

Tabell 4.1 Personer med funktionsnedsättning. Identifierade relevanta systematiska översikter med medelhög eller hög metodologisk kvalitet fördelade per livs och insatsområde.

Insatsområden	Livsområden									
	Lärande	Företa uppgift, hantera krav, egen aktivitetsnivå	Språk, kommunikation	Personlig vård, hälsa, välmående	Boende, hushåll, hemliv	Rörelse, förflyttning	Relationer, interaktioner	Arbete, sysselsättning	Samhällsgemenskap, rättigheter	Personligt stöd
Arbete, sysselsättning, fritidsinriktade		1 [4]	1 [4]				1 [4]	3 [4-6]	1 [7]	
Autonomirelaterade										1 [8]
Beteendeariiktade		6 [9-12, 14-15]		4 [9,11,15,16]			2 [10,11]	2 [10,15]		
Boendelaterade				1 [17]	2 [17,18]		1 [17]	1 [17]	1 [17]	
Delaktighets, socialt främjande		3 [4,10,19]	1 [4]	2 [20,21]			3 [10,19,20]	2 [4,10]		
Fysiska		3 [4,22,23]	1 [4]	3 [23-25]		2 [23,25]	1 [4]	1 [4]	1 [23]	
Föräldraförståelsefrämjande		2 [26,27]			2 [26,27]		2 [26,27]			
Kognitiva		2 [10,11]	1 [28]	1 [11]			3 [10,11,28]	1 [10]		
Kommunikationsinriktade Inga systematiska litteraturöversikter med medelhög eller hög metodologisk kvalitet identifierades.										
Motivationsinriktade Inga systematiska litteraturöversikter med medelhög eller hög metodologisk kvalitet identifierades										
Pedagogiska	1 [29]	2 [29,30]	3 [4,28,30]	2 [21,31]		1 [29]	4 [4,28-30]	1 [4]		
Personlig assistans	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]	6 [32-37]
Psykosociala		7 [9,10,15,38-41]	1 [40]	7 [9,15,21,39,41-43]			3 [38,40,41]	2 [10,15]		2 [41,42]
Sensoriska Inga systematiska litteraturöversikter med medelhög eller hög metodologisk kvalitet identifierades										
Stöd från anhöriga eller andra närstående	1 [45]	5 [4,11,38,44,45]	1 [4]	1 [44]			3 [4,11,38]	1 [4]		1 [8]
Transportrelaterade Inga systematiska litteraturöversikter med medelhög eller hög metodologisk kvalitet identifierades										
Hälsorelaterade		2 [9,16]		2 [9,16]						

Tabell 4.2 Vetenskaplig kunskap och vetenskapliga kunskapsluckor för identifierade relevanta systematiska översikter (SÖ) av medelhög eller hög metodologisk kvalitet för gruppen personer med funktionsnedsättning.

Författare År Land Referens	Population Intervention Design/Antal inkluderade primärstudier	Författarnas slutsats	Viss vetenskaplig kunskap finns (VVK) Vetenskaplig kunskapslucka (VKL)	Åtgärd vid vetenskaplig kunskapslucka
<p>Ali et al 2015 Storbritannien [9]</p>	<p>Personer med intellektuell funktionsnedsättning (IFN).</p> <p>Beteende- och kognitivt inriktade insatser (Behavioural modification interventions, e.g. differential reinforcement of other behaviour, applied behavioural analysis, positive behaviour support. Cognitive-behavioural treatment, e.g. anger management, problem-solving skills training, relaxation, and meditation or 'mindfulness').</p> <p>RCT/6 st.</p>	<p>"At present, there is some evidence that cognitive-behavioural treatments are effective in the short-term management of outwardly directed aggression. Five of the included studies reported significant improvement immediately after treatment was completed, but the effect was imprecise. Unfortunately, we were not able to include behavioural interventions, such as Applied Behavioural Analysis or Positive Behavioural Support, as published studies did not report specific data on aggression. Despite the methodological limitations, there is some indication that mindfulness</p>	<p>VKL: (Beteende-inriktade insatser, mindfulness, personer med IFN).</p> <p>VVK: (Kognitiva - insatser, personer med IFN).</p>	<p>Fler primärstudier behövs</p>

		<p>may be of some help in reducing aggression. Cognitive-behavioural interventions are relatively resource-intensive, but it can be argued that they are preferable to the use of psychotropic drugs, which have significant side-effects. Given that behavioural treatments are often used as first-line or adjunctive treatment in clinical practice for problem behaviours, including outwardly-directed aggression, it is important that their efficacy is further investigated. In addition, no information yet exists on the best way in which they should be implemented, for example, alone or in combination with other approaches. Finally, access to psychological therapies for people with intellectual disabilities is an important issue, and therefore lay therapists delivering such interventions could make</p>		
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		psychological therapies more accessible to this population group.”		
Bjornstad et al 2005 Storbritannien [38]	Barn och ungdomar med ADHD. Familjeterapi (E.g. behavioural parent training, child self-control training, school-based intervention. RCT/2 st.	“Further research examining the effectiveness of family therapy versus a no-treatment control condition is needed to determine whether family therapy is an effective intervention for children with ADHD. There were no results available from studies investigating forms of family therapy other than behavioural family therapy.”	VKL: (Familjeterapi, barn/ungdomar, ADHD).	Uppdaterad SÖ behövs
Cerrillo-Urbina et al 2015 Spanien och Chile [22]	Barn och ungdomar med ADHD. Fysisk träning (Aerobic exercise, yoga). RCT/8 st. med totalt 249 deltagare, varav 19 deltog i yoga.	“Physical Exercise programmes (aerobic and yoga) weakly reduce several symptoms in children with ADHD. However, there is less evidence about the benefits of the yoga programs. The meta-analysis suggests that short-term aerobic exercises (6-10 weeks), based on several aerobic intervention’s formats, reported a moderate to	VKL: (Fysisk träning, barn/ungdomar, ADHD).	Fler primärstudier behövs

		<p>large effect on inattention, hyperactivity, impulsivity, anxiety, executive function and social disorders in children with ADHD. However, the results of this systematic review and metaanalysis should be understood with caution because of the small number of studies and the heterogeneity of their outcome measures. For this reason, more studies are required to obtain consistent clinically relevant conclusions.”</p>		
<p>Chilvers et al 2006 Storbritannien [18]</p>	<p>Personer med omfattande psykisk funktions-nedsättning.</p> <p>Stödboende (I. e. a number of people with severe mental disorder/s living in self-contained accommodation on one site. Professional support staff are on-site and available during office hours at least for either individual or group social support with a minimum aim of maintenance of the tenancy. Social support may involve counselling, emotional support, information, instruction and tangible assistance.)</p>	<p>“There is an urgent need to investigate the effects of supported housing on people with severe mental illness within a randomised trial.”</p>	<p>VKL: (Stödboende, personer med omfattande psykisk funktions-nedsättning).</p>	<p>Uppdaterad SÖ behövs</p>

	RCT, kvasi-RCT/Inga studier inkluderades			
Coren et al 2010 Storbritannien och Sverige [26]	Föräldrar/vårdnads-havare med intellektuell funktionsnedsättning och ett eller flera barn mellan 0-18 år Föräldra-förmåga-främjande insatser RCT, CT/ 3 st. med sammanlagt 125 deltagare	“While the evidence presented here does seem promising with regard to the ability of such interventions to improve parenting knowledge and skill in this population, there is a need for larger RCTs of interventions before conclusions can be drawn about the effectiveness of parent training in this group of parents.”	VKL: (Föräldra-förmåga-främjande insatser, föräldrar/vårdnads-havare med intellektuell funktionsnedsättning och ett eller flera barn mellan 0-18 år).	Uppdaterad SÖ behövs
Crowther et al 2001 Storbritannien och USA [5]	Personer med omfattande psykisk funktionsnedsättning/sjukdom. Arbetsträning/ praktik (Prevocational training) och Supported Employment. RCT/11 st.	“The included trials of prevocational training compared with standard community care were of limited quality, and none met the criteria for the sensitivity analysis. The data available from these trials were insufficient to make judgments on the effectiveness of prevocational training over standard community care.” “Only one trial compared supported employment	VVK: (Arbetsträning/ praktik/Supported Employment, personer med omfattande psykisk funktionsnedsättning/sjukdom).	Uppdaterad SÖ kan behövas då litteratursökningen omfattade referenser fram till 1998. Det vetenskapliga kunskapsläget kan vara förändrat.

		<p>with standard community care. Although this trial suggested that supported employment was superior to standard community care, its findings are difficult to interpret as the group receiving supported employment also received assertive community treatment.”</p> <p>“Supported employment is more effective than prevocational training at helping people with severe mental illness to obtain and keep competitive employment”.</p>		
<p>Daley et al 2014 Storbritannien, Belgien, Nederländerna, Spanien, Tyskland och Danmark [10]</p>	<p>Barn och ungdomar med ADHD.</p> <p>Beteendeoriktade insatser (E. g. behavioral training, social skills training, CBT, behavioral and self-control training, organizational skills training, daily report card).</p> <p>RCT/32 st.</p>	<p>“In summary, although more evidence is required before behavioral interventions can be supported as a front-line treatment for core ADHD symptoms, the authors found evidence that they do have beneficial effects on parenting and parents’ sense of empowerment and independently corroborated effects on</p>	<p>VVK: (Beteende-inriktade insatser, barn och ungdomar, ADHD).</p>	<p>Uppdaterad SÖ kan behövas då litteratursökningen omfattade referenser fram till 2012. Det vetenskapliga kunskapsläget kan vara förändrat.</p>

		conduct problems in children with ADHD.”		
Evans et al 2014 USA [11]	<p>Barn och ungdomar med ADHD.</p> <p>Psykosociala insatser i form av beteende-inriktad föräldrautbildning, beteenderiktad insats i skolan, beteendeinriktade/socialt inriktade insatser för vänskapsrelationer, en kombination av de tre ovanstående insatserna, kognitiv träning, neurofeedback, träning i att organisera material, kombinerad träning avseende organisatoriska och sociala färdigheter (eng. behavioral parent training, behavioral classroom management, behavioral peer interventions, combined behavioral treatment studies; cognitive training, neurofeedback training, organisation training, combined training)</p> <p>Empiriska studier/21 st.</p>	<p>“Consistent with the results of the previous review we concluded that behavioral parent training, behavioral classroom management and behavioral peer interventions were well established treatments. In addition, organization training met the criteria for a well-established treatment. Combined training programs met criteria for Level 2 (Probably Efficacious), neurofeedback training met criteria for Level 3 (Possibly Efficacious), and cognitive training met criteria for Level 4 (Experimental Treatments).”</p>	<p>VVK: (Beteendeinriktad föräldrautbildning, ungdomar, ADHD.</p> <p>Beteenderiktad insats i skolan, barn ADHD.</p> <p>Beteende-inriktade/socialt inriktade insatser för vänskapsrelationer, barn, ADHD.</p> <p>Kombination av de tre ovanstående insatserna, barn, ADHD.</p> <p>Träning i att organisera material, barn och ungdomar, ADHD</p> <p>Kombinerad träning avseende organisatoriska och sociala färdigheter, ungdomar, ADHD).</p> <p>VKL: (Beteenderiktad insats i skolan, ungdomar ADHD</p>	Uppdaterad SÖ behövs

			Kognitiv träning, barn och ungdomar, ADHD Neurofeedback, barn och ungdomar, ADHD)	
Fletcher-Watson et al 2014 Storbritannien [28]	Personer med autismspektrumtillstånd Insatser baserade på den modellen Theory of mind (förståelsen för andras tankar och känslor). RCT/22 st.	“While there is some evidence that ToM, or a precursor skill, can be taught to people with ASD, there is little evidence of maintenance of that skill, generalisation to other settings, or developmental effects on related skills. Furthermore, inconsistency in findings and measurement means that evidence has been graded of 'very low' or 'low' quality and we cannot be confident that suggestions of positive effects will be sustained as high-quality evidence accumulates. Further longitudinal designs and larger samples are needed to help elucidate both the efficacy of ToM-linked interventions and the explanatory value of the ToM mode! itself. It is possible that the	VKL: (Insatser baserade på den modellen Theory of mind, personer med autismspektrum-tillstånd).	Uppdaterad SÖ behövs

		continuing refinement of the ToM mode! will lead to better interventions which have a greater impact on development than those investigated to date.”		
Furlong et al 2012 Irland och Storbritannien [44]	Föräldrar/vårdnads-havare till barn mellan 3-12 år med problem avseende uppförande. Beteende- och kognitivt inriktade samt gruppbaseade föräldrastöd-program (E. g. Incredible Years BASIC Parenting Programme, Barkley's Parent Training programme, Parenting Management Training (PMT), Comet Parent Management Training, Work Place Triple P Parenting Programme). RCT/10 st.; kvasi-RCT/3 st.	”Behavioural and cognitive-behavioural group-based parenting interventions are effective and cost-effective for improving child conduct problems, parental mental health and parenting skills in the short term.”	VVK: (Beteende- och kognitivt inriktade samt gruppbaseade föräldrastöd-program, föräldrar/vårdnads-havare till barn mellan 3-12 år med problem avseende uppförande).	Uppdaterad SÖ kan behövas då litteratursökningen omfattade referenser fram till 2011. Det vetenskapliga kunskapsläget kan vara förändrat.
Hardee et al 2017 USA [23]	Personer med Downs syndrom (DS). Tränings-program. Kohortstudier, fallstudie, RCT, inte RCT/19 st.	“This systematic review does contain data that supports a positive impact of exercise intervention on daily life activities and participation for people with DS; however, this is a preliminary conclusion. More rigorous research is needed with individuals with DS of all ages using	VKL: (Tränings-program, personer, Downs syndrom).	Fler primärstudier behövs.

		objective outcome measures for ICF domains of Activity and Participation. Specifically, MCPDM Level I RCTs with high internal validity should be conducted.”		
Harris et al 2015 Storbritannien [24]	Personer mellan 16-24 år med intellektuell funktionsnedsättning. Fysisk aktivitet. RCT/6 st.	”This review has illustrated the lack of evidence of physical activity interventions specifically designed for young adults with intellectual disabilities. The meta-analysis found that physical activity interventions in young adults with intellectual disabilities did not prevent weight gain or improve body composition. This is due to limitations of the published studies, implementing inadequate duration and dose of the interventions. Although there was no significant effect of physical activity on body weight, physical activity interventions improved health risk factors, which is important for this population group to prevent health inequalities	VVK: (Fysisk aktivitet, personer mellan 16-24 år med intellektuell funktionsnedsättning).	

		in later life. Future high-quality, adequately powered randomised controlled trials, with a long-term intervention and follow-up period are required to elucidate the effects of physical activity interventions on the prevention of weight gain and body composition in young adults with intellectual disabilities.”		
Jones et al 2015 Australien [31]	Vuxna med förvärvad hjärnskada. Program för att öka fysisk aktivitet. RCT, kvasi-RCT/5 st.	“Based on the results of this review, the efficacy of self-management programs in increasing physical activity levels in community dwelling adults following ABI is still unknown. Moreover, the efficacy and acceptability of remotely delivered self-management programs for increasing physical activity levels after ABI is also unknown. Further research into physical activity following self-management interventions for community-dwelling adults with ABI is required in order to properly establish	VKL: (Program för att öka fysisk aktivitet, vuxna, förvärvad hjärnskada).	Fler primärstudier behövs.

		efficacy and implications for practice.”		
Karkhaneh et al 2010 Kanada [30]	Barn och ungdomar med autism-spektrum-tillstånd. Sociala berättelser. RCT/4 st., CCT/2 st.	“This systematic review of controlled trials evaluating Social Stories™ for children with ASD complements previous reviews that highlight the positive effects of this modality for higher functioning children with autism. This rigorous systematic review of six controlled trials demonstrates that Social Stories™ may be beneficial in terms of modifying target behaviours among high functioning children with ASD. Long-term maintenance, effectiveness of the intervention in other, less-controlled settings, and the optimal dose/frequency is unknown and requires further research.”	VVK: (Sociala berättelser, barn och ungdomar, autismspektrum-tillstånd).	Uppdaterad SÖ kan behövas då litteratursökningen omfattade referenser fram till 2006. Det vetenskapliga kunskapsläget kan vara förändrat.
Kok et al 2016 Nederländerna [39]	Barn, ungdomar och unga vuxna (0-22 år) med lindrig intellektuell och samtidig psykisk funktionsnedsättning (psychiatric disorder).	“The vast majority of the included studies investigated the effectiveness of a parent training intervention compared to care as usual. The remaining studies	VVK: (Psykosociala insatser, barn, ungdomar och unga vuxna (0-22 år), lindrig intellektuell och samtidig psykisk funktions-	Uppdaterad SÖ kan behövas då litteratursökningen omfattade referenser fram till 2010. Det vetenskapliga

	<p>Psykosociala insatser (E. g. parent training, social competence training, cognitive behavior therapy).</p> <p>RCT/12 st.</p>	<p>focused on psychosocial training programs for the children and adolescents. Parent training programs focus on improving parent-child interactions, increasing parents' understanding of their child's behavior, and the application of behavioral techniques to reduce problem behavior. In this systematic review, seven different parent training programs were assessed in a total of 243 participants with varying degrees of psychopathology. The overall results appear to show a tendency toward reduced problem behavior and an increase in child positive behavior."</p>	<p>nedsättning (psychiatric disorder).</p>	<p>kunskapsläget kan vara förändrat.</p>
<p>Lorenc et al 2016 Storbritannien [4]</p>	<p>Vuxna med autism-spektrumtillstånd (high-functioning autism).</p> <p>Stödjande insatser inom olika områden (E. g. Job interview training, employment support, social skills training, psychoeducation, music, dance, university student support &</p>	<p>"Evidence from three RCTs suggests that job interview training was effective in improving interview performance (total number of participants 76). Evidence on other outcomes is inconclusive. Evidence from two RCTs, one nRCT and two one-</p>	<p>VKL: (Stöd till universitetsstudenter/säkerhetsrelaterade insatser, vuxna, fysisk aktivitet, autism-spektrumtillstånd).</p> <p>VVK:</p>	<p>Fler primärstudier behövs.</p>

	<p>mentoring, safety general support, peer support groups, specialist multi-disciplinary teams).</p> <p>RCT/9 st., non-RCT/5 st., en-gruppsstudier/13 st./kvalitativa studier/7 st./ekonomiska studier/3 st.</p>	<p>group studies suggests that supported employment was effective in increasing employment rates and earnings (N=174). Evidence on other outcomes is inconclusive. One economic study found supported employment to be cost-effective. Evidence from four RCTs, two nRCTs and eight one-group studies suggests that social skills training was effective in improving self-rated social skills and autism symptoms (N=372). Evidence on other outcomes is inconclusive. Evidence from one nRCT suggests that movement therapy was effective in improving social skills and wellbeing (N=31). Evidence on mentoring and support for university students is inconclusive. Evidence on safety interventions is inconclusive. Evidence from one economic study suggests that specialist multi-disciplinary support</p>	<p>(Träning i anställningsintervju/ Supported Employment /social färdighetsträning, vuxna, autism spektrum-tillstånd).</p>	
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		was cost-saving from a public sector perspective.”		
Mayo-Wilson et al 2008 Storbritannien [32]	Barn och ungdomar (0-18 år) med intellektuell funktionsnedsättning. RCT/ 1 st.	<p>“Existing evidence suggests that personal assistance is generally preferred over other services by people who agree to participate in research; however, some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients; however, the relative total costs to recipients and society are unknown.</p> <p>This review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive.”</p> <p>“...further studies are required to determine (i) what marginal benefits are gained from personal assistance (i.e. the added value compared to other</p>	VVK: (Personlig assistans, barn och ungdomar, intellektuell funktionsnedsättning).	Uppdaterad SÖ behövs eftersom litteratursökningen omfattar referenser fram till 2005. Det vetenskapliga kunskapsläget kan vara förändrat.

		services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient for particular people.”		
Mayo-Wilson et al 2008 Storbritannien [33]	Barn och ungdomar (0-18 år) med fysisk funktions-nedsättning. Personlig assistans. RCT, kvasi-RCT, CT/ Inga studier inkluderades.	“No randomised, quasi- randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There is no reliable evidence about the effectiveness of personal assistance for children and adolescents with physical impairments.”	VKL: (Personlig assistans, barn och ungdomar, fysisk funktions-nedsättning).	Uppdaterad SÖ behövs
Mayo-Wilson et al 2008 Storbritannien [34]	Barn och ungdomar (0-18 år) med både fysisk och intellektuell funktions-nedsättning. Personlig assistans. RCT, kvasi-RCT, CT/ Inga studier inkluderades.	“No randomised, quasi- randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There is no reliable	VKL: (Personlig assistans, barn och ungdomar, både fysisk och intellektuell funktions-nedsättning).	Uppdaterad SÖ behövs.

		<p>evidence about the effectiveness of personal assistance for children and adolescents with both physical and intellectual impairments, though the results from a review of children and adolescents with intellectual impairments might be relevant to users and policymakers.</p> <p>“There have been few controlled studies of personal assistance for children who require a great deal of assistance for any reason and none for children who require assistance due to both physical and intellectual impairments. Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness. Some users may wish to consider evidence from other</p>		
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		populations and discuss their options with family and friends.”		
Mayo-Wilson et al 2008 Storbritannien [35]	Vuxna (19-64 år) med fysisk funktions-nedsättning. Personlig assistans. RCT/1 st.	“Existing evidence suggests that personal assistance is generally preferred over other services by consumers and their representatives who agree to participate in research; however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients, their friends and families; however, the relative total costs to recipients and society are unknown. This review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive.” “...further studies are required to determine (i) what marginal benefits	VVK: (Personlig assistans, vuxna, fysisk funktions-nedsättning).	Uppdaterad SÖ behövs eftersom litteratursökningen omfattar referenser fram till 2005. Det vetenskapliga kunskapsläget kan vara förändrat.

