14651858.CD010625.pub2.	mostly family members/carers
Y1	Which dietary regimens are most effective for providing therapeutic value for health and symptom relief in individuals with neurodevelopmental disorders?	Are there differences in dietary approaches, based on the individual's neurodevelopmental diagnosis which might optimize their health?; Can diet improve any symptoms?; Do nutritional and dietary changes (i.e. Gluten free, casein free diets, antioxidants, amino acids etc) help improve health and behaviour of those with neuro developmental disorders?	None.	mostly family members/carers
Y1	How can the onset of early dementia and Alzheimer's disease be prevented and/or treated in those with Down syndrome?	Are individuals with neurodevelopmental disorder more prone to alzheimer and dementia than others and how can we prevent onset?; Can you prevent early dementia in Down Syndrome?	Systematic review – Livingston N, Manjraj T, McShane R, MacDonald G. Pharmacological interventions for cognitive decline in people with Down syndrome. Cochrane Database of Systematic Reviews 2015, Issue 10. Art. No.: CD011546. DOI: 10.1002/14651858.CD011546.	mostly family members/carers
Z1	Which are the most effective pharmacological and non-pharmacological interventions to reduce anxiety in individuals with neurodevelopmental disorders?	What can be done for a child/adult suffering anxiety linked to their disorder?; What work can be done to catch anxiety early before it become part of the disability and interferes with daily living?; Are there non-pharmacological treatments for anxiety that work well?	Systematic reviews: 1) Therapist-supported Internet cognitive behavioural therapy for anxiety disorders in adults. Cochrane Database of Systematic Reviews 2016, Issue 3. Art. No.: CD011565. DOI: 10.1002/14651858.CD011565.pub2.; 2) Ipser JC, Wilson D, Akindipe TO, Sager C, Stein DJ. Pharmacotherapy for anxiety and comorbid alcohol use disorders. Cochrane Database of Systematic Reviews 2015, Issue 1. Art. No.: CD007505. DOI: 10.1002/14651858.CD007505.pub2.; 3) Wu H, Yu D, He Y, Wang J, Xiao Z, Li C. Morita therapy for anxiety disorders in adults. Cochrane Database of Systematic Reviews 2015, Issue 2. Art. No.: CD008619. DOI: 10.1002/14651858.CD008619.pub2.; 4) James AC, James G, Cowdrey FA, Soler A, Choke A. Cognitive behavioural therapy for anxiety disorders in children and adolescents. Cochrane Database of Systematic Reviews 2015, Issue 2. Art.No.: CD004690. DOI: 10.1002/14651858.CD004690.pub4.; 5) O'Riordan R, Amos T, Bergman H, Soares-Weiser K, Ipser JC, Stein DJ. Augmentation of cognitive and behavioural therapies (CBT) with D-cycloserine for anxiety and related disorders. Cochrane Database of Systematic Reviews 2015, Issue 5. Art. No.: CD007803. DOI: 10.1002/14651858.CD007803.pub2.	mostly family members/carers

Z21	Which interventions are most effective to reduce eating and/or feeding issues in individuals with neurodevelopmental disorders?	Are there early intervention programs that can address the eating challenges (i.e. selective eating) of individuals on the Autism spectrum?; How do we engage a child who does not enjoy eating? What would be the bare minimum requirements for a growing child when they refuse to eat?	None.	family members/carers, service provider and patient
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