		<p>are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient for particular people.”</p>		
<p>Mayo-Wilson et al 2008 Storbritannien [36]</p>	<p>Vuxna (19-64 år) med både fysisk och intellektuell funktionsnedsättning.</p> <p>Personlig assistans.</p> <p>RCT/1 st., kvasi-RCT, CT/1 st.</p>	<p>“Existing evidence suggests that personal assistance may be preferred over other services by consumers and their representatives who agree to participate in research; however, some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients, their friends and families; however, the relative total costs to recipients and society are unknown.</p> <p>This review does not indicate that personal assistance would be superior to other services</p>	<p>VVK: (Personlig assistans, vuxna, både fysisk och intellektuell funktionsnedsättning).</p>	<p>Uppdaterad SÖ behövs eftersom litteratursökningen omfattar referenser fram till 2005. Det vetenskapliga kunskapsläget kan vara förändrat.</p>

		<p>for people who are already satisfied with the assistance they receive.”</p> <p>“...further studies are required to determine (i) what marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient for particular people.”</p>		
<p>Montgomery et al 2008 Storbritannien [37]</p>	<p>Äldre vuxna (65 år och äldre) utan demens.</p> <p>Personlig assistans.</p> <p>RCT/1 st., kvasi-RCT, CT/1 st.</p>	<p>Existing evidence suggests that personal assistance is generally preferred over other services by consumers and their representatives <i>who agree to participate in research</i>; however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients, their friends and families. Paid assistance probably substitutes for informal care and may cost</p>	<p>VVK: (Personlig assistans, äldre vuxna utan demens).</p>	<p>Uppdaterad SÖ behövs eftersom litteratursökningen omfattar referenser fram till 2005. Det vetenskapliga kunskapsläget kan vara förändrat.</p>

		<p>government more than alternative arrangements; however, the relative <i>total</i> costs to recipients and society are unknown. Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness.”</p> <p>“This review indicates that personal assistance is safe for older adults, though it may be difficult to manage. People who choose to receive personal assistance may prefer it to other services, particularly services over which users have little control. However, this review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive. Personal assistance appears to benefit informal</p>		
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		<p>caregivers as well. Individuals considering personal assistance may wish to discuss their options with family and friends.”</p> <p>“...further studies are required to determine (i) what marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) at what total relative cost and (iii) which models of personal assistance are most effective and efficient for particular people.”</p>		
<p>Reichow et al 2012 USA [20]</p>	<p>Barn, ungdomar och unga vuxna (6-21 år) med autismspektrum-tillstånd.</p> <p>Social färdighetsträning i grupp.</p> <p>RCT/5 st.</p>	<p>“The results of the meta-analyses in this review suggest that participants in social skills groups may make modest gains in social competence, have better friendships, and experience less loneliness. To put these gains in more concrete terms, if measuring everyday social skills using the Vineland (Sparrow 2005), for example, an average</p>	<p>VKL: (Social färdighets-träning i grupp, barn och ungdomar under 7 och över 13 år, autismspektrum-tillstånd).</p> <p>VVK: (Social färdighets-träning i grupp, barn och ungdomar 7-13 år, autism-spektrum-tillstånd).</p>	<p>Uppdaterad SÖ behövs.</p>

		<p>participant from these studies would increase their repertoire of social skills from 123 to 147 after participating in the social skills group, which is a clinically significant increase.”</p> <p>“This review is not without limitations, however. It includes only five studies with relatively small sample sizes that evaluated different social skills group curricula and assessed effects using different measures of social competence and a narrow range of additional outcomes. Given these limitations, we cannot formulate specific practice guidelines on the characteristics of the most successful social skills groups.”</p> <p>“The results of this review suggest much work remains to be done in establishing the efficacy of social skills group</p>		
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		<p>interventions. Although many quasi-experimental studies of social skills group interventions have been conducted (for example, pre-/post-treatment comparison, non-randomised group comparison), we located only five RCTs. Future research should be conducted using true experimental designs with adequate power to detect clinically important effects. Research should also focus on expanding the participant age range (that is, also including participants under 7 years of age and participants above 13 years of age) and cognitive functioning levels (that is, including individuals with below average cognitive abilities) to increase the generalizability of findings. Finally, although non-randomised studies have been conducted outside of the US, well designed RCTs are needed in settings</p>		
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		outside of the US to evaluate how well social skills group interventions work in different social and cultural contexts.”		
Schrank et al 2015 Storbritannien och Österrike [27]	<p>Personer med omfattande psykisk funktionsnedsättning/sjukdom (SMI) som är föräldrar till barn över 1 år.</p> <p>Föräldraförmåga-stödjande insatser.</p> <p>The most frequent intervention components were:</p> <p>(1) Parenting skills training, mainly focusing on managing child behaviour and</p> <p>(2) Educating parents on the impact of SMI on parenting, Home based programmes, complex community-based programmes, online programmes.</p> <p>RCT/4 st., kohortstudier utan kontrollgrupp/7 st. interventionsstudier/3 st., retrospektiv studie/1 st.</p>	<p>“This review establishes the evidence base and identifies areas for development. Based on the heterogeneity of the interventions and their findings, future interventions might offer a combination of different strategies covering a wide range of areas, such as online and face-to-face techniques or a combination of trans-diagnostic and more diagnosis specific aspects. Flexible application of these strategies will accommodate the complex and varying needs of parents with SMI. Rigorous trials should include a direct assessment of both parents and children, relevant public health outcomes, and establish long-term effects ideally until children have reached</p>	VKL: (Föräldra-förmåga-stödjande insatser, personer med SMI som är föräldrar till barn över 1 år).	Fler primärstudier behövs.

		18 years of age. More understanding is also needed about intervention components and the processes underlying the interventions. Integrating qualitative and quantitative evidence on processes and outcomes will improve our understanding on the effectiveness of complex interventions for parents with SMI.”		
Sharp et al 2014 Storbritannien [25]	Personer med Parkinson’s sjukdom. Dans. RCT/8 studier kvalitativ syntes; 5 studier kvantitativ syntes.	“Dance demonstrates short term clinically meaningful benefits in Parkinson’s disease. Future RCT’s should be well designed and determine the long-term effects of dance, which dose and type of dance is most effective and how dance compares to other exercise therapies.”	VVK: (Dans, Parkinson’s sjukdom).	
Spain et al 2017 Storbritannien [40]	Familjer som har minst en person; barn, ungdom eller vuxen, med diagnosen autism-spektrum-tillstånd. Familjeterapi (E. g. systemic therapy; structural family therapy; strategic family therapy; Milan approaches; solution-	“In spite of uncertainty about effects, it may be that family therapy is deemed clinically appropriate, either in conjunction with other prescribed treatments or as a stand-alone intervention. Decisions to	VKL: (Familjeterapi, familjer som har minst en person; barn, ungdom eller vuxen, med diagnosen autism-spektrum-tillstånd).	Fler primärstudier behövs.

	<p>focused therapy; narrative therapy; and behavioural family therapy).</p> <p>RCT, kvasi-RCT/ Inga studier inkluderade.</p>	<p>use family therapy should be made in consultation with suitably qualified multi-disciplinary professionals. Also, the use of family or systemic therapies should be informed by best practice guidance for clinical work with this population..."</p>		
<p>Storebo et al 2011 Danmark [19]</p>	<p>Barn och ungdomar mellan 5-18 år med diagnosen ADHD.</p> <p>Social färdighets-träning.</p> <p>RCT/11 st.</p>	<p>"It is not possible to recommend or refuse social skills training for children with ADHD at the moment. Parent and participant satisfaction with the treatment is rated as high and most teachers would recommend the treatment to others, but in two trials there was no difference in this outcome between the social skills training groups and the control group."</p> <p>"This review highlights the need for more standardised treatment interventions that can be investigated in more high quality trials, with low risk of bias and with sufficient</p>	<p>VKL: (Social färdighets-träning, barn och ungdomar 5-18 år, ADHD).</p>	<p>Uppdaterad SÖ behövs.</p>

		numbers of participants, investigating the effects of social skills training versus no training for children as well as adolescents with ADHD. There is a need for pre published protocols, which could help with the problem with multiple outcomes and the difficulty of identifying the primary outcomes and the secondary outcomes.”		
Sukhodolsky et al 2013 USA [43]	Barn med diagnosen autism-spektrumtillstånd (high-functioning). Kognitiv beteende-terapi. RCT/8st.	“Eight randomised controlled studies of CBT for anxiety in children and adolescents with ASD were located and yielded significant effects of CBT relative to waitlist or TAU control conditions. Parent ratings and clinician assessments of anxiety but not child self-reports of anxiety were sensitive to treatment change. Future studies should evaluate CBT for anxiety against attention control conditions in samples of children with ASD that are well characterized with regard to ASD diagnosis	VVK: (Kognitiv beteendeterapi, barn med diagnosen autismspektrum-tillstånd (high-functioning)).	

		and co-occurring anxiety symptoms.”		
Tate et al 2014 Australien [27]	<p>Vuxna med förvärvad (traumatic) hjärnskada.</p> <p>Socialt- och fritidsinriktade aktivitetsprogram (E. g. door fitness/adventure programmes, leisure education, contingency management, individually brokered leisure services).</p> <p>RCT 2 st, non-RCT 1 st, Fallseriestudie 5 st, single case design 1 st.</p>	<p>“In summary, this systematic review identified nine studies evaluating interventions to increase leisure/social activity in people with TBI. But only two studies (one RCT and one controlled but nonrandomised clinical trial) had sufficient scientific rigour to provide a valid evaluation of the intervention. Although the studies evaluated different interventions (Tai Chi Qigong vs. outdoor adventure experience and goal setting), both studies showed significant between-group differences in mood (Tai Chi Qigong) and quality of life (outdoor adventure and goal setting) favouring the experimental group. They therefore provide support for the conclusion that active leisure programmes improve psychological wellbeing in people with TBI. In spite of these</p>	VVK: (Socialt- och fritidsinriktade aktivitetsprogram, vuxna med förvärvad (traumatic) hjärnskada).	

		positive studies, the evidence base is limited and there is a need for a larger number of better-designed studies. “		
Tsang et al 2016 Hong Kong [21]	<p>Personer med omfattande psykisk funktionsnedsättning/sjukdom.</p> <p>Terapeutiska insatser (Psychoeducation approach with inclusion of a combination of other components such as CBT, social skills training, goal attainment program, and narrative therapy).</p> <p>RCT 7 st, CT 3 st, Okontrollerade studier 4 st.</p>	<p>“Most programs we reviewed showed significant effects in reducing internalized stigma. As an emerging area, studies were still limited. The programs are implemented by professionals including clinicians, psychiatric nurse, social worker, and non-professionals who are trained according to the program manuals. Among different intervention approaches, psychoeducation seems to be more promising and two novel techniques (i.e., coming out proud and photovoice) deserve more attention. In future, more innovative approaches to reducing internalized stigma should be developed and more RCTs on particular intervention components using</p>	VVK: (Terapeutiska insatser, personer med omfattande psykisk funktions-nedsättning/sjukdom).	

		standard outcome measure should be conducted so that meta-analysis could be conducted, and effects of the intervention could be compared. All of the above adds to evidence-based practice in internalized stigma reduction.”		
Westbrook et al 2015 USA [6]	<p>Ungdomar och unga vuxna 14-22 år med diagnosen autismspektrum-tillstånd.</p> <p>Insatser avseende övergång mellan skola och arbetsliv.</p> <p>RCT, kvasi-RCT, single-subject experimental design.</p> <p>Inga (0) studier identifierades.</p>	<p>“This review intended to identify elements of a school-to-work transition program that implemented interventions designed to meet the specific transition needs of individuals with ASD. The available data for drawing a “what works” conclusion did not serve as a foundation for the authors to determine the effectiveness of interventions in approaching job searching, job placement, or on-the-job supports such as job coaching to achieve successful employment outcomes for transition program participants with ASD. The scientific quality of the available studies is weak and generally do not</p>	VKL: (Insatser avseende övergång mellan skola till arbetsliv, ungdomar och unga vuxna 14-22 år, autism-spektrum-tillstånd).	Uppdaterad SÖ behövs

		utilize comparison group study designs. In addition, as stated earlier, studies do not link transition interventions to successful employment outcomes for subjects.”		
Weston et al 2016 Storbritannien [41]	<p>Barn, ungdomar och vuxna med diagnosen autismspektrum-tillstånd.</p> <p>Individuell eller gruppbaseade kognitiv beteendeterapi (KBT).</p> <p>RCT, qvasi-RCT.</p> <p>48 studier.</p>	<p>“The results of the meta-analysis indicated that cognitive behavioural therapy (CBT) is associated with a small to medium effect size when used to treat co-morbid affective disorders with children, adolescents, or adults who have ASDs, but this varied according to whether the outcome data was taken from self-report, informant-report, clinician-report, or task-based measures.”</p> <p>“Turning to consider CBT for symptoms associated with ASDs, the findings from the meta-analysis were very similar to that found for CBT when used to treat co-morbid affective disorders.”</p>	VVK: (Individuell eller gruppbasead KBT, barn, ungdomar och vuxna, autism-spektrum-tillstånd).	

<p>Virues-Ortega et al 2013 Kanada och Spanien [29]</p>	<p>Barn, ungdomar och vuxna med diagnosen autismspektrumtillstånd.</p> <p>Tydliggörande pedagogik/ TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children).</p> <p>Jämförande studier med före- och eftermätning.</p> <p>13 studier.</p>	<p>“In summary, the present meta-analysis suggests that: (a) TEACCH effects over perceptual, motor, verbal and cognitive skills may be of small magnitude, (b) effects over adaptive behavioral repertoires including communication, and activities of daily living may be within the negligible to small range; (c) effects over social behavior and maladaptive behavior may be moderate to large; (d) the evidence base currently available does not allow to identify specific characteristics of the intervention (duration, intensity, and setting) and the target population (developmental age) that could be driving the magnitude of effects; and (e) effects are, in general, replicated across age groups, although the magnitude and consistency of intervention effects are greater among school-age children and adults.”</p>	<p>VVK: (TEACCH, barn, ungdomar och vuxna med diagnosen autism-spektrumtillstånd).</p>	
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		<p>“...it is important to acknowledge that these preliminary conclusions are grounded in very limited data.”</p> <p>“... our conclusions should be considered preliminary.”</p>		
<p>Ziviani et al 2012 Australien [15]</p>	<p>Barn och ungdomar (0-15 år) som inte bor med förälder/vårdnadshavare (placerade barn och ungdomar):</p> <ul style="list-style-type: none"> • Med en komplex problembild av psykologisk och/eller beteendemässig karaktär • Med funktions-nedsättning <p>Fostering Individualized Assistance Program (FIAP) Beteendearikad träning i liten grupp (Small group training on challenging behaviour management) Parent-child interaction therapy (PCIT).</p> <p>RCT, CT, kohortstudier.</p> <p>4 studier, men ingen av dem omfattade barn med funktions-nedsättning.</p>	<p>“The authors originally aimed to review studies of CYP with behaviour issues related to, or secondary to, disability, in out-of-home care. As no studies of CYP with disabilities were identified, and given the additional support needs of these CYP, research pertaining to this group would be highly beneficial.”</p>	<p>VKL: (FIAP, beteende-inriktad träning i liten grupp, PCIT, placerade barn och ungdomar med en komplex problembild av psykologisk och/eller beteendemässig karaktär med funktions-nedsättning).</p>	<p>Uppdaterad SÖ behövs</p>

<p>Zwi et al 2011 Storbritannien och Danmark [45]</p>	<p>Föräldrar till barn (5-18 år) med diagnos avseende hyperaktivitet, ADHD eller ADD.</p> <p>Beteende- och kognitivt inriktad föräldrautbildning genomförd i grupp, individuellt eller inom ramen för parrelation. RCT, kvasi-RCT.</p> <p>5 studier.</p>	<p>“There is some indication that parent training may have a positive effect on difficulties experienced by children with ADHD, particularly in terms of general behaviour.”</p> <p>“However, data concerning ADHD specific behaviour are more ambiguous.”</p> <p>“Overall, data from this review do not provide sufficiently strong evidence on which to base recommendations for practice.”</p>	<p>VKL: (Beteende- och kognitivt inriktad föräldrautbildning genomförd i grupp, individuellt eller inom ramen för parrelation., beteende relaterat till ADHD, barn, ADHD).</p> <p>VVK: (Beteende- och kognitivt inriktad föräldrautbildning genomförd i grupp, individuellt eller inom ramen för parrelation., generellt beteende hos barn, ADHD).</p>	<p>Uppdaterad SÖ behövs</p>
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Tabell 4.3 Sammanfattande tabell med vetenskapliga kunskap och de vetenskapliga kunskapsluckor som identifierats i Tabell 4.2, samt vetenskapliga kunskapsluckor för de insatsområden och funktionsnedsättningsgrupper där inga systematiska översikter av medelhög eller hög metodologisk kvalitet identifierats.

Insatsområde	Psykisk funktionsnedsättning	Neuropsykiatrisk funktionsnedsättning	Intellektuell funktionsnedsättning	Sensorisk funktionsnedsättning	Fysisk funktionsnedsättning	Dyslexi, dyskalkyli, språknedsättning	Flera olika funktionsnedsättningar
Arbete, sysselsättning, fritidsinriktade insatser	VVK [5] (a) (uppdaterad SÖ) VVK [7]	VVK [4] VKL [6] (uppdaterad SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Autonomirelaterade insatser	VKL (nya SÖ)	VKL (nya SÖ) [8] (b)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Beteendearbetande insatser	VKL [15] (uppdaterad SÖ)	VVK [10] VVK [11] (uppdaterad SÖ) VKL [15]	VKL [9] (fler primärstudier) VKL [15] (uppdaterad SÖ)	Fastställs inte	Fastställs inte	Fastställs inte	Fastställs inte

		(uppdaterad SÖ) [12] (c) [14] (c)	[16] (c)				
Boende- relaterade insatser	VKL [18] (uppdaterad SÖ)	VKL (nya SÖ)	VKL (nya SÖ) [17] (b)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Delaktighets, socialt främjande insatser	VVK [21]	VVK [4] VVK [10] VVK [20] VKL [19] (uppdaterad SÖ) VKL [20] (uppdaterad SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Fysiska insatser	VKL (nya SÖ)	VKL [4] (fler primärstudier)	VVK [24] VKL [23]	VKL (nya SÖ)	VVK [25]	Fastställs inte	Fastställs inte

		VKL [22] (fler primärstudier)	(fler primärstudier)				
Föräldra- förmåga- främjande insatser	VKL [27] (fler primärstudier)	VKL (nya SÖ)	VKL [26] (uppdaterad SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Kognitiva insatser	VKL (nya SÖ)	VVK [10] VVK [11] (uppdaterad SÖ) VKL [28] (uppdaterad SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte	Fastställs inte	Fastställs inte
Kommunika- tionsinriktade insatser	Fastställs inte	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	VKL (nya SÖ)	Fastställs inte
Motivations- inriktade insatser	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Pedagogiska insatser	VVK [21] VKL [31]	VVK [29] VVK [30]	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte

	(fler primärstudier)	VKL [28] (uppdaterad SÖ)					
Personlig assistans	VKL (nya SÖ)	VVK [32] (barn och ungdomar) (uppdaterad SÖ) VKL (vuxna) (ny SÖ)	VVK [32] (barn och ungdomar) (a) (uppdaterad SÖ) VKL (vuxna) (ny SÖ)	VKL (nya SÖ)	VVK [35] (vuxna) (a) (uppdaterad SÖ) VKL [33] (barn och ungdomar) (uppdaterad SÖ)	VKL (nya SÖ)	VVK [36] (vuxna med både fysisk och intellektuell funktionsnedsättning) (a) (uppdaterad SÖ) VVK [37] (äldre vuxna) (a) (uppdaterad SÖ) VKL [34] (barn och ungdom med både fysisk och intellektuell funktionsnedsättning) (uppdaterad SÖ)

Psykosociala insatser	VVK [21]	VVK [10]	VVK [11]	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
	VKL [15] (uppdaterad SÖ)	VVK [39]	VVK [36]				
	[42] (d)	VVK [41]	VKL [6] (uppdaterad SÖ)				
		VVK [43]					
		VKL [15] (uppdaterad SÖ)					
		VKL [38] (uppdaterad SÖ)					
		VKL [40] (fler primärstudier)					
Sensoriska insatser	Fastställs inte	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte	Fastställs inte
Stöd från anhöriga eller andra närstående	VKL (nya SÖ)	VVK [11] (uppdaterad SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
		VVK [44]					

		(uppdaterad SÖ) VVK [45] VKL [4] (fler primärstudier) VKL [38] (uppdaterad SÖ) VKL [45] (uppdaterad SÖ) [8] (b)					
Transport-relaterade insatser	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
Hälsa-relaterade insatser	VKL (nya SÖ)	VKL (nya SÖ)	VVK [9] [16] (c)	VKL (nya SÖ)	VKL (nya SÖ)	Fastställs inte	Fastställs inte
VKL = Vetenskaplig kunskapslucka (åtgärd). Åtgärd = uppdaterad Systematisk översikt (SÖ) behövs, fler primärstudier behövs; VVK = Viss vetenskaplig kunskap finns (åtgärd i de fall litteratursökningen är äldre än 2014). Åtgärd= uppdaterad Systematisk översikt (SÖ) behövs							

[referens]

(a) = Uppdaterad systematisk översikt (SÖ) kan behövas då litteratursökningen är äldre än 2014. Kunskapsläget kan vara förändrat.

(b) = För systematisk översikt (SÖ) baserad på kvalitativa data fastställs inte VVK/VKL.

(c) = För systematisk översikt (SÖ) baserad på originalstudier med studiedesign före- och efterstudie med en eller ett fåtal studiedeltagare (single case studies) fastställs inte VVK/VKL.

(d) = VVK/VKL fastställs inte då resultaten är deskriptiva till viss del.



Bilaga till rapport:

Funktionstillstånd och funktionshinder – kunskapsläget för arbetsmetoder och insatser

Identifiering av vetenskaplig kunskap och kunskapsluckor utifrån systematiska översikter

SBU Kartläggare • Rapport 305/2019

Bilaga 8 Sammanfattning av innehållet i identifierade relevanta systematiska översikter med medelhög och hög kvalitet.

Table 1 Main characteristics of included systematic reviews with high or moderate study quality.

Author Year Country Reference	Objectives of the systematic review	Inclusion criteria for the systematic review	Characteristics of the studies included in the systematic review	The conclusions of the systematic review's author
Ali et al 2015 UK [1]	Objectives: To evaluate the efficacy of behavioural and cognitive-behavioural interventions on outwardly directed aggressive behaviour in people with intellectual disabilities when compared to standard intervention or wait-list controls.	Population: Children and adults with intellectual disabilities (mild-to-severe/ profound) who exhibit aggressive behaviour. We considered studies of participants with pervasive developmental disorders, such as autism, if they stated that the participants also met criteria for intellectual disabilities by some standardised measure or were recorded as having been assessed in the past. We also include studies where participants had other comorbid conditions in addition to intellectual disabilities and	Characteristics of included studies: 6 studies. Country of origin: Four studies were conducted in the United Kingdom (UK), and the remaining two in the United States of America (USA). Participants: One study included only men and, in all studies, apart from one, the majority of participants were men. All studies focused on adults, only one study included participants aged 17 years. The mean ages were 23.1 and 23.4 for control and treatment arms respectively in two studies. One study reported a median age	“The existing evidence on the effectiveness of behavioural and cognitive-behavioural interventions on outwardly-directed aggression in children and adults with intellectual disabilities is limited. There is a paucity of methodologically sound clinical trials and a lack of long-term follow-up data. Given the impact of such behaviours on the individual and his or her support workers, effective interventions are essential. We recommend that randomised controlled trials of sufficient power are carried out using primary outcomes

		<p>aggressive behaviour if it was possible to extract data on aggressive behaviour as distinct from other symptoms. We exclude studies where the participants had an adult-onset organic brain disorder such as dementia. In this updated version of the review, we include syndromes associated with an aggressive behavioural phenotype such as Prader-Willi syndrome, Williams syndrome, fragile X syndrome, and tuberous sclerosis, as studies of interventions targeting these behaviours may have been completed and published in the interim. We decided to include these syndromes in this update as people with aggressive behavioural phenotypes are often the most difficult to treat, and the evidence base for the management of aggressive behaviour in these people is limited. Including these participants in the review would therefore increase the generalisability of the results and</p>	<p>of 38 years. Ethnicity was only available for two studies, with both reporting a majority of white participants.</p> <p>DSM/ICD/Disability: The majority of included studies focused on participants with mild intellectual disabilities.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: One study compared modified relaxation training, four studies compared cognitive-behavioural treatment, one study compared a mindfulness-based approach.</p> <p>Outcome: Reduction in aggressive behaviour (frequency/severity of, improved ability to control anger, improvement in adaptive functioning, improvement of mental state, improvement in quality of life, frequency of service utilization (and costs).</p> <p>Study design: RCT</p> <p>Follow-up time: Follow-up data for both control and</p>	<p>that include reduction in outward-directed aggressive behaviour, improvement in quality of life, and cost effectiveness.”</p>
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		<p>help clinicians to make better decisions about the treatment of people with aggressive behaviour and intellectual disabilities, including those with behavioural phenotypes.</p> <p>Intervention:</p> <ol style="list-style-type: none"> 1. Behavioural modification interventions, e.g. differential reinforcement of other behaviour, applied behavioural analysis (ABA), positive behaviour support (PBS). 2. Cognitive-behavioural treatment, e.g. anger management, problem-solving skills training, relaxation, and meditation or 'mindfulness'. <p>Comparison/control:</p> <p>Standard intervention or wait-list controls.</p> <p>Outcome:</p> <p><i>Primary outcomes:</i></p> <ol style="list-style-type: none"> 1. Education in aggressive behaviour (frequency/severity of incidents). 2. Improved ability to control anger. 	<p>treatment groups were available for only two studies: One study followed up participants for four months and the other provided follow-up data at 10 months.</p> <p>Number of participants:</p> <p>The total number of participants from the six included studies was 309. The number of participants in each study ranged from 12 to 179.</p>	
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		<p>3. Improvement in adaptive functioning.</p> <p>4. Adverse effects, such as death, or side effects from treatment.</p> <p><i>Secondary outcomes:</i></p> <p>1. Improvement of mental state.</p> <p>2. Reduction in (additional) medication.</p> <p>3. Reduction in care needs.</p> <p>4. Improvement in quality of life.</p> <p>5. Frequency of service utilisation (and costs if available).</p> <p>Study design: Randomised controlled trials (RCTs) or quasi-randomised controlled trials (q-RCTs).</p> <p>Settings: We did not restrict interventions to specific settings but covered hospitals, community day centers, and individuals' own homes.</p> <p>Other criteria: We did not examine interventions provided to carers (e.g. parent training), unless carers were</p>		
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		involved in the delivery of the intervention to individuals with intellectual disabilities.		
		Studies published: Up to 2014.		
Bee et al 2014 UK [2]	<p>Objectives: To provide a systematic and descriptive overview of all the evidence for community-based interventions for improving quality of life (QoL) in children and adolescents of parents with severe mental illness (SMI), with specific reference to intervention format and content, participant characteristics, study validity and QoL outcomes measured</p> <p>To examine the clinical effectiveness of community-based interventions in terms of their impact on a range of predetermined outcomes, particularly those likely to be associated with QoL for children and</p>	<p>Population: Children or adolescents aged ≤ 18 years of age and/or the parents of these children. To be eligible for inclusion, ≥ 50% of the sample had to have a serious parental mental illness (SMI) as defined by a current or lifetime clinical diagnosis or comparable symptom profile.</p> <p>SMI was defined to include schizophrenia and schizoaffective disorder, puerperal and non-puerperal psychosis, borderline personality disorder and personality disorder, with or without substance misuse and other mental health to morbidities. Severe unipolar depression and severe postnatal depression were also included.</p> <p>Intervention: Any community-based (i.e. non-residential)</p>	<p>Characteristics of included studies: 57 studies included in one or more syntheses.</p> <p><u>Synthesis 1 (> 50% SMI) 11 studies:</u> Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled. Cost-effectiveness: 0 Acceptability: 10</p> <p><u>Synthesis 2 (> 50% severe depression) 41 studies:</u> Clinical effectiveness: 26 RCTs, 4 non-RCTs, 11 uncontrolled Cost-effectiveness: 1 nRCT. Acceptability: 37</p> <p>Country of origin: <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) 5 studies were conducted in the USA, 4 studies were conducted in Australia, 1 in UK, and 1 in Canada.</p>	<p>Conclusions: “Evidence for community-based interventions to enhance QoL in children of SMI parents is lacking. The capacity to recommend evidence-based approaches is limited. Rigorous development work is needed to establish feasible and acceptable child- and family-based interventions, prior to evaluating clinical effectiveness and cost-effectiveness via a randomised controlled trial (RCT). A substantial programme of pilot work is recommended to underpin the development of feasible and acceptable interventions for this population. Evaluations should incorporate validated, child-centred QoL outcome measures, high-quality cost data and nested, in-depth acceptability</p>

<p>adolescents of parents with SMI.</p> <p>To examine, when possible, potential associations between intervention effect and delivery including intervention format and content, prioritisation of child outcomes, child age group, parental mental health condition, family structure and residency.</p> <p>To explore all available data relating to the acceptability of community-based interventions intended to improve QoL for children and adolescents of parents with SMI, with specific reference to intervention uptake, adherence and patient satisfaction (data on the acceptability studies not reported in this table).</p> <p>To assess key factors influencing the acceptability of and barriers to the</p>	<p>psychological or psychosocial intervention that involved professionals or paraprofessionals and parents or children, for the purposes of changing knowledge, attitudes, beliefs, emotions, skills or behaviours related to health and well-being.</p> <p>Comparison/control: Comparisons of two or more active interventions or of an active treatment with a 'no treatment' comparator were included. The 'no treatment' category extended to include waiting list controls, delayed treatment and usual care management.</p> <p>Outcomes: <i>Primary outcomes:</i> Validated measures of children's: 1. Quality of life (QoL) and/or 2. Emotional well-being</p> <p><i>Secondary outcomes:</i> Children's 1. Physical health. 2. Safety. 3. Social function. 4. Self-esteem. 5. Mental health.</p>	<p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) 11 studies were conducted in the USA, 4 studies were conducted in Australia, 4 in UK, 3 in Canada and 1 in France, Pakistan, Chile and Sweden respectively.</p> <p>Participants (n of studies): <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) All mothers (4), fathers (0), Mixed (60-75 % female) (3), Not reported (4).</p> <p>Child age range: 0-5 years (4), 6-12 years (8), 13-16 years (4).</p> <p>Child gender: <75 % female (6), Not reported (5).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs). All mothers (21), Mixed (>50 % female) (4), Unclear, not reported (1).</p> <p>Child age range: 0-5 years (4), 6-12 years (8), 13-16 years (4).</p>	<p>studies. New age-appropriate instruments that better reflect the life priorities and unique challenges faced by children of parents with SMI may need to be developed."</p>
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	<p>delivery and implementation of community-based interventions for improving QoL in children and adolescents of parents with SMI (data on the acceptability studies not reported in this table).</p> <p>To provide a systematic and descriptive overview of all the economic evidence for community-based interventions for improving QoL in children and adolescents of parents with SMI, with specific reference to intervention resources, cost burden, study validity, method of economic evaluation and economic outcomes measured.</p> <p>To examine the cost-effectiveness of community-based interventions in improving QoL for children and adolescents of parents with SMI</p>	<p>6. Literacy. 7. Coping skills. 8. Family function. 9. Parental mental health symptoms.</p> <p>Study design: Priority was given by the authors to the systematic review to those designs in which a comparator or control group was present, i.e. RCTs, quasi-RCTs and controlled observational studies (e.g. case-control studies).</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2012.</p>	<p>Child gender: <75 % female (6), Not reported (5).</p> <p>DSM/ICD/Disability (n of studies): <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) Parent diagnosis Psychosis/psychotic Symptoms (5), Schizophrenia and related (5), Bipolar disorder (6), Personality disorder and Related (5).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) Severe depression diagnosis 100 % (17), >=75 %-99 % (5), >=50%-74 % (2), Unclear, judged on symptom scores (2).</p> <p>Comorbidity or factors that may affect the outcome: <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) Other diagnosis in the sample: MDD (2), Postnatal depression (1), Depression (3), Depression/Anxiety (2), Depression/PTSD 1).</p>	
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	<p>using a decision-analytic model.</p> <p>To identify, from the perspective of the UK NHS and personal social services, research priorities and the potential value of future research into interventions for improved QoL in this population.</p>		<p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs). Other diagnosis in the sample, Minor affective disorders (7), Bipolar (1), Schizophrenia-affective disorder (1).</p> <p>Intervention (n of studies): <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled).</p> <p>Model: Psychoeducation (6), Psychotherapy (5), Extended care (4).</p> <p>Delivery: Face-to-face (15), Individual (6), Group (11).</p> <p>Session duration: Up to one hour (5), 1-2 hours (3), > 2 hours to 1 day (4), Not reported/Not applicable (3).</p> <p>Session frequency: Two or more times a week (4), Weekly (7), Fortnightly (1), Not reported/Not applicable (3).</p> <p>Total duration: Up to 8 weeks (4), 9-16 weeks (6), Up to 1 year (3), > 1 year (1), Unclear/not reported (1).</p>	
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			<p>Total scheduled contact: 11-15 hours (2), 16-20 hours (5), > 26 hours (4), Not reported/not applicable (4).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs)</p> <p>Model: Psychoeducation (6), Psychotherapy (30), Extended care (1), Psychosocial (1).</p> <p>Delivery: Face-to-face (37), Non-face to face (1), Individual (1), Group (13).</p> <p>Session duration: Up to one hour (14), 1-2 hours (11), Not reported/Not applicable (15).</p> <p>Session frequency: Weekly (22), Variable (5), Not reported/Not applicable (11).</p> <p>Total duration: Up to 8 weeks (11), 9-20 weeks (19), 6 months to 1 year (5), 1 year (1), Unclear/not reported (3).</p> <p>Total scheduled contact: 0-11 hours (11), 12-20 hours (7), > 20 hours (5),</p>	
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			<p>Not reported/not applicable (15).</p> <p>Comparison/control (n of studies): <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) Waiting list (2), Standard care (3), Active intervention (3).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) Waiting list (5), Standard care (16), Active intervention (9).</p> <p>Outcome (n of studies): <u>Synthesis 1 (> 50% SMI) 11 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled) Parent well-being (1), Parent relationship (3), Children well-being (7), Hybrid/dual focus (4).</p> <p><i>Primary outcomes:</i> <u>Synthesis 1 (> 50% SMI) 7 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs) Quality of Life (1), Emotional well-being (2)</p> <p><i>Secondary outcomes:</i></p>	
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			<p><u>Synthesis 1 (> 50% SMI) 7 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs) Physical health (0), Safety (0), Social function/behaviour (5), Social relationship quality (2), Recreational engagement (1), Family function (2), Parent-child relationship (4), Parent mental health symptoms (2), Cognitive function (4), Problem-based coping (3), Mental health literacy (1), Self-esteem (2).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs).</p> <p><i>Primary outcomes:</i> QoL Emotional well-being.</p> <p><i>Secondary outcomes:</i> Physical health (1) Safety (0) Social function/behaviour (12) Social relationship quality (1), Recreational engagement (1), Family function (2), Parent-child relationship (8), Parent mental health symptoms (19),</p>	
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			<p>Cognitive function (5), Problem-based coping (0), Mental health literacy (1), Self-esteem (2).</p> <p>Study design: <u>Synthesis 1 (> 50% SMI) 11 studies:</u> Clinical effectiveness: 3 RCTs, 4 non-RCTs, 4 uncontrolled.</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies):</u> Clinical effectiveness: 26 RCTs.</p> <p>Follow-up time (n of studies): <u>Synthesis 1 (> 50% SMI) 7 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs) 0–6 months (4) 7–12 months (2) > 12 months (2).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) 0–6 months (23) 7–12 months (6) > 12 months (5).</p> <p>Settings (n studies) 7 studies: <u>Synthesis 1 (> 50% SMI):</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs) Home (2), Community (4), Clinic (5), Unclear/not reported (4).</p>	
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			<p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) Home (9), Community/Clinic (18), Mixed (5), Unclear/not reported (6).</p> <p>Number of participants (n studies): <u>Synthesis 1 (> 50% SMI) 7 studies:</u> (Clinical effectiveness: 3 RCTs, 4 non-RCTs) Sample size at baseline: n=0-25 (2), n=26-50 (4), n=50+ (2).</p> <p><u>Synthesis 2 (> 50% severe depression) 26 studies:</u> (Clinical effectiveness: 26 RCTs) Sample size at baseline: n < 50 (9), n=50-100 (8), n=100+ (6), n=200+ (3).</p> <p>Economic evaluation: <u>Synthesis 2 (> 50% severe depression) 1 study:</u> The study was a cost-effectiveness analysis of psychiatric day hospital compared with routine primary care for the treatment of postnatal depression, carried out as part of a non-randomised prospective cohort study.</p>	
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<p>Bjornstad et al 2005 UK [3]</p>	<p>Objectives: To determine whether family therapy will reduce symptoms of inattention, impulsivity and hyperactivity for children with ADHD or ADD when compared to no treatment or standard treatment.</p>	<p>Population: Children or adolescents as defined by triallists, with diagnoses of ADHD or ADD as determined by DSM-III or DSM-IV criteria, diagnoses of Hyperkinetic Disorder as determined by ICD-9 or ICD-10 criteria, or a cut-off score on a well-validated assessment measure (e.g. Conners' Parent Rating Scale). Diagnoses must have been based on symptoms from at least two settings. Definition of 'child' or 'adolescent' was left up to the triallists to account for cultural differences in these definitions. Participants may have had comorbid diagnoses, given the substantial prevalence of comorbid diagnoses which ADHD such as Oppositional Defiant Disorder or Conduct Disorder. Children must not be taking medication for their symptoms during the trials.</p>	<p>Characteristics of included studies: 2 studies.</p> <p>Country of origin: Not stated</p> <p>Participants: <u>Study 1:</u> Age: M=8.27 years (SD= 1.37)</p> <p><u>Study 2:</u> Ages 7-9.9 years. 465 Males, 114 Females.</p> <p>DSM/ICD/Disability: <u>Study 1:</u> Diagnosed with ADHD using standard teacher and parent report measures and a clinical interview plus psychometric testing.</p> <p><u>Study 2:</u> Meeting DSM-IV criteria for ADHD Combined Type.</p> <p>Comorbidity or factors that may affect the outcome:</p> <p><u>Study 1:</u> Eight participants were also diagnosed with comorbid conduct disorder and 46 were also diagnosed with comorbid oppositional defiant disorder.</p> <p><u>Study 2:</u> Not excluded for comorbid diagnoses.</p>	<p>Conclusions: "Further research examining the effectiveness of family therapy versus a no-treatment control condition is needed to determine whether family therapy is an effective intervention for children with ADHD. There were no results available from studies investigating forms of family therapy other than behavioural family therapy."</p>
<p>Interventions: Family therapy interventions which include functional</p>				

		<p>family therapy, cognitive-behavioural family therapy, or behavioural family therapy, all of which must include components with at least one parent and the child participating in some therapy sessions with therapist were included.</p> <p>Comparison/control: No treatment or standard treatment.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Incidence or severity of symptoms of inattention, impulsivity, and hyperactivity.</p> <p><i>Secondary outcomes:</i> 1. Attentional problems and impulsive or disruptive behaviour at home or at school, or both.</p> <p>2. School expulsions, grades in school, or juvenile offending were also considered.</p> <p>3. Any assessments of participant satisfaction with treatment and adverse effects were included when available.</p>	<p>Intervention: <u>Study 1:</u> Behavioural treatment: Behavioural parent training plus child self-control training including at-home practice and reinforcement of skills (N=). Other groups received high or low doses of stimulant medication with or without family therapy (N=). Controls received medication placebo only (N=).</p> <p><u>Study 2:</u> Behavioural Treatment: parent training, child-focused treatment, and school-based intervention (N= 144).</p> <p>Control: Community care group received various treatments in their communities, often including medication (N= 146). Other treatment groups not relevant to this review (N=289).</p> <p>Outcome: <u>Study 1:</u> Parent and teacher reports of symptoms using standard measures. Independent observations of motor activity and</p>	
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		<p>Study design: Randomised controlled trials.</p> <p>Settings: Not clearly stated.</p> <p>Other criteria: No</p> <p>Studies published: Up to 2004</p>	<p>inattention. Consumer Satisfaction Questionnaire for parent training only.</p> <p><u>Study 2</u> Parent and teacher report of ADHD symptoms, oppositional and aggressive symptoms, and social skills on standardised measures, parent, teacher, and child reports of internalising symptoms on a standardised measure, parent-child relations on a questionnaire, and academic achievement on a standardised measure. Observational data was also collected to enhance data from measures.</p> <p>Follow-up time: <u>Study 1:</u> Follow-up measures given nine months after termination of treatment.</p> <p><u>Study 2:</u> Not stated.</p> <p>Number of participants: <u>Study 1:</u> N = 196 (N =32 in treatment conditions relevant to this review).</p> <p><u>Study 2:</u> N=579 (N=290 in treatment conditions</p>	
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			relevant to this review).	
Boshoff et al 2016 Australia & UK [4]	<p>Objectives: To consolidate the literature focusing on parents' experiences of advocating for their child with ASD.</p> <p>A meta-synthesis of qualitative research was undertaken to address the following review question: How do parents of children with ASD describe their experience of advocating for their children?</p>	<p>Population: Parents to children with ASD raising a child 1-10 years. Parents own experiences of advocacy as per operational definition. Parents, mother, father, carer or caregiver. Children diagnosed with ASD, including Asperger's syndrome and pervasive developmental disorder according to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders criteria. In studies with mixed diagnoses population groups, the majority of the population (50 % or more) needed to include children with ASD to ensure that the study findings were relevant to our population of interest</p> <p>Intervention: Not applicable.</p> <p>Comparison/control: Not applicable.</p> <p>Outcomes: Parents experiences.</p> <p>Study design:</p>	<p>Characteristics of included studies: 24 studies, Qualitative interview.</p> <p>Country of origin: 12 studies were conducted in USA, 8 in Canada, 1 in China, 1 in Cyprus 1 in Israel, and 1 in Australia</p> <p>Participants: Parents to children with ASD raising a child 1-10 y</p> <p>DSM/ICD/Disability: Not reported.</p> <p>Comorbidity or that may affect the outcome: Not reported.</p> <p>Intervention: No.</p> <p>Outcome: Parents experiences.</p> <p>Follow-up time: No.</p> <p>Number of participants: 532</p>	<p>Conclusion: “The findings from 24 studies were integrated to form a more comprehensive in-depth understanding of the experience of 532 parents regarding advocating for their child with ASD. The advocacy role is described by parents as complex and intensive, with personal and societal benefits while being a challenge. At the same time, parents also articulated the enabling role of social support and also barriers to advocating for their children (such as being from a lower socioeconomic background, as well as from a different cultural background as the service provider and being less articulate). Several practice implications arise from this review, empha-sizing the need for service providers to have an understanding of the advocating role of parents and making opportunity for parents' voices to be heard during service delivery. Encouraging parents to obtain social</p>

		<p>Primary research studies with qualitative design.</p> <p>The Johanna Briggs Institute (JBI) approach to systematic reviews, which supports the review, meta-aggregation, integration and interpretation of evidence from qualitative sources to synthesize findings, was used.</p> <p>Settings: Not stated.</p> <p>Other criteria: Peer-reviewed publications.</p> <p>Studies published: Up to 2015.</p>		<p>support will assist parents with their advocacy role. Service providers need to be sensitive to parents from different cultural and language backgrounds, low socio-economic areas and less articulate parents in order to promote advocacy. Incorporating the child's, the parents' and the family's needs in intervention will promote well-being and a balanced family life.</p>
<p>Brown et al 2013 Australia [5]</p>	<p>Objectives: To evaluate the efficacy of parenting interventions on child and parent behavioural and emotional outcomes for parents of children with traumatic brain injury (TBI).</p>	<p>Population: Parents of children (up to 18 years old) with TBI.</p> <p>Intervention: Parenting intervention, which could include any program (group or individual) that taught parenting skills such as improving parenting style or managing child behaviour and/or emotions. Studies were not excluded if the intervention included other components of treatment or if it</p>	<p>Characteristics of included studies: 8 articles.</p> <p>Country of origin: USA.</p> <p>Participants: The age range of the children varied across studies, with 1 study focusing specifically on younger children and 2 focusing specifically on adolescents. Time since injury also varied across studies, the majority required that the injury had occurred within the last 18 to 24 months.</p> <p>DSM/ICD/Disability:</p>	<p>Conclusions: "Given the important role parents play in child outcome and the effectiveness of parent implemented rehabilitation programs for other skills, parenting interventions may be a powerful tool for reducing child behavioural and emotional problems after TBI and improving long-term outcomes for child and family. This systematic review has identified a limited number of studies in this area. While our results</p>

		<p>involved the child's participation as well.</p> <p>Comparison/control: Not reported.</p> <p>Outcomes: <i>Primary outcomes:</i> Child behavioural or emotional outcome and/or the study assessed parenting style or skill and/or parental coping and adjustment, and the tools of assessment were either direct observation of frequency of behaviour or standardized parent- or child-report measures.</p> <p><i>Secondary outcomes:</i> Not stated.</p> <p>Study design: RCT, pre-post design.</p> <p>Setting: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2011.</p>	<p>Parents of children with moderate to severe TBI.</p> <p>Comorbidity or factors that may affect the outcome: All included studies had the same first author.</p> <p>Intervention: Online parenting intervention and problem-solving interventions. All interventions included a component of training parents in behaviour management (i. e. a component of parenting intervention), although in the problem-solving interventions, this was not the primary focus. All interventions were conducted by clinical psychologists or graduate students in clinical psychology.</p> <p>Comparison/control: Not reported.</p> <p>Outcome: All studies used standardised parent-reported measures of aspects of child behaviour, global measures of behaviour, specific aspects of cognition and behavioural and emotional adjustment (e.g. depression, executive functioning,</p>	<p>suggest the potential usefulness and feasibility of such programs in this population, further studies involving high-quality randomized trials that isolate the unique effects of parenting interventions are required to specifically validate their use in this population.”</p>
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			<p>and antisocial behaviour). Some studies included child-reported measures of depression and executive functioning.</p> <p>Several studies also investigated the effects of the intervention on parent adjustment by using standardized measures, parenting skill through blinded observers.</p> <p>Study design: Four articles detailed 3 RCTs, and 4 articles described 3 pre-post studies.</p> <p>Follow-up time: Not clear.</p> <p>Number of participants: Sample sizes ranged from 5 to 40 families.</p>	
<p>Cerrillo-Urbina et al 2015 Spain & Chile [6]</p>	<p>Objectives: To examine the evidence for the effectiveness of Physical Exercise interventions on symptoms such as inattention, hyperactivity/impulsivity, anxiety and cognitive functions in children and adolescents with ADH</p>	<p>Population: Children and/or adolescents aged 6-18 years diagnosed with ADHD and regular medication. Type of study (RCT, in which the control group received no PE intervention). Type of intervention (PE programmes). Main outcome (we selected those studies evaluating ADHD symptoms, taking into account primary outcomes,</p>	<p>Characteristics of included studies: 8 RCT-studies, 7 evaluated Aerobic programs and 1 Yoga exercise.</p> <p>Country of origin: Not reported.</p> <p>Participants: Children and/or adolescents aged 6-18 years diagnosed with ADHD and 249 children diagnosed with ADHD. Subjects were diagnosed with ADHD by psychiatrists or psychologists by</p>	<p>Conclusions “Physical Exercise programmes (aerobic and yoga) weakly reduce several symptoms in children with ADHD. However, there is less evidence about the benefits of the yoga programs. The meta-analysis suggests that short-term aerobic exercises (6-10 weeks), based on several aerobic intervention’s formats, reported a moderate to large</p>

		<p>such as inattention, hyperactivity and impulsivity, and secondary outcomes that include related ADHD symptoms such as anxiety, executive function, social disorders and cognitive performance),</p> <p>Diagnostic criteria (Conners or DSM in any of its editions), and</p> <p>Language (all languages were accepted). Because of the intensity and type of exercises, programmes were categorized in aerobic and yoga (considered as complementary and alternative medicine) no restrictions on frequency or duration of training were imposed. The exclusion criteria were as follows:</p> <p>(i) Interventions in which exercise was part of a multicomponent therapy involving a combination of exercise and alternative therapy.</p> <p>(ii) Studies with a low quality (four or more high-risk bias points), and</p>	<p>clinical or using standardized instruments such as DSM III-R and DSM-IV 230 children participated in aerobic exercise and 19 in yoga</p> <p>DSM/ICD: Not reported.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Seven studies evaluated the effect of aerobic exercise in children with ADHD the mean duration of the interventions was around 5 weeks, the mean duration of sessions was 50 min, with an average frequency of two to three times per week. Intensity was monitored in the aerobic exercise by a heart rate monitor in five studies and by V02peak in one study, one study did not report intensity.</p> <p>Outcome: The benefits, symptoms or problems that have been studied were (in frequency order) attention, impulsiveness, hyperactivity, anxiety, executive function, social disorders,</p>	<p>effect on inattention, hyperactivity, impulsivity, anxiety, executive function and social disorders in children with ADHD. However, the results of this systematic review and metaanalysis should be understood with caution because of the small number of studies and the heterogeneity of their outcome measures. For this reason, more studies are required to obtain consistent clinically relevant conclusions.”</p>
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		<p>(iii) Those studies that were limited to testing the effect of exercise on improving physical ability or aerobic or gross motor. The search was conducted between 20 and 30 November 2014</p> <p>Intervention: Physical Exercise (PE) program.</p> <p>Comparison/control: No treatment in 6 studies and Education program in 2 studies.</p> <p>Outcomes: Studies evaluating ADHD symptoms, taking into account primary outcomes, such as inattention, hyperactivity and impulsivity, and secondary outcomes that include related ADHD symptoms such as anxiety, executive function, social disorders and cognitive performance.</p> <p><i>Primary outcomes:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p><i>Secondary outcomes:</i> Which one of the outcomes above considered</p>	<p>behaviour disorders, cognitive performance, emotional disorders, somatic disorders, aggressiveness, depression and sleep.</p> <p><i>Primary outcomes:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p><i>Secondary outcomes:</i> Which one of the outcomes above considered secondary not clearly stated.</p> <p>Follow-up time: Not specified.</p> <p>Number of participants: 249</p>	
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		<p>secondary not clearly stated.</p> <p>Study design: Randomised controlled trials with ADHD and regular medication): (ii) Type of study (RCT, in which the control group received no PE intervention.</p> <p>Settings: No stated.</p> <p>Other criteria: No</p> <p>Studies published: Up to 2014.</p>		
<p>Chilvers et al 2006 UK [7]</p>	<p>Objectives: Primary objective: To determine the effects of supported housing schemes versus outreach support schemes for people with severe mental disorder/s living in the community.</p> <p>Secondary objective: To determine the effects of supported housing schemes versus 'standard care' for people with severe mental disorder/s living in the community.</p>	<p>Population: Adults with 'severe mental disorder/s' however diagnosed, including those with multiple diagnoses. They had to be living alone or with a partner and/or child, but not living with their parents or extended family, and of an age where assistance other than that for the mental disorder was not likely to be needed."</p> <p>Substance abuse was not considered a severe mental disorder in its own right, but participants were eligible for inclusion if they had a problem with</p>	<p>Characteristics of included studies: No studies met the inclusion criteria.</p>	<p>Conclusions: "Dedicated schemes whereby people with severe mental illness are located within one site or building with assistance from professional workers have potential for great benefit as they provide a 'safe haven' for people in need of stability and support. This, however, may be at the risk of increasing dependence on professionals and prolonging exclusion from the community. Whether or not the benefits outweigh the risks can only be a matter of opinion in the absence of reliable evidence. There is an urgent need to investigate</p>

		<p>substance abuse in addition to a mental disorder. Learning disability was not considered a severe mental disorder and trials were excluded where the majority of clients were suffering from a learning disability. Trials where included where the clients had a physical disorder that was identified as the main reason for entry into the supported housing scheme.</p> <p>Interventions: 1. Supported housing schemes. These schemes involve a number of people with severe mental disorder/s living in self-contained accommodation on one site. Professional support staff are on-site and available during office hours at least for either individual or group social support with a minimum aim of maintenance of the tenancy. Social support may involve counselling, emotional support, information, instruction and tangible assistance.</p> <p>Comparison/control: 1." Outreach support schemes. In these</p>	<p>the effects of supported housing on people with severe mental illness within a randomised trial."</p> <p>"For people with severe mental illness. At present, the choice between dedicated supported housing schemes and outreach services is based on a combination of personal preference, professional judgement and availability of re-sources. Decisions of this nature should be made with the full understanding that no one intervention has been shown to be more effective than another in making a difference to symptoms, future use of services, quality of life or other measures of importance. Furthermore, the efficacy of supported housing remains untested. Participating in trials that test the effectiveness of such services should be encouraged.</p> <p>2. For practitioners In the absence of evidence of their relative efficacy, decisions on the</p>
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		<p>schemes people with severe mental disorder/s also live in self-contained accommodation but they do not share a site with other people with severe mental disorder/s. These people are not part of a specialised housing scheme but do receive regular (at least fortnightly) home visits by professional outreach workers for individual social support with the minimum aim of maintenance of the tenancy.”</p> <p>2. “Standard care For the purposes of the review we defined this as the normal level of psychiatric care provided in the area where the trial was conducted.”</p> <p>Outcomes: <i>Primary outcomes:</i> “1. Service utilization. 1.1 Eviction from tenancy. 1.2 Hospitalisation. 1.3 Imprisonment. 1.4 Psychiatric service contact. 2. Medical/mental state changes. 2.1 Death (including suicide). 2.2 General mental state. 2.3 Self-esteem.</p>	<p>provision of alternative forms of accommodation and continued support for people with mental illness can only be based on a combination of professional judgement, patient preference and availability. This should be made clear to the patient or client who has to make this important decision. Practitioners may wish to actively support or participate in trials to test the effectiveness of supported housing schemes for people with severe mental illness.</p> <p>3. For managers and policymakers Policies in favour of dedicated supported housing schemes should be viewed with some caution and should not be implemented without plans for evaluation using rigorous methods or should be delayed pending further evidence of their effectiveness. Forming alliances with researchers within this field may result in a fruitful collaboration that would not only</p>
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		<p>2.4 Specific symptoms including well-being.</p> <p>3.Satisfaction.</p> <p>3.1 Professional support workers' satisfaction.</p> <p>3.2 Tenant or respondent satisfaction.</p> <p>4. Social functioning.</p> <p>4.1 Employment status.</p> <p>4.2 General social function.</p> <p>5. Quality of life.</p> <p>5.1 General quality of life.</p> <p>6. Economic.</p> <p>6.1 Capital expenditure.</p> <p>6.2 Total cost of care per tenant or respondent.</p> <p>6.3 Total health costs per tenant or respondent.</p> <p>When feasible, we would have grouped the outcomes into time periods - short term (less than six months), medium term (six months - one year) and long term (over one year)."</p> <p><i>Secondary outcomes:</i> Not stated.</p> <p>Study design: Randomised controlled trials or quasi-randomised trials, where allocation to intervention was determined by, for example, day of</p>		<p>inform local policies on this issue, bur would also provide much needed evidence base on its effectiveness."</p>
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		<p>week, or alphabetical order.</p> <p>Settings: The review focuses on two types of supported housing for people with severe mental disorder/s who are living alone or with a partner and/or child: dedicated supported housing schemes and tenancies with outreach support schemes.</p> <p>Dedicated supported housing schemes involve having self-contained apartments located in one building or site, specifically for tenants with severe mental illness. Office-based professional workers are available on site, usually during office hours, to support tenants, to maintain the tenancy, and to prevent homelessness.</p> <p>Independent tenancies with outreach support schemes are 'ordinary', private, local authority or housing association tenancies with regular visits from professional outreach workers to support tenants with severe mental illness</p>		
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		<p>in order to maintain the tenancy and prevent homelessness.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2006 (second update).</p>		
<p>Coren et al 2010 UK & Sweden [8]</p>	<p>Objectives: To assess the effectiveness of parent training interventions to support the parenting of parents with intellectual disabilities.</p>	<p>Population: Parents or primary care givers with intellectual disability. and independent or shared care of one or more children aged 0-18 years</p> <p>Intervention: Parenting intervention with any theoretical background.</p> <p>Comparison/control: Usual care or control group.</p> <p>Outcomes: <i>Primary outcomes:</i> The attainment of parenting skills specific to intervention, safe home practices and understanding of child health.</p> <p><i>Secondary outcomes:</i> Parent-child interaction, parents' retention of child/return to independence care of the child, lifting of any child-related court order.</p>	<p>Characteristics of included studies: Three (3) studies.</p> <p>Country of origin: <u>Study 1:</u> Canada.</p> <p><u>Study 2:</u> USA</p> <p><u>Study 3:</u> Australia.</p> <p>Participants: <u>Study 1:</u> Mean age intervention group 25, 2 years, control group 26, 6 years.</p> <p><u>Study 2:</u> Maternal age range was 16-43 years, with a mean of 25,4 years in the intervention group and 22,6 years in the control group.</p> <p><u>Study 3:</u> Parents were aged 22-45 years with a mean age of 32 years. The mean age in the control group was 22,6 years. 40 were women and 5 were men.</p>	<p>Conclusions: “While the evidence presented here does seem promising with regard to the ability of such interventions to improve parenting knowledge and skill in this population, there is a need for larger RCTs of interventions before conclusions can be drawn about the effectiveness of parent training in this group of parents.”</p>

		<p>Study design: RCT, quasi-randomised studies.</p> <p>Setting: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2009.</p>	<p>DSM/ICD/Disability: <u>Study 1:</u> Mental retardation (WAIS-R IQ test).</p> <p><u>Study 2:</u> IQ less than 85.</p> <p><u>Study 3:</u> Intellectual disability.</p> <p>Comorbidity or factors that may affect the outcome:</p> <p>Intervention: <u>Study 1:</u> Home based individual training program focused on teaching infant and childcare skills.</p> <p><u>Study 2:</u> Support to Access Rural Services (STARS). Small groups of mothers met weekly in the community in spaces provided by local churches, with a family service worker.</p> <p><u>Study 3:</u> Home Learning Program (HLP) to equip parents with knowledge and skills to manage home dangers, accidents and child illness. Ten one-to-one sessions.</p> <p>Comparison/control: <u>Study 1:</u> Waiting list.</p>	
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			<p><u>Study 2:</u> A support intervention – monthly contacted by telephone for 12 months.</p> <p><u>Study 3:</u> Treatment as usual.</p> <p>Outcomes: <u>Study 1:</u> Observation of daily childcare routines in the home using a childcare and safety skills checklists.</p> <p><u>Study 2:</u> Maternal-child interaction using NCATS (Nursing Child Assessment Teaching Scale).</p> <p><u>Study 3:</u> Measures of child health and home safety.</p> <p>Study design: RCT/CT.</p> <p>Setting: Home.</p> <p>Follow-up time: Not clear.</p> <p>Number of participants: <u>Study 1:</u> 22 mothers of children aged 1- 23 months.</p> <p><u>Study 2:</u> 40 mothers of children aged 12-36 months.</p> <p><u>Study 3:</u></p>	
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			63 parents of whom 45 completed the study.	
Crowther et al 2001 UK & USA [9]	<p>Objectives: To determine the most effective way of helping people with severe mental illness to obtain competitive employment—that is, a job paid at the market rate, and for which anyone can apply.</p> <p>It is unclear how far prevocational training and supported employment are effective at helping people with severe mental illness to obtain competitive employment. We aimed to evaluate the effectiveness of the two approaches.</p>	<p>Population: People with severe mental illness.</p> <p>Interventions: Prevocational training and supported employment. They are different ways of helping people with severe mental illness return to work.</p> <p>Prevocational training assumes that people with severe mental illness require a period of preparation before entering into competitive employment—that is, a job paid at the market rate, and for which anyone can apply. This includes sheltered workshops, transitional employment (working in a job that is “owned” by a rehabilitation agency), work crews, skills training, and other preparatory activities.</p> <p>Supported employment places clients in competitive jobs without extended preparation and provides on the job support from trained</p>	<p>Characteristics of included studies: 11 studies.</p> <p>Country of origin: 9 studies were conducted in the USA, 1 in UK and 1 was not stated.</p> <p>Participants: Most subjects were aged 18 to 65.</p> <p>DSM/ICD/Disability: Schizophrenia, bipolar disorder, or depression with psychotic features.</p> <p>Comorbidity or factors that may affect the outcome: Supported employment versus standard care (one trial): The intervention combined supported employment with assertive community treatment. Supported employment versus prevocational training (Five trials): In one trial the intervention combined supported employment with assertive community treatment, whereas the control was standard community care.</p>	<p>“The included trials of prevocational training compared with standard community care were of limited quality, and none met the criteria for the sensitivity analysis. The data available from these trials were insufficient to make judgments on the effectiveness of prevocational training over standard community care.”</p> <p>“Only one trial compared supported employment with standard community care. Although this trial suggested that supported employment was superior to standard community care, its findings are difficult to interpret as the group receiving supported employment also received assertive community treatment.”</p> <p>“Supported employment is more effective than prevocational training at helping people with severe mental illness to obtain and keep</p>

		<p>“job coaches” or employment specialists. The core principles of supported employment are that:</p> <p>(a) The goal is competitive employment in work settings integrated into a community's economy.</p> <p>(b) Clients are expected to obtain jobs directly, rather than after lengthy pre-employment training.</p> <p>(c) Rehabilitation is an integral component of treatment of mental health rather than a separate service.</p> <p>(d) Services are based on client's preferences and choices.</p> <p>(e) Assessment is continuous and based on real work experiences, and (f) Follow on support is continued indefinitely.</p> <p>Comparison/control: Prevocational training and standard community care.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. The number of subjects in competitive employment - that</p>	<p>Funding: The research was supported by the NHS Health Technology Assessment Program (grant number 96/41/3). The views expressed in this paper are not necessarily those of this programme.</p> <p>“Competing interests: GRB has a close collaborative relationship with Bob Drake and Debbie Becker, developers of the individual placement and support model.”</p> <p>Intervention: Prevocational training versus standard care (Five trials).</p> <p>Supported employment versus standard care (One trial).</p> <p>Supported employment versus prevocational training (Five trials).</p> <p>Outcome: <i>Prevocational training versus standard care (Five trials):</i> Two trials provided data on the primary outcome of number of subjects in</p>	<p>competitive employment”</p>
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		<p>is, a job paid at the market rate, and for which anyone can apply.</p> <p><i>Secondary outcomes:</i> 1. Other employment outcomes, clinical outcomes, and costs.</p> <p>Study design: Randomised controlled trials.</p> <p>Settings: Work.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 1998.</p>	<p>competitive employment, three trials reported data on number of subjects in any form of employment.</p> <p><i>Supported employment versus standard care (One trial):</i> Competitive employment, any form of employment, participation rates and number of hospital admissions, mean monthly healthcare costs</p> <p><i>Supported employment versus prevocational training (Five trials):</i> Competitive employment (five trials), any form of employment (one trial), more hours per month in competitive employment (three trials), mean monthly earnings (four trials), self-esteem, quality of life, and severity of symptoms (two trials), programme costs and overall healthcare costs (two trials).</p> <p>Follow-up time: Prevocational training versus standard care: 3-18 months.</p> <p>Supported employment versus standard care: 12-36 months.</p>	
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			<p>Supported employment versus prevocational training: 4-28 months.</p> <p>Number of participants: Prevocational training versus standard care: 1204 subjects.</p> <p>Supported employment versus standard care: 256 subjects.</p> <p>Supported employment versus prevocational training: 491 subjects.</p>	
<p>Daley et al 2014 UK, Belgium, The Netherlands, Spain, Germany & Denmark [10]</p>	<p>Objectives: In this article, the authors build on the previous meta-analysis to address the broader impact of behavioural interventions for children with ADHD.</p> <p>They address the related questions: 1. Given that most, although not all, interventions are implemented by changes in the behaviour of responsible adults (typically parents or teachers).</p> <p>2. Do behavioural interventions improve adult responses to children with ADHD?</p>	<p>Population: Children and adolescents with ADHD, 3-18 years old and have an ADHD diagnosis (any subtype) or have met accepted cutoffs on validated ADHD rating scales.</p> <p>Intervention: Behavioural interventions were defined as those interventions directed at changing behaviours (increasing desired and decreasing undesired behaviours). They encompass classic contingency management, behaviour therapy (mainly through mediators such as parents or teachers), and cognitive</p>	<p>Characteristics of included studies: 32 studies. 31 studies had a parent-based component implemented at home. 4 had an additional school-based, teacher-focused element. 14 included direct intervention with the child</p> <p>Country of origin: Not reported.</p> <p>Population: Persons with ADHD 3-18 years old.</p> <p>DSM/ICD/Disability: Not reported.</p> <p>Comorbidity or factors that may affect the outcome: ODD</p> <p>Intervention:</p>	<p>Conclusion: “... although more evidence is required before behavioural interventions can be supported as a front-line treatment for core ADHD symptoms, the authors found evidence that they do have beneficial effects on parenting and parents’ sense of empowerment and independently corroborated effects on conduct problems in children with ADHD. Initial evidence from proximal outcomes relating to academic achievement and social skills needs to be confirmed by probably blinded analyses, and greater exploration is needed on the</p>

	<p>3. Do they improve the sense of efficacy and competence and decrease the mental health problems of adults working with children with ADHD.</p> <p>4. Do they decrease levels of child oppositional behaviour and other comorbidities and other aspects of impairment such as social skills and academic performance?</p>	<p>behaviour therapy (such as verbal self-instruction, problem solving strategies, or social skills training). The treatment search terms covered a wide variety of intervention types with the aim of including trials involving any form of behaviourally based therapies, implemented in any setting (home or school), and indirectly by an adult or directly to the child (see protocol).</p> <p>Comparison/control: control conditions were "treatment as usual," "wait list," or "active" controls.</p> <p>Outcomes: -Pre- to posttreatment changes in positive and negative parenting, -Parent mental health (e.g., anxiety, depression) - Parenting self-concept (e.g., sense of competence and efficacy), Child ADHD, conduct problems (i.e., negative and noncompliant behaviour including symptoms of oppositional defiance (ODD) and</p>	<p>Behavioural training, social skills training, CBT, behavioural and self-control training, organizational skills training, daily report card. Some in combination with medical treatment.</p> <p>Outcome: Lots of different rating scales.</p> <p>Follow-up time: Not specified.</p> <p>Number of participants: Not stated.</p> <p>Setting: Not stated.</p>	<p>moderating impact of child age on intervention outcome.</p>
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		<p>conduct disorders (CD), social skills, and academic achievement.</p> <p><i>Primary outcomes:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p><i>Secondary outcome:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p>Study design: RCTs</p> <p>Settings: Not stated.</p> <p>Other criteria: Trials involving only rare comorbid disorders (e.g., fragile X syndrome) were excluded.</p> <p>Studies published: 1989-2012</p>		
<p>Evans et al 2014 USA [11]</p>	<p>Objectives: Objectives: to critically evaluate the empirical literature of treatment studies published during the last five years and incorporate the findings with those in the Pelham and Fabiano (2008) review to: 1. Determine current levels of evidence for psychosocial interventions for</p>	<p>Population: Children and adolescents (< 18 years) with ADHD.</p> <p>Intervention: Psychosocial interventions.</p> <p>Comparison/Control: Another treatment.</p> <p>Outcomes: Not clearly stated.</p> <p>Study design: Empirical studies.</p>	<p>Characteristics of included studies: 21 studies</p> <p>Country of origin: Not reported</p> <p>Participants: Children 4-12 years old.</p> <p>DSM/ICD/Disability: Not reported</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p>	<p>Conclusion: “Consistent with the results of the previous review we concluded that behavioural parent training, behavioural classroom management and behavioural peer interventions were well established treatments. In addition, organization training met the criteria for a well-established treatment.</p>

	<p>children with ADHD, and</p> <p>2. Report and review characteristics of interventions, participants, and measures that may influence the outcomes of psychosocial treatment research.</p>	<p>Settings: Not reported.</p> <p>Other criteria: No.</p> <p>Studies published: October 2008 up to August 2013.</p>	<p>Intervention: Psychosocial interventions: Behavioural parent training, Behavioural classroom management, Behavioural peer interventions, Combined behavioural treatment studies Training Interventions: Cognitive training, Neurofeedback training, Organization Training, Combined Training</p> <p>Comparison/control: Waitlist, self-monitoring, parent-monitoring, routine care, no treatment etc.</p> <p>Outcome: ADHD symptoms, academic functioning, peer relations, family functioning, behavioural functioning, neurological or physiological performance.</p> <p>Follow-up time: Not specified.</p> <p>Number of participants: Not specified.</p>	<p>Combined training programs met criteria for Level 2 (Probably Efficacious), neurofeedback training met criteria for Level 3 (Possibly Efficacious), and cognitive training met criteria for Level 4 (Experimental Treatments).”</p> <p>“This review provides an update on the state of the science for psychosocial interventions for youth with ADHD. It highlights the innovations that have occurred in the last five years including innovations to existing well-established treatments to reach new populations, an increase in research on adolescents and preschool children with ADHD, and the development of a new category of interventions (i.e., Training Interventions). We also highlighted several critical issues to be incorporated into the next generation of research, such as attention to characteristics of participants, diagnostic procedures,</p>
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				outcome measures, and the system classifying levels of evidence.”
Fisher et al 2015 Australia [12]	Objectives: Examine the evidence underpinning family involvement in the managing of behavioural problems following ABI in the community.	Population: Family members who choose to not be caregiver to a person with ABI but find themselves in this position without skills and support needed to effectively manage behavioural problems. Individuals with ABI who were 16 years or older and sustained an ABI at 15 years or above. Intervention: Not specified more than family involvement. Comparison/control: No. Outcomes: Effects of family involvement. Study design: Inclusion limits were not placed on study design. Settings: Home and community settings. Other criteria: No. Studies published: Up to 2013	Characteristics of included studies: 10 studies. Country of origin: US (n=6), Australia (n=3), UK (n=1). Participants: 112 participants, 77 males and 35 females with mild to severe ABI. Family members involved in studies predominately included parents and spouses and were also identified as ‘relatives’, adult children and ‘other’. Information on all care givers are not available. DSM/ICD/Disability: Three studies specifically concerned participants with traumatic brain injury (TBI), and the remaining studies consisted more broadly of participants with acquired brain injury (ABI). The cause of brain injury varied significantly, with TBI resulting from motor vehicle accidents, falls, construction related accidents and assaults and ABIs resulting from meningitis, anoxia, stroke,	Conclusions: “There is limited research and lack of high evidence studies evaluating family involvement in behaviour management following ABI therefore, no conclusions can be drawn regarding its efficacy. More research is needed, with larger sample sizes and more rigorous design, including proper comparison groups.”

			<p>arteriovenous malformations, encephalopathy, electrocution, aneurysm and brain tumors. Five articles did not specify the cause of brain injury.</p> <p>Comorbidity or factors that may affect the outcome: Overall, the studies included in this review were of poor quality. The highest quality studies consisted of two level II evidence randomized controlled studies. All remaining studies consisted of level III-3 evidence studies. The inclusion of two of the studies should be viewed with caution as it was inferred that caregivers were included in the 'caregiver system', even though it was not explicitly stated that they were included in the family. The relationship of the caregiver to the individual with ABI was not specified in two studies and in one study no detail was provided regarding the involvement of paid vs. unpaid caregivers in the intervention.</p> <p>Intervention: 1. A natural setting behavioural management</p>	
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			<p>programme (NSBM) (2 studies). 3-week education phase for persons with ABI and their caregivers.</p> <p>2. Web-based interventions (3 studies). Two studies evaluated the outcome of Teen Online Problem-Solving intervention (TOPS). 16 self-directed sessions to family members.</p> <p>A web-based intervention: Six video-based conferences providing education and interactive problem solving for family members, evaluating their levels of perceived burden and satisfaction rating. Community based interventions (n=6) were family members were supported by professionals to develop individualized treatment plans in managing behavioural problems in their relatives with ABI. One study evaluated the outcome of a half day group workshop for family members of individuals with primary brain tumor.</p> <p>Comparison/control: No.</p> <p>Outcome:</p>	
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			<p>The target behaviours varied significantly across the studies, including, aggressive/inappropriate behaviour (damaging property and verbal aggression), elopement, disinhibited and potentially dangerous behaviour while driving, routine behaviours such as maintaining cleanliness of bathroom, independently collecting belongings required for day's activity and putting them away on return, communication with spouse regarding payment of bills and telephone messages, independence carrying out morning routine (including preparing breakfast, sitting at dining table and eating breakfast) and 'temper outbursts'. Six studies did not provide details regarding problem behaviours exhibited by participants.</p> <p>Outcomes measured included: observed change in targeted Behaviours, levels of burden, stress and depression experienced by family members, levels of family functioning, improved knowledge</p>	
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			<p>regarding ABI and compensatory strategies to manage behavioural/cognitive change following ABI, and satisfaction with interventions among family members/caregivers. The outcome measures varied between studies with those most utilized including: Observation of target behaviours using structure checklists, sub-scales of the Questionnaire on Resources and Stress for Families with Chronically Ill of Handicapped Members (QRS), an adapted version of the Maslach Burnout Inventory (MBI), attitudinal and satisfaction surveys, purpose designed questionnaires, and interviews.</p> <p>Study design: Two RCT studies, six single case designs, one single case design with a concurrent control group and one pre–post-test mixed-method study.</p> <p>Follow-up time: There was a lack of rigorous follow-up data specific to the improvement of target behaviours. The most reliable follow-up data was recorded</p>	
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			<p>following the RCT (Carnevale et al.) at 30 weeks post-baseline. Carnevale also collected follow-up data at 12 months post-baseline, however, the validity of these results is limited due to weak study design and data collection methods. Of the remaining four studies that collected follow-up data only one study reported on the frequency of target behaviours with data collected at 1-month post-intervention.</p> <p>Number of participants: The numbers of caregivers are only available in some of the studies. The number of persons with ABI: 112.</p> <p>Setting: Home-based, community settings, Home-based videoconferences, Training session based on knowledge of homebased interactions</p>	
Fletcher-Watson et al 2014 UK [13]	<p>Objectives: To assess the effect of interventions, based on the Theory of Mind (ToM) model, for autism spectrum disorders (ASD), on symptoms in the core diagnostic domains</p>	<p>Population: Participants of any age with a diagnosis of ASD, including autism, atypical autism, Asperger's syndrome, and PDD-NOS, according to either ICD-10 (International</p>	<p>Characteristics of included studies: 22 studies.</p> <p>Country of origin: 2 studies were conducted in Scandinavia, 2 in mainland Europe, and</p>	<p>Conclusions: “While there is some evidence that ToM, or a precursor skill, can be taught to people with ASD, there is little evidence of maintenance of that skill, generalisation</p>

	<p>of social and communication impairments in autism, and on language and ToM skills. In addition, in so doing, to test the applied value of the ToM model of autism.</p>	<p>Classification of Diseases), DSM-IV or DSM-V (Diagnostic Statistical Manual of Mental Disorders) criteria. Participants must have received a 'best estimate' clinical diagnosis, confirmed by the study authors. That is, at a minimum, diagnosis by a multidisciplinary clinical team using standard procedures with reference to the international classification systems. Use of a particular diagnostic tool, such as the Autism Diagnostic Observation Schedule (ADOS) or the Autism Diagnostic Interview (ADI-R), was desirable but not required.</p> <p>Co-morbid cases were also eligible for inclusion since these individuals are just as needful of intervention for their specifically autistic difficulties.</p> <p>Interventions: Interventions eligible for inclusion in this review</p> <ol style="list-style-type: none"> 1. Explicitly state that they are designed to teach ToM or 2. Explicitly state they are designed to 	<p>5 in UK and Ireland, 2 in far east, 9 in USA.</p> <p>Participants: Participants varied widely in age-range from preschoolers to adolescents and adults, but a majority focused on either pre-school or primary-school aged children.</p> <p>Studies with young children and preschoolers largely described participants as having 'core' autism, or ASD.</p> <p>Studies recruiting participants with high-functioning autism and/or Asperger's syndrome had participants in the adolescent and adult age-range or late childhood.</p> <p>Almost all studies included both boys and girls, though the proportion of male participants was much higher than females, corresponding to the known greater prevalence of diagnosed ASD in males. Four studies reported an all-male sample.</p> <p>Sample sizes varied from n = 10 to n= 61.</p> <p>DSM/ICD/Disability: Participants were reported as having a</p>	<p>to other settings, or developmental effects on related skills. Furthermore, inconsistency in findings and measurement means that evidence has been graded of 'very low' or 'low' quality and we cannot be confident that suggestions of positive effects will be sustained as high-quality evidence accumulates. Further longitudinal designs and larger samples are needed to help elucidate both the efficacy of ToM-linked interventions and the explanatory value of the ToM model itself. It is possible that the continuing refinement of the ToM model will lead to better interventions which have a greater impact on development than those investigated to date."</p>
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		<p>reach precursor skills of ToM, or</p> <p>3. Explicitly state that they are based on or inspired by ToM models of autism or</p> <p>4. Explicitly state that they aim to rest the ToM model of autism.</p> <p>ToM describes the ability to understand another's thoughts, beliefs, and other internal states and is encapsulated in a rest of false belief. Prior to the development of false belief understanding (at about four years old in typical development), associated precursor skills are in evidence such as joint attention, imitation, and emotion recognition. Relevant interventions include those which explicitly teach children to understand others' mental states (e.g. using visual representations of mental states) and those which use naturalistic teaching to develop imitation skills.</p> <p>All 'doses' (that is the number and length of treatment</p>	<p>range of ASD diagnoses, including autism, autism spectrum disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS), high-functioning autism (HFA), and Asperger's syndrome (AS).</p> <p>All studies reported some measure of general intellectual ability such as verbal mental age. Almost half of the included studies included a sample in the normal intellectual range and the rest reported on a sample with intellectual disability. One study split the participant group into those with and without associated intellectual delay.</p> <p>Comorbidity or factors that may affect the outcome: On the whole, very small proportions of participants failed to complete the interventions. The maximum drop-out rate was 27 % from a small sample, but many studies reported no drop-out at all.</p> <p>Intervention: 1. Interventions that explicitly state that</p>	
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		<p>sessions per week), durations, and methods were eligible for inclusion.</p> <p>Comparison/control:</p> <ol style="list-style-type: none"> 1. Treatment-as-usual/wait-list control. 2. 'Placebo' interventions, for example a 'contact control' such as watching Thomas the Tank Engine DVDs. 3. Intervention with no therapeutic content, (e.g. group leisure activities). <p>Outcomes: <i>Primary outcomes:</i> Primary outcomes at a participant symptom level:</p> <ol style="list-style-type: none"> 1. Communication: overall level of non-echoed language stereotyped or idiosyncratic use of words or phrases, pointing, gestures, conversation. 2. Social function: unusual eye-contact, facial expressions directed to others, spontaneous initiation of joint attention, shared enjoyment in interaction, quality of rapport. 	<p>they are designed to teach ToM.</p> <ol style="list-style-type: none"> 2. Interventions that explicitly state that they are designed to teach precursor skills of ToM. <p>The vast majority of studies stated that they were designed to teach precursor skills of ToM. Within this category we could also identify some common intervention targets including emotion recognition, joint attention and social communication, and imitation skills.</p> <p>Three studies reported on the use of a computer program to deliver the intervention and all of these studies had emotion recognition as the target skill. Three studies investigated the effect of a set of specially designed cartoons on emotion recognition. Eight studies investigated the effects of one-to-one therapist-led interventions and two of these used the same manualised treatment program and one was a group music therapy approach. Non-expert intervention delivery was rare with only four studies reporting</p>	
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		<p>The diagnostic domain of Restricted and Repetitive Behaviours (imaginative play or creativity, unusual sensory interests, unusually repetitive interests or stereotyped behaviours, compulsions or rituals) is not included as an expected primary outcome.</p> <p><i>Secondary outcomes:</i> Participant, direct measurement</p> <p>1. Intervention-specific: Change in targeted cognitive skill such as false-belief understanding.</p> <p>2. Change in participant behaviour or quality of interpersonal interaction, or both, measured by direct observation parent, teacher (or other individual in caring or educational relationship to the participant) report.</p> <p>3. Change in participant behaviour and skills or deficits such as: adaptive skills, school success, challenging behaviours, social participation measured by parent,</p>	<p>a parent-training element and one study reporting on teacher-training for intervention delivery in the classroom.</p> <p>Intervention durations varied widely from two or three to six months.</p> <p>Dose was more consistent, with most falling within a range of 30 minutes per week to 3.5 hours per week, and one outlying intervention which reported therapist contact time of 2.5 hours per day.</p> <p>Most studies had waitlist or treatment-as-usual control conditions.</p> <p>Six studies included control conditions, which were not expected to have an impact on intervention outcome but were included as a contact control only. These included toy play, non-synchronous one-to-one time, using art software, group leisure activities, and watching a Thomas the Tank Engine DVD.</p> <p>Outcome: On the whole, studies rarely identified a single primary outcome measure. The outcome</p>	
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		<p>teacher or other report.</p> <p>4. Acceptability of intervention (time, cost).</p> <p>Other:</p> <p>5. Intervention process measures e.g. rate of drop-out.</p> <p>6. Economic data e.g. financial cost of intervention, time commitment required.</p> <p><i>The following outcomes measures are specified for a 'Summary of findings' table:</i></p> <p>1. Symptom level, communication domain.</p> <p>2. Symptom level, social interaction domain.</p> <p>3. General communication ability (e.g. vocabulary).</p> <p>4. 'Theory of Mind' ability (e.g. false-belief test score).</p> <p>Study design: Randomised and quasi-randomised trials (defined as trials in which allocation was made by, for example, alternate allocation</p>	<p>measures used most commonly included:</p> <p>1. Recognition of emotion from a variety of stimuli, including static images of faces, static images of the eyes, film clips, short stories, and cartoons.</p> <p>2. Joint attention and joint engagement behaviours, often measured using video coding of parent-child or teacher-child interactions.</p> <p>3. Direct assessment of ToM abilities.</p> <p>4. Imitation skills.</p> <p>5. Diagnostic outcome.</p> <p><i>Also, the following additional outcome measures were reported:</i></p> <p>6. Caregiver measures such as quality of involvement, adherence to treatment, mental health or satisfaction surveys.</p> <p>7. General social skills measures, including rating scales and observation.</p> <p>8. Symbolic play measures or assessments of play variety.</p>	
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		<p>or allocation by date of birth).</p> <p>Settings: Not clearly stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2013 (apart from ASSIA which was no longer available to us.)</p>	<p>9. Language and conversational skills.</p> <p>10. fMRI (functional magnetic resonance imaging – assessment of brain activity in facial recognition areas).</p> <p>11. Adaptive function and general intellectual abilities.</p> <p>Follow-up time: Follow-up periods ranged from six weeks to five years.</p> <p>Number of participants: 695 participants.</p>	
<p>Furlong et al 2012 Ireland & UK [14]</p>	<p>Objectives: To examine the effectiveness of behavioural and cognitive-behavioural group-based parenting programmes for children with early-onset conduct problems in improving:</p> <p>a) Child behaviour outcomes, and</p> <p>b) Parenting skills and parental mental health.</p> <p>To critically appraise and summarise current evidence on the incremental</p>	<p>Population: Parents or primary caregivers of children aged 3 to 12 years who manifested either:</p> <p>(a) Conduct problems, as identified by a score above the clinical cut-off point on an outcome measure, such as the Eyberg Child Behaviour Inventory (ECBI), or</p> <p>(b) A clinical or psychiatric diagnosis of Conduct Disorder (CD) or Oppositional Defiant Disorder (ODD), or both, as classified by the Diagnostic and Statistical Manual of mental disorders (DSM-IV 2000) or the International</p>	<p>Characteristics of included studies: 13 trials (10 RCTs and three quasi-randomised trials).</p> <p>Country of origin: Five studies were conducted in the USA, one of which was located in Massachusetts and four in Seattle. Seven studies were conducted in Europe, three in various locations in the UK, one in Ireland one in Belgium, one in Norway and one in Sweden. One study was conducted in Australia.</p> <p>Participants: Participants were predominantly</p>	<p>Conclusions: "Behavioural and cognitive-behavioural group-based parenting interventions appear to be effective in improving clinically significant conduct problems, parental mental health and parenting practices, with most outcomes achieving a moderate effect size". "Although there were only two included costs studies, they showed that the Incredible Years Parenting programmes can reduce clinical levels of conduct problems to non-clinical levels for modest costs, as</p>

<p>resource use, costs and cost-effectiveness of behavioural and cognitive-behavioural group-based parenting programmes when compared to treatment as usual.</p>	<p>Statistical Classification of Diseases and Related Health Problems, 10th Revision (WHO 2009).</p> <p>Primary caregivers were of either gender and were single parents or two-parent families. Studies involving parents of children older than 12 years or younger than 3 years were only included if more than 90 % of the sample fell within the age range specified above.</p> <p>Interventions: The review evaluated structured behavioural and cognitive-behavioural group-based parenting programmes provided on a regular basis (for example, weekly or fortnightly) for at least three sessions of between one and two hours.</p> <p>Comparison/control: Control conditions of a waiting list, treatment as usual or no treatment.</p> <p>Outcomes: <i>Primary outcomes:</i> <u>(A) Child outcomes:</u></p>	<p>Caucasian (80 % to 100 % across studies) and comprised primary caregiver-index child pairs. Within three studies the primary caregiver was the mother. In six studies the primary caregiver was predominantly the mother but also involved the father in between 3 % to 17 % of the sample. Four studies obtained separate reports from both parents in cases where both parents were involved in parenting. Parents ranged in age from 18 to 57 years, with a mean age of 33 years. Four of the studies involved self-referred participants, two involved professionally referred participants, whilst the samples in the remaining seven studies included a mix of self- and professionally-referred participants, approximately one half to two thirds of whom were referred by professionals. The gender distribution of children, which was reported in all but one of the studies showed that 68.3% were boys (n = 707 boys, n = 325 girls).</p> <p>The mean age of the children across the</p>	<p>indicated above. These costs are modest, especially when juxtaposed with the potential economic benefits relating to savings of \$118.350 to \$355.100 per case in offsetting the long-term health, social, educational and legal costs associated with CD and conduct problems.”</p> <p>”Parenting programmes appear effective for parents regardless of socioeconomic status, trial setting and severity of conduct problems at baseline (that is diagnosed with CD or ODD, or scored above the clinical cut-off point on a validated measure of conduct problems). However, practitioners should note that faithful implementation of the programme appears to be an important component of clinical effectiveness and, thus, they should consider whether their organisation is willing to provide sufficient resources so that they can deliver the intervention with fidelity.”</p>
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		<p>1. Conduct problems.</p> <p>(B) Parent outcomes:</p> <p>1. Mental health (for example, stress, depression, anxiety levels, sense of confidence).</p> <p>2. Appropriate parenting skills and knowledge (self-report and direct observation).</p> <p>(a). Positive parenting practices (for example, praise, positive affect, physical positive, play, talk, proactive discipline).</p> <p>(b). Negative parenting practices (for example, criticism, yell, threaten, physical negative, laxness).</p> <p><i>Secondary outcomes:</i></p> <p>(A) Child outcomes</p> <p>1. Emotional problems (for example, depression and anxiety).</p> <p>2. Educational and cognitive ability.</p> <p>3. Long-term outcomes in adolescence and adulthood.</p> <p>(a) Criminal justice system involvement (police contacts, court appearances, imprisonment).</p> <p>(b) Unemployment.</p>	<p>studies was 64 months (five years and four months), children were aged between three and nine years in all but three of the studies where a small number of children (less than 10% of the samples) were just under three years old.</p> <p>DSM/ICD/Disability: The severity of conduct problems varied considerably between studies. In seven trials, all children at pre-treatment scored above the clinical cut-off point on a validated measure for conduct problems, whereas six studies reported that at pre-treatment all or most of the children were diagnosed with either Conduct Disorder (CD) or Oppositional Defiant Disorder (ODD) as well as scoring above the clinical cut-off point on a validated questionnaire.</p> <p>Comorbidity or factors that may affect the outcome: Five studies reported a low level of comorbidity with Attention Deficit Hyperactive Disorder (ADHD).</p>	<p>”Practitioners should also note that this review could not find any long-term measures of outcomes which compared the intervention and control groups within studies, all outcomes were measured either immediately post-treatment or up to three months post-treatment. The lack of long-term assessment compromises the likelihood of finding an improvement in educational abilities, as these outcomes typically emerge in the longer term ... whilst this also means that we cannot be sure that the benefits did not fade significantly after the three-month follow-up period. In relation to this last point, some long-term research has been conducted on group-based parenting programmes for the intervention group alone, which indicates the maintenance of treatment gains at 12- and 18-month follow-ups and up to eight to 12 years later.... However, other research has</p>
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		<p><u>(B) Parent outcomes</u> 1. Increased level of social support.</p> <p><u>(C) Adverse outcomes:</u> 1. Financial and psychological burden to family in attending and accessing course (for example, childcare issues).</p> <p>2. Conflict within family in relation to introduction of new parenting techniques.</p> <p><u>(D) Economic data:</u> 1. Costs per parent of running programme: (a) Non-recurrent costs: materials (programme kit), training for deliverers of programme. (b) Recurrent costs: staff costs (salary per hour) in delivering programme, including delivering session, preparation, travel and supervision. (c) Recurrent costs: facilities provided for parents (for example, transport, creche, money for babysitting, refreshments provided).</p>	<p>Seven studies were based on population samples characterised by high levels of socioeconomic disadvantage. All but one of the remainders included samples whose socioeconomic status was comparable to population norms one study did not provide any information in this respect.</p> <p>Intervention: Nine studies involved an evaluation of the Incredible Years BASIC Parenting Programme, five of which were independent replications. This programme consisted of brief videotaped vignettes of typical parent-child interactions, group discussions, role-plays and homework to promote positive parenting skills. Most of the studies of Incredible Years Parenting interventions comprised 9 to 16 weekly 2 to 2.5-hour sessions, although two studies provided 22 to 24 weekly two-hour sessions.</p> <p>One study devised and evaluated the effectiveness of the Barkley's Parent Training programme, which taught positive</p>	<p>found poor maintenance of outcomes for a substantial number of treatment completers at one-year follow-up. These findings are useful, although it is difficult to draw conclusions, at this stage, in the absence of control groups against which to compare the results.”</p> <p>”Finally, these results are only generalisable to group-based parenting interventions, based on social learning theory, and to children aged 3 to 12 years with a clinical level of conduct problems at baseline.”</p>
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		<p>(d) Recurrent costs: managerial overheads (for example, venue rental).</p> <p>(e) Utilisation of health, social care and special education services by children and parents at different time-points (for example, at six-month follow-up, one-year follow-up).</p> <p>(f) Number and costs of visits to primary care and hospital (for example, doctor, nurse, hospital, speech therapists, paediatrician).</p> <p>(g) Number and costs of visits to social services.</p> <p>(h) Number and costs of visits to special education services (for example, resource hours, special needs assistant).</p> <p>3. Incremental cost-effectiveness ratios (ICER) at different follow-up time-points. An ICER point estimate compares the costs and consequences of running a behavioural or cognitive-behavioural parenting intervention relative to the costs and consequences of a specified alternative,</p>	<p>parenting skills and consisted of 10 weekly sessions followed by five monthly booster sessions.</p> <p>One study devised and evaluated a Parenting Management Training (PMT) derived from the behavioural principles of the Parent Management Training, Oregon and the Incredible Years Parenting interventions. The programme involved 11 two-hour fortnightly sessions and taught positive parenting skills as well as providing material on dealing with parent-related stress factors, social support, and other risk or protective factors.</p> <p>One study devised and evaluated Comet Parent Management Training, Practitioner-assisted training (PMT-P), which included behavioural parent-training components based on the work of Barkley, Webster-Stratton, Bloomquist and Schnell. The intervention, which involved 11 weekly 2.5-hour sessions, consisted of video-clips, roleplay, discussions and homework in teaching positive parenting skills.</p>	
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		<p>which is most commonly chosen to be the status quo. ICERs are a central component of full economic evaluations. We also searched for economic studies accompanying eligible RCT studies that included costs data.</p> <p>Study design: Randomised controlled trials (RCTs), with or without cluster randomisation, and quasi-randomised studies (that is where allocation is by a quasi-random method such as alternate days, date of birth etc.) conducted in either research or service settings.</p> <p>Settings: Samples were drawn from community, clinical or research settings.</p> <p>Other criteria: Studies that reported on conduct problems comorbid with ADD and ADHD if they reported outcomes for conduct problems separately from ADD and ADHD outcomes were included.</p>	<p>One study devised and evaluated the Work Place Triple P Parenting Programme, which taught 17 core positive parenting and child management strategies using video modelling, practice, homework, feedback and goal setting. The intervention involved four weekly two-hour sessions followed by four weekly 15-minute telephone calls. Group sizes across studies ranged from 5 to 15 parents, although most had 8 to 12 parents per group. The number of sessions attended by participants in each study also varied quite considerably, from 35 % to 94 %, hence, seven studies had 83 % to 94 % attendance, five studies had 64 % to 77 % attendance (and one study reported only a 35 % session attendance. Most studies reported a reasonably high level of implementation fidelity, to the extent that adherence to treatment protocols and checklists, quality of delivery, training of leaders and supervision were adequately covered. However, treatment integrity was compromised in two</p>	
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		<p>Studies involving children with comorbid physical and intellectual impairments, such as autism spectrum disorders, Down Syndrome, tic disorders, significant language delay and learning problems were excluded.</p> <p>Studies published: Up to 2011.</p>	<p>studies due to the very low levels of parental attendance in one study and the relatively low coverage of programme content (76 %) in another.</p> <p>Comparison/control: All group-based parenting programmes were compared to a waiting-list control condition.</p> <p>Outcome: Child conduct problems (all studies). Parental mental health (8 studies). Parenting practices (7 studies). Child emotional problems (3 studies). Child educational and cognitive abilities (4 studies). Parental social support (1 study).</p> <p>Follow-up time: All outcomes were measured either immediately post-treatment or up to three months post-treatment.</p> <p>Number of participants: 1 078 participants (646 in the intervention group, 432 in the control group).</p> <p>There was considerable variation</p>	
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			<p>in sample size between studies. The number of participants (parent and index child pair) initially randomised per study ranged from 28 to 153, three studies included over 100 participants, seven involved 50 to 100 participants, and three studies were based on sample sizes of less than 50.</p> <p>Settings: Six of the studies were conducted in urban, university-based research clinics. Seven studies were conducted within both urban and rural community-based agencies: a medical centre in Massachusetts, in various Family Nurturing Network clinics in Oxford city and county, in 11 Sure Start Service areas within predominantly rural areas of North and Mid Wales, routine social services in Stockholm, two child psychiatric outpatient clinics in Trondheim and Tromsö, in various community-based family support and psychology services in Dublin and Eastern Ireland and in a range of Child and Adolescent Mental Health Services</p>	
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			<p>(CAMHS) within London and West Sussex.</p> <p>Economic evaluation: Two cost-effectiveness studies met the eligibility criteria for inclusion. Economic data were available in one study for 116 parents (73 families in the intervention group, 43 families in the control group). In the other study economic data were available for 112 parents (74 families in the parent training, 38 families in the control group.) Within both costs' studies, the families not included in the economic analyses were shown to be comparable at baseline to those who were included, in terms of their demographic characteristics and scores on the ECBI intensity scale. Both studies compared the cost-effectiveness of receiving the Incredible Years Parenting intervention in community-based settings versus a waiting-list control (WLC) of receiving services as usual (that is health, social and special educational services within their respective countries).</p>	
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			<p>The outcomes measured in both studies included:</p> <ul style="list-style-type: none"> (i) Costs of programme per parent. (ii) A comparison of service utilisation for the intervention and control conditions, and (iii) The calculation of an incremental cost-effectiveness ratio (ICER) to give the cost of obtaining a one unit decrease on the clinical outcome measure employed in the RCTs (that is the ECBI) when using the intervention versus an alternative. One of the studies also conducted a long-term cost-benefit analysis based on the assumption that the intervention will have a differential impact on later costs, such as generating savings in relation to reduction in crime, unemployment and improvement in education. <p>Both economic evaluations adopted a multiagency, public sector, analytic perspective, including health, social and special educational services within their respective countries. One of the studies reported results using 2003 to 2004 GBP (£) prices whilst the results in the other</p>	
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			<p>study were based on 2009 Ireland EUR (EURO) prices. Both currencies were converted to 2011 international dollar (\$) values within the text of the review in order to facilitate like-with-like comparisons between the studies. The time horizons of costs and effects adopted in these two studies were within one year.</p>	
<p>Gallagher et al 2016 Scotland [15]</p>	<p>Objectives: To synthesis published recommendations for therapy modification following brain injury from non-progressive traumatic, vascular or metabolic causes and to determine how often such modifications have been applied to cognitive behavioural therapy for post injury emotional adjustment problems</p>	<p>Separate inclusion criteria were created for review articles and intervention studies.</p> <p>Population: Review studies: People with brain injury.</p> <p>Intervention studies: Participants aged 16 years or older diagnosed with brain injury, either traumatic or non-traumatic, including stroke, hypoxia, ruptured aneurysm or metabolic encephalopathy.</p> <p>Intervention: Review studies: Alterations to CBT. Intervention studies: CBT in one- to-one format.</p> <p>Comparison/control: Not reported.</p>	<p>Characteristics of included studies: 8 review articles (2001-2013). 16 interventions studies (1991-2013).</p> <p>Country of origin: Not reported.</p> <p>Participants: <u>Interventions studies</u> Adult persons with brain injury.</p> <p>DSM/ICD/Disability: Brain injury.</p> <p>Comorbidity or factors that may affect the outcome: Considerable variability was found between studies on all other levels of the quality-measurement scale (n = 16 studies, median quality rating = 4, range = 1-5,). Single-case studies showed a higher median quality rating (rating = 4; n = 11 studies) than</p>	<p>Conclusions: “Much remains to be learned about the diverse nature of helping people recover from emotional dysregulation and poor adaptation following brain injury. Progress in this field will be accelerated if the quality and clarity of required specific therapy adaptations is improved. The modification checklist developed as part of this review could improve the capacity of future research to report intervention protocols. Such improvements in precision should lead to more effective and focused interventions that are well suited to the specific needs of people who are struggling to</p>

		<p>Outcomes: Intervention studies: Primary outcomes were measure of depression, "low mood", or anxiety, described as: "anxiety", obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), panic disorder, generalized anxiety disorder (GAD), or social anxiety</p> <p>Study design: Review studies were required to: Be a narrative review, systematic review, or other type of review.</p> <p>Settings: Not stated.</p> <p>Other criteria: No</p> <p>Studies published: Up to 2014.</p>	<p>randomised controlled trials (rating = 3; n = 5 studies). Only two out of the 16 studies measured adherence to treatment.</p> <p>Five studies, from 16, indicated that a treatment manual was used in the study, and was available. Each of the five intervention trial authors were contacted twice to request manuals with the aim of determining whether the adaptations extracted from the inter-vention study descriptions reflected the true state of the adaptations. Five authors were contacted, and none provided the manual (two authors did not reply, one manual was not available in English, one manual was currently being used in another research trial, and one author was unable to locate the manual). Obtaining the original intervention manuals would have helped to determine whether all of the modification-related themes had emerged, and thus reached the saturation recommended within narrative synthesis guidance. The difficulty obtaining manuals points to another area that</p>	<p>overcome the challenges that com-monly emerge in the aftermath of brain injury."</p>
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			<p>needs to improve in order to advance the development of suitably targeted interventions for post-brain injury adjustment.</p> <p>Intervention: Education, memory aids, modelling homework completion and generalizing home-work as adaptations, therapists used concrete examples and helped clients to generate alternative solutions, motivational interviewing, modified diary forms, using personalised metaphors and discussed clients' personal role models, Frequent, mid-week prompting to complete homework through telephone calls, Specific, Measurable, Realistic, Achievable, and Time Limited (SMARD goals).</p> <p>Comparison/control: <u>Intervention studies</u> Wait list, matched pairs.</p> <p>Outcome: Modifications of CBT for brain injury.</p> <p>Study design: <u>Intervention studies</u> Randomised controlled trials and single-case studies.</p>	
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			<p>Follow-up time: Not reported.</p> <p>Number of participants: <u>Intervention studies</u> 208.</p> <p>Setting: Not reported.</p>	
Gjermestad et al 2017 Norway [16]	<p>Objectives: To gain a deeper understanding of the multidimensional aspects and complexity of the lived everyday life of people with intellectual disability</p>	<p>Population: Adults with intellectual disability, their everyday life as viewed from their own perspective. The study's informants or participants are adult people with intellectual disability living independently or in community housing. Studies were not included if the theoretical focus was not empirical, they focused on other types of disability or they reported the staff and family's perspective</p> <p>Intervention: Not applicable.</p> <p>Comparison/control: Not applicable.</p> <p>Outcomes: Everyday life of people with intellectual disability viewed from their own perspective.</p> <p>Study design:</p>	<p>Characteristics of included studies: 12 studies.</p> <p>Country of origin: 3 articles from the United Kingdom, 2 articles from Australia and 1 article each from Iceland, Ireland, Malta, the Netherlands, Norway, Sweden and the USA</p> <p>Participants: Persons with intellectual disability living alone or in community housing. Age, and gender are not reported in all studies</p> <p>DSM/ICD/Disability: Not reported</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Not applicable.</p> <p>Outcome: Participation, self-determination, choice and control in everyday life.</p>	<p>Conclusions: "Although the reviewed studies revealed that staff attitudes and relational skills as well as different aspects of service organization and delivery were crucial for individualization and agency, the findings also highlighted the role of family, friends and neighbours as the most important factor for social participation and participants' feelings of belonging. Studies from nine countries were included in the review. The differences between the countries in terms of culture, values, accommodation and service delivery systems and practices may imply that concepts which emerged from the analysis were biased. However, the articles corresponded in terms of themes and concepts, which may</p>

		<p>Qualitative interpretive synthesis, eight studies are individual semi-structured interviews, and in three of these eight interviews are supplemented by other methods such as group discussions, ethnographic observation and art methodology. Three of the studies employed focus group interviews. Four studies used inclusive research strategies that included persons with intellectual disability.</p> <p>Settings: The participants own apartment or community housing</p> <p>Other criteria: User perspective</p> <p>Studies published: Up to 2014.</p>	<p>Follow-up time: Not applicable.</p> <p>Number of participants: 348 + 1 group with not specified number of participants</p>	<p>imply that everyday life today has many common dimensions that are valued across countries and regions.”</p>
<p>Hardee et al 2017 USA [17]</p>	<p>Objectives: To evaluate the effectiveness of exercise intervention on daily life activities and social participation in individuals with down syndrome (DS) using all study designs in published literature.</p>	<p>Population: Child participants (18 years and younger) and adult participants (18 years and older) diagnosed with DS (trisomy 21, translocation or mosaicism).</p> <p>Intervention: All type of exercise interventions.</p> <p>Comparison/</p>	<p>Characteristics of included studies: 19 studies.</p> <p>Country of origin: Not reported.</p> <p>Participants: 525 individuals (428 children and adults with DS and 97 participants without DS). Age of those with DS: range from 3-65.5. 11 of the studies and 55 % of the subjects</p>	<p>Conclusions: “This systematic review does contain data that supports a positive impact of exercise intervention on daily life activities and participation for people with DS, however, this is a preliminary conclusion. More rigorous research is needed with individuals with DS of all ages using</p>

		<p>control: Not reported.</p> <p>Outcomes: Activity limitation and societal participation using an objective measure.</p> <p>Study design: All group of study designs.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2016.</p>	<p>under the age of 18. One study did not report the age but specified that participants were children. 56 % of the participants were male.</p> <p>Of the studies that contained both male and female participants, no studies reported a significant proportion difference in gender. The case studies each contained a female participant, and 2 studies contained just male participants.</p> <p>DSM/ICD/Disability: Down syndrome.</p> <p>Comorbidity or factors that may affect the outcome: A limitation of the study is the inability to complete a meta-analysis for further analyses of data.</p> <p>Intervention: <u>Participants younger than 18.</u> Traditional exercise programs (n=3). Non-traditional interventions, bike riding, dance, rhythm and music, jumping (n=8). Individual and group training were represented.</p>	<p>objective outcome measures for ICF domains of Activity and Participation. Specifically, MCPDM Level I RCTs with high internal validity should be conducted. Possible objective Activity and Participation outcome measures based on the result of this study include amount of activity measured with accelerometers, quantitative horizontal/vertical distance of jump, GMFM-88, TUG, the Cognitive Emotional Barriers to Exercise Scale, The Exercise Perceptions Scale, the Life Satisfaction Scale, and the Self-efficacy Measure (adopted from Self Efficacy to Exercise Regularly Scale). Furthermore, the use of common outcome measures across studies would enable an easier comparison across studies and allow for an eventual systematic review with a meta-analysis. This would afford a more complete analysis and greater inter-disciplinary applicability of the evidence on the impact of exercise intervention on daily life activities and</p>
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			<p><u>Participants older than 18.</u> Traditional exercise programs (n=6). Non-traditional interventions, swimming and judo (n=2).</p> <p>Individual and group training were represented.</p> <p>Comparison/control: Not clear.</p> <p>Outcome: The International Classification of Functioning, Disability, and Health (ICF) model was used to categorize intervention and outcome measures for each study.</p> <p>The following outcome measure data were extracted from the studies:</p> <p><u>Children younger than 18 (11 studies):</u> 9 studies reported a total of 47 outcome measures. 11 of the 47 outcome measures were common across studies.</p> <p><u>Participants older than 18 years:</u> Seven of the 8 studies (reported a total of 33 outcome measures.</p>	social participation in individuals with DS.”
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			<p>Study design: Studies represented in the paper were designed as cohort study, case study, randomized controlled trial, non-randomized controlled trial.</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: 525 individuals (428 children and adults with DS and 97 participants without DS).</p> <p>Setting: Not reported</p>	
Harris et al 2015 UK [18]	<p>Objectives: Systematically assess the literature on randomized controlled trials on the effects of physical activity interventions to prevent weight gain in young adults with intellectual disabilities.</p> <p>Specific objectives include the evaluation of the effect of physical activity interventions on body composition outcomes (body mass index [BMI], waist circumference, percentage body fat, fat mass and lean mass) in young</p>	<p>Population: Participants diagnosed with intellectual disabilities across the age range 16–24 years.</p> <p>Interventions: Physical activity as a single component intervention.</p> <p>Comparison/control: Not stated.</p> <p>Outcomes: <i>Primary outcomes:</i> Studies had to report a specific objective measure of body weight and could include measures of body composition (i.e. BMI, waist circumference, percentage body fat</p>	<p>Characteristics of included studies: 6 studies.</p> <p>Country of origin: Three studies were conducted in Spain, two studies in Belgium, and one in Portugal.</p> <p>Participants: Participants' ages ranged from 10 to 30 years and were classified as normal weight to overweight and obese across studies.</p> <p>DSM/ICD/Disability: Participants were diagnosed with mild to moderate level of intellectual disabilities. Four studies included participants with Down syndrome only.</p>	<p>Conclusions:” This review has illustrated the lack of evidence of physical activity interventions specifically designed for young adults with intellectual disabilities. The meta-analysis found that physical activity interventions in young adults with intellectual disabilities did not prevent weight gain or improve body composition. This is due to limitations of the published studies, implementing inadequate duration and dose of the interventions. Although there was no significant effect of physical activity</p>

<p>adults with intellectual disabilities.</p>	<p>at baseline and follow-up).</p> <p><i>Secondary outcomes:</i> Not stated.</p> <p>Study design: Randomized controlled trial study design.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2014.</p>	<p>Two studies did not exclude individuals with Down syndrome, but none of the participants in the study were diagnosed with Down syndrome.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Seven types of interventions were prescribed in the included studies, including a bicycle ergometer intervention and an aerobic training program, strength and endurance training intervention, conditioning and plyometric jumps training, whole body vibration, which included isometric exercise, an aerobic treadmill ergometer intervention and an aerobic rowing ergometer intervention.</p> <p>The mean duration of intervention programs was 15.3 weeks (range 10–21 weeks).</p> <p>The frequency of physical activity sessions was two to three sessions per week for a duration range of 5–65 min across studies. The aerobic training</p>	<p>on body weight, physical activity interventions improved health risk factors, which is important for this population group to prevent health inequalities in later life. Future high-quality, adequately powered randomized controlled trials, with a long-term intervention and follow-up period are required to elucidate the effects of physical activity interventions on the prevention of weight gain and body composition in young adults with intellectual disabilities.”</p>
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			<p>component of the interventions was predominately performed at moderate to vigorous intensities (55–75 % heart rate reserve or peak heart rate). Strength/conditioning-based exercise was performed only in two studies. The intensity varied between individuals based on a participant's capacity (29), to a set intensity of 60–80 % of 1RM for three sets of 10 repetitions.</p> <p>Comparison/control: Participation in usual everyday scholar activities without supervised exercise training (1 study).</p> <p>Participation in the daily school activities, including physical education lessons (1 study).</p> <p>No training (4 studies).</p> <p>Outcome: All studies assessed the effect of physical activity on body weight.</p> <p>Four studies investigated BMI as an outcome.</p> <p>Measures of body composition reported in the included studies were waist circumference,</p>	
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			<p>percentage body fat, fat mass and lean mass.</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: A total of 178 participants were recruited across the six studies. The mean total sample size was 30 (range 16–54) participants.</p>	
Hartling et al 2014 Canada [19]	<p>Objectives: To evaluate the effectiveness of sibling-oriented programs interventions and delivery models that aims to improve behavioural and emotional outcomes in well siblings of children with chronic illness or disability.</p>	<p>Population: The study population was children (younger than 18) who were well siblings of children with a chronic illness or disability.</p> <p>Intervention: The study evaluates a program, support service, or therapy for well siblings.</p> <p>Comparison/control: Not reported.</p> <p>Outcomes: The study reported quantitative data for at least on well sibling outcome.</p> <p>Study design: First the design was randomized or non-controlled trial, an interrupted time series or controlled before and after. A post hoc decision was made to include</p>	<p>Characteristics of included studies: 14 studies. Controlled trials (n=5) Uncontrolled studies (n=9).</p> <p>Country of origin: Not reported.</p> <p>Participants: Well siblings of children with chronic illness or disability. CT: 398 siblings UCT: 309 siblings, 47 parents.</p> <p>DSM/ICD/Disability: Siblings with children of different disabilities.</p> <p>Comorbidity or factors that may affect the outcome: CT: Risk of bias was unclear in three studies and high in one for sequence generation, unclear in three studies or high in two studies for</p>	<p>Conclusions: “Study findings highlight the potential for enhancing the care and outcomes of well siblings, however, the findings were inconsistent across studies in terms of outcomes and differences observed. Methodological rigor is required in future research to avoid bias resulting from a number of sources including lack of appropriate controls. and blinding of researchers and study participants. Innovative methods to address the methodological imitations in this topic area are required in order to provide accurate estimates of effect. Careful consideration of</p>

		<p>uncontrolled before-alter studies to provide a comprehensive description of sibling-oriented care and impact and to generate recommendations for future study.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2008.</p>	<p>allocation concealment, high for blinding (in all studies), unclear in two or high in two studies for missing outcome data, low for selective outcome responding (all studies), and, unclear in two or high in two for other sources of bias.</p> <p>UCT: Results should be interpreted cautiously due to the potential for bias that results from the lack of a comparison group.</p> <p>Intervention: All studies included psychoeducation or social, but interventions differed by where they were conducted, intensity and content.</p> <p>Comparison/control: CT: One used a concurrent control group matched for age and sex, one non-equivalent control group.</p> <p>Outcome: CT: Sibling outcomes measured in the CT included behaviours, attitudes and effect, knowledge, social adjustment and support. In four studies, the sibling-oriented intervention under evaluation was associated with an</p>	<p>intervention outcomes and well siblings at high risk of negative out-comes may yield more consistent and applicable results.”</p> <p>CT: “Study results should be interpreted in light of the potential risk of bias, particularly due to lack of blinding of study person-nel, participants, and outcome assessments. Such bias may have resulted in an over-estimation of intervention impact on well sibling outcomes.</p> <p>UCT: “Study findings cannot be directly attributed to the intervention and may result from other factors such as regression to the mean, confounders or the Hawthorne effect.”</p>
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			<p>improvement in sibling behavioural and/or emotional health, but these improvements were not consistently demonstrated across studies.</p> <p>UCT: Reduced anxiety, depression and increased self-esteem and self-concept, increased involvement with siblings, increased knowledge, and improved mood state, feelings and attitudes, change in siblings' perceptions of the impact of their brother/sister's illness, increase in medical knowledge, improvement in intrapersonal perceptions of cancer and fear of disease, and positive influence on self-reported and parent-reported mood.</p> <p>Study design: CT: Two trials were randomized, one used a concurrent control group matched for age and sex, and two used a non-equivalent control group.</p> <p>All nine uncontrolled studies used a before-and-after design.</p> <p>Follow-up time: CT: Length of follow-up ranged from immediately to 12</p>	
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			<p>months post-intervention.</p> <p>UCT: Four studies assessed outcomes immediately after the intervention. Five studies conducted long-term evaluations that occurred at: 6 to 8 weeks, 3 months, '0." 6 months and 12 months post-intervention. In one study, the timing of outcome assessment was not specified.</p> <p>Number of participants: 707 siblings.</p> <p>Setting: Three of the CT studies were hospital-based and two were community-based. The UCT seven studies evaluated hospital-based, support groups, two studies evaluated community based, residential camps</p>	
<p>Heyvaert et al 2014 Belgium [20]</p>	<p>Objectives: Effectiveness of restraint interventions (RIs) for reducing challenging behaviour (CB) among persons with intellectual disabilities (ID).</p>	<p>Population: Persons with intellectual disabilities (ID).</p> <p>Intervention: Studies focusing on restraint interventions (RIs) for reducing challenging behaviour (CB) and studies reporting on effectiveness of RIs for the population.</p>	<p>Characteristics of included studies: 59 studies.</p> <p>Country of origin: Not reported</p> <p>Participants: 94 participants mean age 24.38 (range 3-58). 46 male and 48 females. 82 participants reported on a level for intellectual disability</p>	<p>Conclusions: "The analyses of the 59 SCE articles show that RIs were on average highly effective in reducing CB for people with intellectual disabilities and that this reduction in CB was statistically significant. From the seven coded participant and study characteristics, the multilevel model</p>

		<p>Comparison/control: No restraint condition.</p> <p>Outcomes: Reduction of CB.</p> <p>Study design: Single case experiments (SCE).</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2011.</p>	<p>DSM/ICD/Disability: Persons with intellectual disabilities (ID).</p> <p>For 82 participants, the specific intellectual disabilities level was reported: there were two participants with mild, four with moderate, 21 with severe and 55 with profound intellectual disabilities.</p> <p>Comorbidity or factors that may affect the outcome: No.</p> <p>Intervention: Personal restraint (52 participants) Mechanical restraint (32 participants), Environmental restrains (6 participants) Combinations of Ris (4 participants).</p> <p>Comparison/control: No-restrains conditions.</p> <p>Outcome: Reduction of CB, e.g. aggression, destructive behaviour, self-injurious behaviour, stereotyped behaviour.</p> <p>Study design: Single-case experiments (SCEs).</p>	<p>only showed a statistically significant moderating effect for the variable Gender: the Ris on average were more effective for female than for male participants. We conducted a sensitivity analysis to study the influence of an outlying case on our results and conclusions: the conclusions regarding the main statistical analysis and the moderator analysis are the same for the full data set as for the data set without the one outlier.</p> <p>The intervention effects varied significantly over the participants, with an estimated variance of 12.21 ($SO = 2.50$; $Z = 4.89$, $P < 0.0001$). When Gender, Age, CB type, intellectual disabilities level, Restraint type, Publication year and Study quality were taken into account, the intervention effects still varied significantly over the participants, with the estimated variance reduced to 9.82 ($SO = 2.07$; $Z = 4.73$, $P < 0.0001$). Accordingly, there remain important</p>
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			<p>Follow-up time: Not reported.</p> <p>Number of participants: 94 participants</p> <p>Setting: Not reported</p>	inter-individual differences that cannot be explained by the seven coded variables. Further research is warranted to study this remaining between-participants variance.”
Jones et al 2015 Australia [21]	<p>Objectives:</p> <p>1. How effective are self-management programs in improving physical activity in community-dwelling adults with Acquired brain injury (ABI)?</p> <p>2. How effective and acceptable is remote delivery of self-management programs aimed at improving physical activity in community-dwelling adults with ABI?</p> <p>3. Which features of self-management programs for community-dwelling adults with ABI are associated with the best clinical outcomes and client satisfaction?</p>	<p>Population: Adults (18 years and over) with a non-degenerative acquired brain injury (ABI). Currently living in the community. Are not undergoing significant medical or surgical intervention.</p> <p>Interventions: Self-management program which includes at least one of the following components: Problem-solving, goal-setting, decision-making, self-monitoring, coping strategies, or another approach to facilitate behaviour change. Has at least a component of the program focusing on increasing physical activity.</p> <p>Self-management reflects an individual’s responsibility for the day-to-day management of their disease including decisions regarding</p>	<p>Characteristics of included studies: 5 studies.</p> <p>Country of origin: 2 studies were conducted in the USA, 1 in Australia, 1 in Korea, and 1 in Hong-Kong.</p> <p>Participants: The mean age of all stroke participants (n = 336) was 64.42 (SD = 10.81) years, while the TBI participants (n = 74) had a mean age of 43.83 (SD = 15.34) years.</p> <p><u>Study 1:</u> Gender: Male: Intervention group (IG) = 29 (78.4%) Control group (CG) = 32 (86.5%) Female: IG = 8 (21.6%) CG = 5 (13.5%).</p> <p><u>Study 2:</u> Gender: Male: IG = 30 (100%) CG = 32 (97.0%) Female: IG = 0 (0%) CG = 1 (3.0%).</p> <p><u>Study 3:</u></p>	<p>Conclusions: ”The field of self-management of chronic health conditions is rapidly growing, and successes have been demonstrated in a range of conditions, such as depression and chronic pain. The application of this approach for individuals with ABI is emerging. To date, there are a limited number of trials that have specifically investigated the efficacy of self-management to improve physical activity in this population. However, the risk of bias of these studies is generally high, and analysis is limited by heterogeneity in study interventions, methodology, measures, and diversity of the ABI population. Based on the results of this review, the efficacy of self-management programs in increasing physical</p>

		<p>engagement in healthy behaviours.</p> <p>Comparison/control: <u>Review Question 1:</u> Usual care, waiting list control, no treatment, written information only, education and advice only, or an alternative treatment that is not considered to be self-management.</p> <p><u>Review Question 2:</u> Those papers that met all the inclusion criteria for review question 1, and delivered the self-management program via face-to-face delivery.</p> <p>Outcomes: <i>Primary outcomes:</i> Must include at least one of the following: 1. A measure of physical activity: either from a physical activity monitoring device (for example, accelerometer, pedometer) or a self-report measure</p> <p>And/or</p> <p>2. A study outcome associated specifically with physical activity, for example, physical activity self-efficacy, physical self-</p>	<p>Gender: Male: IG = 5 (35.7%) CG = 6 (75%) Female: IG = 9 (64.3%) CG = 2 (25%).</p> <p><u>Study 4:</u> Gender: Male: IG = 19 (59.4%) CG = 19 (65.5%) Female: IG = 13(40.6%) CG = 10 (34.5%).</p> <p><u>Study 5:</u> Gender: Male: IG = 55 (51.4%) CG = 50 (60.2%) Female: IG = 52 (48.6%) CG = 33 (39.80%).</p> <p>DSM/ICD/Disability: ABI was defined as damage to brain occurring after birth. However, for the purpose of this review, studies examining individuals with degenerative ABI (for example Parkinson’s disease or multiple sclerosis), cerebral palsy, developmental delay, fetal alcohol spectrum disorder (FASD), concussion, or transient ischaemic attacks (TIA) were not included.</p> <p>Four of the studies examined participants following stroke, while one studied participants with traumatic brain injury (TBI).</p>	<p>activity levels in community dwelling adults following ABI is still unknown. Moreover, the efficacy and acceptability of remotely delivered self-management programs for increasing physical activity levels after ABI is also unknown.</p> <p>Further research into physical activity following self-management interventions for community-dwelling adults with ABI is required in order to properly establish efficacy and implications for practice. This research should be designed, undertaken, and reported on in a manner that reduces the potential for bias and allows for establishment of efficacy. Remote delivery methods also warrant further research given the potential they offer in regard to improving access, overcoming barriers, and changing health behaviours.”</p>
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		<p>concept, or stages of change in relation to physical activity.</p> <p><i>Secondary outcomes:</i></p> <ol style="list-style-type: none"> 1. Self-efficacy (general). 2. Participation measures. 3. Activity measures. 4. Impairments. 5. Quality of Life measures. 6. Participant satisfaction. 7. Cost-effectiveness. <p>Study design: Randomized controlled trial (RCT), Quasi-randomized controlled trial (QRCT) - for example, allocation by date of birth, location, medical record number</p> <p>Settings: A variety of settings, such as private home, a hospital or community center. The participants must be community-dwelling and studies of people residing in nursing homes or other non-independent care facilities, or who are inpatients in a hospital or other</p>	<p>Measure of severity of ABI was reported in two of the five studies. Four out of the five studies reported eligibility criteria that required cognitive and communication skills to be adequate for participation in a self-management program, however, assessment of this criterion differed in each study.</p> <p>Comorbidity or factors that may affect the outcome: No study collected objective measures of physical activity such as from accel the common diversity seen in an ABI population.</p> <p>Studies examining both individuals with stroke and those with TBI were included in this review. There are obvious differences between these populations, for example, etiology and average age. There was also limited information regarding the specific mobility or physical activity status of the included participants ergometers or other devices.</p> <p>Intervention: Most of the interventions were</p>	
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		<p>health care facility will be excluded.</p> <p>Other criteria: People less than 18 years of age and pregnant women were excluded because the pharmacological treatments for these people are often different from those offered to the general population. No restrictions for people with physical or psychological illness</p> <p>Studies published: Up to 2014</p>	<p>delivered during an 8- to 12-week time frame. All the interventions included at least some element of face-to-face delivery, however, two studies delivered the majority of their intervention remotely via telephone. The three studies that utilized only face-to-face delivery all did this via group sessions. Standardized manuals or workbooks to assist in the delivery of the intervention were utilized in three studies. All interventions were facilitated by health professionals, including a multidisciplinary team facilitating sessions in two of the five studies. Nurses were most commonly engaged in the role of facilitator.</p> <p>Comparison/control: Wait-list control (Study 1), written patient educational materials on stroke warning signs and pamphlets from the American Stroke Association on prevention of secondary strokes. Telephone calls were also made by the case manager on the same schedule as IG to discuss how participant felt that day (Study 2), no</p>	
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			<p>intervention (Study 3), control received the 1 × face-face session but no ongoing telephone coaching (Study 4), Conventional medical treatment and health promotion pamphlets on stroke and stroke prevention (Study 5).</p> <p>Outcome: Three studies measured physical activity specifically, self-reported time spent in aerobic activity each week, weekly metabolic equivalent of task (MET) minutes by using self-reported information from a translated version of the International Physical Activity Questionnaire (IPAQ), physical activity data as the proportion of the group that participated in walking exercise. The remaining two studies utilized different validated questionnaires regarding physical activity, including the Health Promoting Lifestyle Profile – II (HPLP-II) Physical Activity subscale, the Self-Rated Abilities for Health Practices (SRAHP) Exercise subscale, and the Cerebrovascular Attitudes and Beliefs Scale - Revised (CABS-R) Exercise subscale.</p>	
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			<p>In addition to these specific physical activity measures, a wide variety of secondary outcome measures were used by the authors to examine other factors associated with self-management of acquired brain injury, such as self-efficacy for communicating with physicians or smoking and alcohol behaviour and Parti Diener Satisfaction with Life Scale, Participation Assessment, Stroke-Specific Health-Related Quality of Life (SSQOL)</p> <p>Study design: RCT or QRCT.</p> <p>Follow-up time: Three months and 6 months (study 1), three months and 6 months (study 2), three weeks (study 3), eight weeks (study 4), one week and three months (study 5).</p> <p>Number of participants: n=74, n=66, n=26, n=61, and n=190 in the studies 1-5 respectively (417 in total).</p>	
Karkhaneh et al 2010 Canada [22]	Objectives: To identify and synthesize all available controlled trials evaluating	Population: Children with autism. Intervention: Social stories.	Characteristics of included studies: 6 studies: 4 RCT, and 2 CCT.	Conclusion: "This systematic review of controlled trials evaluating Social Stories™ for

	Social Stories™ for ASD.	<p>Comparison/control: Any other intervention in individuals with ASD.</p> <p>Outcomes: Social skills.</p> <p>Study design: RCT or CCT.</p> <p>Settings: Not reported.</p> <p>Other criteria: No.</p> <p>Studies published: 2002-2006.</p>	<p>Country of origin: USA.</p> <p>Participants: Children with ASD 4-14 years.</p> <p>DSM/ICD/Disability: DSMIV-TR.</p> <p>Comorbidity or factors that may affect the outcome: The comparison groups varied across studies.</p> <p>Intervention: Social stories.</p> <p>Comparison/control: Regular school instruction, no intervention, regular stories.</p> <p>Outcome: Game playing skills, reading comprehension, story comprehension and social skills comprehension, aggressive behaviour.</p> <p>Follow-up time: Not specified</p> <p>Number of participants: 135</p>	children with ASD complements previous reviews that highlight the positive effects of this modality for higher functioning children with autism. This rigorous systematic review of six controlled trials demonstrates that Social Stories™ may be beneficial in terms of modifying target behaviours among high functioning children with ASD. Long-term maintenance, effectiveness of the intervention in other, less-controlled settings, and the optimal dose/frequency is unknown and requires further research.”
Kenyon et al 2013 Australia [23]	<p>Objectives: Bring together evidence regarding the validity of pedometers in populations with physical disabilities. How valid are</p>	<p>Population: Adults and children with physical disabilities.</p> <p>Physical disability was defined as a disability with</p>	<p>Characteristics of included studies: 7 studies</p> <p>Country of origin: Not reported.</p> <p>Participants:</p>	<p>Conclusion: “Pedometers are useful tools for measuring ambulatory physical activity. This systematic review identified 7 studies</p>

	<p>pedometers compared to direct observation in counting the steps of adults and children with physical disabilities?</p>	<p>primarily neurologic or physical origins that affected mobility. Disabilities of primarily medical origin (e.g., cardiovascular disease), intellectual/mental origin (e.g., Down syndrome or autism spectrum disorder), or defined by the presence of pain (e.g., chronic back pain) were excluded from this definition of physical disability, to produce a reasonably homogenous population, which in turn would allow the results of the review to be meaningful and reproducible.</p> <p>Interventions: Validation of a measurement method, there was no intervention.</p> <p>Comparison/control: The comparison between pedometer step counts and step counts from direct observation.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Validity data</p> <p><i>Secondary outcomes:</i> Not reported.</p> <p>Study design:</p>	<p>Adults and children with physical disabilities.</p> <p>DSM/ICD/Disability: A variety of participants with physical disabilities, including stroke, multiple sclerosis, Parkinson's disease, transtibial amputation, developmental disabilities and children and adults with mixed neurologic disabilities.</p> <p>Comorbidity or factors that may affect the outcome: Suppliers: (a) DWSW-200; Yamasa Tokei Keiki Co, Ltd, 1-5-7, Chuo-cho, Meguro-ku, Tokyo 152-8691 Japan. (b) W4L Duo; Walk4Life, 1981 Weisbrook Dr, Unit D, Oswego, IL 60543. c. International Microtech, 9960 Bell Ranch Dr, Unit 103, Santa Fe Springs, CA 90670.</p> <p>Five different models of pedometer were used in the 7 studies. The Yamax Digi-Walker SW-200a was used in 4 studies, 18-20, 23 and 4 other models Yamax Digi-Walker SW-401, a Yamax Digi-Walker SW-700, a Walk4Life Duo, b and Elexis</p>	<p>investigating the validity of pedometers in a variety of populations with physical disabilities, including stroke, multiple sclerosis, Parkinson's disease, transtibial amputation, and children and adults with mixed neurologic disabilities. While the validity of pedometers appeared to be somewhat lower in populations with physical disabilities compared with populations without disabilities, the validity was still moderate to high. These findings provide preliminary evidence that pedometers may be used in clinical and research settings in populations with disabilities. Further research examining the validity of pedometers in less heterogeneous populations of people with disabilities, and particularly children, is warranted to determine validity for specific disability populations. In addition, future research should investigate pedometer reliability</p>
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		<p>Quasi-experimental or observational.</p> <p>Settings: Not clearly stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2011.</p>	<p>Trainer FM-180cd were each used in a single study.</p> <p>All studies reported different durations of testing, some were restricted by a time limit and others by distance. The shortest distance covered in a single test was 3m, and the longest 160m, while time limits ranged from 1 to 6 minutes.</p> <p>It appears that the presence of a physical disability affects the validity of pedometers. This poorer validity may be explained by the gait abnormalities associated with physical disabilities. The altered gait patterns associated with physical disabilities may mean that hip acceleration thresholds that the pedometers require to count a step are not consistently reached in individuals with physical disabilities, resulting in poorer validity.</p> <p>Intervention: Validation of a measurement method (pedometers), there was no intervention.</p> <p>Comparison/control: The comparison between pedometer</p>	<p>and optimal placement of pedometers with regard to dominant and nondominant sides and affected and nonaffected sides in populations with disabilities.”</p> <p>“There is no universally accepted cut off for what is considered to constitute acceptable pedometer validity. However, Schneider et al. proposed that a pedometer model can be considered to have acceptable validity for use in clinical settings if the percentage error is less than 20 % for self-selected walking speeds in adults without disabilities, and that for research purposes, the percentage error should be less than 3 %. With the use of these cut offs, all the studies in this review satisfied the 20 % error cut off for use in a clinical setting, but only 1 study found validity high enough to justify pedometer use in a research setting (Yamax Digi-Walker SW-200 and Yamax Digi-Walker SW-401, in adults with multiple sclerosis).”</p>
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			<p>step counts and step counts from direct observation via hand tally count and video recording.</p> <p>Outcome: Step counts.</p> <p>Follow-up time: After walking.</p> <p>Number of participants: n=197 (18 were children), sample sizes varied between 16-45.</p>	<p>"...We propose that pedometers with 10 % to 15 % error when used in populations with disabilities may be suitable for research purposes, provided the researchers are cognizant of their limitations."</p> <p>"The results of this review are unable to inform recommendations for use of a particular pedometer model in populations with physical disabilities, as only 1 study examined the validity of more than 1 model."</p>
<p>Kok et al 2016 The Netherlands [24]</p>	<p>Objectives: To evaluate the currently available, qualitatively sound research concerning the effectiveness of psychosocial interventions, specifically directed at psychiatric disorders in children with mild to borderline intellectual disability (MBID)?</p> <p><u>Research questions:</u> 1. What is the quality of research with respect to the effectiveness of psychosocial interventions for psychiatric disorders in children with MBID?</p>	<p>Population: Children with MBID younger than 22 years. IQ scores between 50-85, diagnosed with any psychiatric disorder.</p> <p>Intervention: Psychosocial interventions: Parent training, Cognitive behaviour therapy.</p> <p>Comparison/control: Wait-list control group.</p> <p>Outcomes: Not clear.</p> <p>Study design: RCT</p> <p>Settings: Not reported.</p>	<p>Characteristics of included studies: 12 studies where only 10 could be included in a quantitative synthesis (meta-analysis).</p> <p>Country of origin: Not reported.</p> <p>Participants: Children with MBID younger than 22 years.</p> <p>DSM/ICD/Disability: DSM-III-R, DSM-IV</p> <p>Comorbidity or factors that may affect the outcome: ODD, ASD.</p> <p>Intervention:</p>	<p>Conclusion: "The vast majority of the included studies investigated the effectiveness of a parent training intervention compared to care as usual. The remaining studies focused on psychosocial training programs for the children and adolescents. Parent training programs focus on improving parent-child interactions, increasing parents' understanding of their child's behaviour, and the application of behavioural techniques to reduce problem behaviour."</p>

	<p>2. What can be concluded from these studies with regard to effect sizes when compared to a control condition?</p>	<p>Other criteria: No.</p> <p>Studies published: Up to 2010.</p>	<p><i>Psychosocial interventions:</i> Parent training, Social competence training, Cognitive behaviour therapy.</p> <p>Outcome: Antisocial and disruptive behaviour, child autism symptoms, pre-school behaviour, parental stress.</p> <p>Follow-up time: Not specified.</p> <p>Number of participants: 456.</p>	<p>In this systematic review, seven different parent training programs were assessed in a total of 243 participants with varying degrees of psychopathology. The overall results appear to show a tendency toward reduced problem behaviour and an increase in child positive behaviour.”</p>
<p>Lorenc et al 2016 UK [25]</p>	<p>Objectives: To do a systematic review of international research evidence on the effectiveness and cost-effectiveness of low-level support services for adults with high-functioning autism (HFA).</p> <p><u>Review question:</u> What is known about the effectiveness, cost-effectiveness, and barriers and facilitators of low-level support services for adults with HFA?</p>	<p>Population: Participants with HFA aged 18 years or over, or their families or carers.</p> <p>Included were any autism spectrum disorder (ASD), including Asperger’s Syndrome (AS), without learning disability, participants without a formal diagnosis if the intervention was mainly aimed at ASD at abstract stage if population was reported as ASD but not further specified (i.e. if it is unclear whether participants are high- or low functioning), but excluded at full text if there was no information on</p>	<p>Characteristics of included studies: 37 studies.</p> <p>Country of origin: Most studies were carried out in the USA.</p> <p>Participants: <u>Effectiveness studies:</u> Mean age between 18-36 years in the 27 effectiveness studies respectively.</p> <p><u>Qualitative studies:</u> Not summarized by the authors of the systematic review.</p> <p><u>Economic studies:</u> Not summarized by the authors of the systematic review.</p> <p>DSM/ICD/Disability:</p>	<p>Conclusions: “Evidence from three RCTs suggests that job interview training was effective in improving interview performance (total number of participants N=76). Evidence on other outcomes is inconclusive. Evidence from two RCTs, one nRCT and two one-group studies suggests that supported employment was effective in increasing employment rates and earnings (N=174). Evidence on other outcomes is inconclusive. One economic study found supported employment to be</p>

		<p>IQ or learning disability. Included as high-functioning participants with reported IQ\geq70, 'normal' or 'average' cognitive level, and/or with a diagnosis of Asperger's Syndrome.</p> <p><i>Included were:</i> Studies of mixed populations including HFA along with other populations (either non-autistic and/or learning-disabled) if people with HFA represent \geq50% of the sample, otherwise excluded.</p> <p><i>Included were:</i> Studies where the mean age of the sample was \geq18 years. At abstract stage abstracts were excluded if describing population as 'children' or 'schoolchildren' but included were those describing them as 'young people' or 'adolescents' or focusing on transitions to adulthood (also excluded were non-ASD parents of young children with ASD).</p> <p>Interventions:</p>	<p>Varying, not summarized by the authors of the systematic review.</p> <p>Comorbidity or factors that may affect the outcome: Not stated.</p> <p>Intervention: Job interview training, Employment support, Social skills training & psychoeducation, Music/dance, University student support & mentoring, Safety General support, Peer support groups, Specialist multi-disciplinary teams.</p> <p>Comparison/control: Varying, not summarized by the authors of the systematic review.</p> <p>Outcome: A wide range of outcome measures was used in the studies.</p> <p><u>Effectiveness studies:</u> Autism symptoms/ Empathy etc. Quality of life/wellbeing Mental health Social support/quality of social life Social skills (questionnaire) Service use Other employment.</p> <p><u>Qualitative studies</u></p>	<p>cost-effective. Evidence from four RCTs, two non-RCTs and eight one-group studies suggests that social skills training was effective in improving self-rated social skills and autism symptoms (N=372). Evidence on other outcomes is inconclusive. Evidence from one nRCT suggests that movement therapy was effective in improving social skills and wellbeing (N=31).</p> <p>Evidence on mentoring and support for university students is inconclusive. Evidence on safety interventions is inconclusive. Evidence from one economic study suggests that specialist multi-disciplinary support was cost-saving from a public sector perspective."</p>
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		<p>Low level support interventions.</p> <p><i>Included were:</i> Any service designed to support individuals in their daily lives, including: the provision of advice, information, or advocacy services, assistance in accessing services, peer support or support groups, supported employment, support with social interaction or participation.</p> <p><i>Excluded were:</i> Clinical interventions including individual psychotherapy and cognitive-behavioural therapy, any intervention mainly focused on reducing specific psychological morbidity (e.g. anxiety, sensory disorders, repetitive behaviour), and facilitated communication.</p> <p>Comparison/control: Any</p> <p>Outcomes: <i>Excluded were:</i> Tests of purely cognitive or knowledge outcomes, for example: tests of recognition of facial affect (e.g. Face</p>	<p>Not summarized by the authors of the systematic review.</p> <p><u>Economic studies</u> Not summarized by the authors of the systematic review.</p> <p>Study design: <u>Effectiveness studies:</u> RCT, randomised controlled trials (n=9), nRCT, non-randomised controlled trials (n=5), 1-G, one-group studies (n=13).</p> <p><u>Qualitative studies:</u> (n=7), not summarized by the authors of the systematic review.</p> <p><u>Economic studies:</u> (n=3), not summarized by the authors of the systematic review.</p> <p>Follow-up time: Varying, not summarized by the authors of the systematic review.</p> <p>Settings: Varying, not summarized by the authors of the systematic review.</p> <p>Number of participants: Between 3-68 participants in the 27 effectiveness studies respectively.</p>	
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		<p>Emotion Identification Test), tests of emotional cognition (e.g. Cambridge Mind Reading battery, Hinting Task), tests of knowledge about social skills (e.g. Test of Young Adult Social Skills Knowledge), tests of cognitive skills or memory, correct task performance or rule-following.</p> <p><i>Included were:</i> All other outcomes, either self-rated or observer rated. For example: social behaviour, including questionnaire instruments (e.g. Social Responsiveness Scale) or ratings of observed behaviour, participation in social situations, quality of social relationships (e.g. Index of Peer Relations), any outcome relating to attitudes or perceptions, quality of life or wellbeing, autism symptoms, job performance, employment or wages earned, any mental health outcome (e.g. depression, anxiety), independence or activities of daily living, etc.</p>		
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		<p><i>Primary outcomes:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p><i>Secondary outcomes:</i> Which one of the outcomes above considered secondary not clearly stated.</p> <p>Study design: Any evaluation study reporting pre-post data or random allocation, including trials, one-group studies and retrospective studies with pre-post data, process evaluations and qualitative research which reports substantive data on an intervention, any economic analyses (cost-effectiveness or cost benefit analyses) of interventions.</p> <p><i>Excluded were:</i> Observational or qualitative studies which may include data on services generally, but do not relate to: (a) Specific intervention(s), case studies without primary qualitative or quantitative data, studies with minimal qualitative data (i.e. one or two quotes only) at full-text</p>		
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		<p>stage, cost-only studies, non-systematic reviews, retain systematic reviews whose scope may overlap with this review for reference checking.</p> <p>Settings: Any</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2015</p>		
<p>Mayo-Wilson et al 2008 UK [26]</p>	<p>Objectives: To assess the effectiveness of personal assistance for children and adolescents (0-18) with intellectual impairments, and the impacts of personal assistance on others, compared to other interventions.</p>	<p>Population: Children and adolescents (0-18) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and to participate in normal activities due to permanent intellectual impairments. Intellectual impairments include 'learning impairments', 'learning disabilities', 'intellectual disabilities', 'mental retardation', and impairments resulting from acquired brain injuries or 'traumatic brain injury'.</p> <p>Young people living in institutions for people with</p>	<p>Characteristics of included studies: 1 study.</p> <p>Country of origin: The study (1) were conducted in the USA.</p> <p>Participants: At baseline, most participants were under 13 years old.</p> <p>DSM/ICD/Disability: Children and adolescents qualified if they had sufficient need, low intelligence quotient, and a diagnosis of mental retardation, autism, spina bifida, cerebral palsy or Prader Willi syndrome.</p> <p>Comorbidity or factors that may affect the outcome: The intervention enrolment process was described as complex and</p>	<p>Conclusions: “There have been relatively few controlled studies of personal assistance for children who require a great deal of assistance. Existing evidence suggests that personal assistance is generally preferred over other services by people who agree to participate in research, however some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients, however the relative total costs to recipients and society are unknown. This review does not indicate that personal assistance would be superior to other services for</p>

	<p>impairments are excluded.</p> <p>Children and adolescents with physical impairments are excluded because these impairments affect activities and participation differently.</p> <p>Interventions: Personal assistance, defined as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., not rehabilitation or respite care).</p> <p>Personal assistance is paid support given children and adolescents with impairments in various settings to enable them to participate in mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance may aim to improve mental and physical health, but it differs</p>	<p>discouraging, only 22 % of participants received cash assistance within 3 months, 29 % never received assistance, and 20 % disenrolled during the following year (of whom, 88 % withdrew before the assistance started).</p> <p>The average monthly payment at enrolment was \$1108. Of those still living in the community, 69 % of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 79 % and 65 % of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 237 hours and 247 hours in total ($p = 0.23$), 40 and 30 of which was paid ($p < 0.01$). Of those who hired a worker in the first 9 months, 41 % hired a worker who lived with them.</p> <p>The review was funded by a grant from the Swedish government, the Unit for Disabilities Issues and the Institute for Evidence-Based Social Work Practice, the Swedish National Board of Health and Welfare</p>	<p>people who are already satisfied with the assistance they receive.”</p> <p>“In 1986, Ratzka noted that 'there has been surprisingly little in the way of policy evaluation. The work that has been done in this area is restricted to gathering descriptive statistics on number of hours provided by one type of service, number of consumers, staff, and expenditures'. While several studies have been conducted since the 1980s, few studies have compared directly personal assistance and other services and further evaluations are required to determine the relative merits of different ways of organising assistance. It would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to different models of personal assistance in locations with long-standing</p>
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		<p>from services by professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.</p> <p>Twenty hours of assistance is the minimum required to qualify a person for personal assistance in several countries with national schemes.</p> <p>Comparison/control: Other forms of support or to 'no intervention' (which may include unpaid care).</p> <p>Comparisons could have included, either singly or in combination, informal care (which might be delivered by parents or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols,</p>	<p>(Socialstyrelsen). The reviewers have no known conflicts of interest.</p> <p>Intervention: Eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003.</p> <p>Participants in the intervention group were contacted by a counsellor who helped them develop spending plans, provided advice and monitored services. They received more paid care than control participants, who often paid for care out of pocket (20 versus 15 hours per week).</p> <p>Outcome: <i>Primary outcomes:</i> Quality of life User satisfaction The study measured participation, but these data were not reported.</p> <p><i>Secondary outcomes:</i> Unmet needs Physical health Mortality Morbidity and Medical Care Impact on others Abuse and Neglect Costs</p>	<p>personal assistance services.”</p> <p>“Services for children and adolescents with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine: (i) What marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) At what total relative cost and (iii) Which models of personal assistance are most effective and efficient for particular people.”</p>
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		<p>transportation services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups were eligible even if other services received were not described. Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Global quality of life, both: (a) Generic measures and (b) Specific measures designed for children with particular impairments. Though well-validated measures for the general population were considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents.</p> <p>Other measures were included.</p> <p>2. User satisfaction. Direct reports were</p>	<p>Study design: RCT.</p> <p>Follow-up time: 9 months.</p> <p>Number of participants: 1 002 participants. 501 in each the intervention and control group.</p>	
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		<p>preferred, though proxies were used if users were unable to communicate.</p> <p>3. Participation, including social activities, ability to participate in spontaneous activities, time outside the home, and mobility.</p> <p><i>Secondary outcomes:</i></p> <p>1. Unmet needs, particularly the inability to perform activities of daily living.</p> <p>2. Developmental outcomes, including cognitive milestones and acquisition of skills.</p> <p>3. Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as nutrition, emergency room visits or need for hospitalisation or institutionalisation</p> <p>4. Psychiatric outcomes, including self-harm, pica (eating non-food substances), and outwardly directed challenging behaviour. Measures might have included items from the externalising scale of</p>		
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		<p>the Behaviour Problem Inventory.</p> <p>5. Impact on others, including parental (maternal) employment, satisfaction, and quality of family life. For example, measures might have included the Short-Form Health Survey or General Health Questionnaire.</p> <p>6. Direct and indirect costs, both immediate and long-term.</p> <p>Study design: Randomised controlled trials, quasi randomised controlled trials and nonrandomised controlled studies of personal assistance in which participants are prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes.</p> <p>Settings: Community.</p> <p>Other criteria: Outcomes were grouped by length of follow-up.</p>		
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		<p>No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages.</p> <p>No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Studies published: Up to 2005.</p>		
<p>Mayo-Wilson et al 2008 UK [27]</p>	<p>Objectives: To assess the effectiveness of personal assistance for children and adolescents (0-18) with physical impairments, and the impacts of personal assistance on families and carers, compared to other interventions.</p>	<p>Population: Children and adolescents (0-18) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and to participate in normal activities due to permanent physical impairments.</p> <p>Intervention: Twenty hours of assistance is the minimum required</p>	<p>Characteristics of included studies: No eligible studies were found.</p>	<p>Conclusions: “No randomised, quasi-randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There is no reliable evidence about the effectiveness of</p>

		<p>to qualify a person for personal assistance in several countries with national schemes. This review defines personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week.</p> <p>Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Comparison/control: Comparisons could have included, either singly or in combination, informal care (which might be delivered by parents or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance.</p>	<p>personal assistance for children and adolescents with physical impairments.”</p>
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		<p>Outcomes:</p> <p><i>Primary outcomes:</i></p> <p>1. Global quality of life, both (a) Generic measures and (b) Specific measures designed for people with particular impairments. For example, measures might have included the Child Health Questionnaire or the Pediatric Quality of Life Inventory.</p> <p>2. User satisfaction. For example, measures might have included the Client Satisfaction Inventory.</p> <p>3. Participation, including sense of control, school attendance, social life, ability to participate in spontaneous activities, time outside the home, and mobility. For example, measures might have included the Lifestyle Assessment Questionnaire.</p> <p>Secondary outcomes:</p> <p>1. Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as</p>		
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		<p>hospitalisation, emergency room visits or need for institutionalisation.</p> <p>2. Developmental outcomes, including educational achievement and attainment, university attendance, and cognitive milestones.</p> <p>3. Psychiatric outcomes, including psychological disorders (e.g., anxiety and depression), self-harm, suicide and substance abuse. For example, measures might have included the Strengths and Difficulties Questionnaire.</p> <p>4. Impact on others, including parental (maternal) employment, satisfaction, and quality of family life. For example, measures might have included the Short-Form Health Survey or the Euroqol.</p> <p>5. Direct and indirect costs, both immediate and long-term.</p> <p>Study design:</p>		
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		<p>Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance compared to other forms of support or to 'no-intervention' (which may include unpaid family care) in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2005.</p>		
<p>Mayo-Wilson et al 2008 UK [28]</p>	<p>Objectives: To assess the effectiveness of personal assistance for children and adolescents (0-18) with both physical and intellectual impairments, and the impacts of personal assistance on families and carers, compared to other interventions.</p>	<p>Population: Children and adolescents (0-18) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) and to participate in normal activities due to permanent physical and intellectual impairments.</p> <p>With the exception of young people living in student</p>	<p>Characteristics of included studies: No eligible studies were found for this review.</p>	<p>Conclusions: "No randomised, quasi-randomised, or controlled prospective studies were found. Consequently, no studies could be included in this review. Several related reviews found evidence about the effectiveness of personal assistance for other groups. There is no reliable evidence about the effectiveness of</p>

		<p>accommodation (e.g. residential schools), young people living in institutions for people with impairments were excluded. Children and adolescents with physical impairments only and intellectual impairments only were excluded because these impairments affect activities and participation differently.</p> <p>Interventions: Personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., <i>not</i> rehabilitation or respite care).</p> <p>Personal assistance is paid support given children and adolescents with impairments in various settings to enable them to participate in mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc.</p>	<p>personal assistance for children and adolescents with both physical and intellectual impairments, though the results from a review of children and adolescents with intellectual impairments might be relevant to users and policymakers.</p> <p>“There have been few controlled studies of personal assistance for children who require a great deal of assistance for any reason and none for children who require assistance due to both physical and intellectual impairments. Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness. Some users may wish to consider evidence from other populations and discuss their options with family and friends.”</p> <p>“In 1986, Ratzka noted that ‘there has been surprisingly little in the way of policy evaluation.</p>
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		<p>Personal assistance may aim to improve mental and physical health, but it differs from services by professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.</p> <p>Twenty hours of assistance is the minimum required to qualify a person for personal assistance in several countries with national schemes.</p> <p>Comparison/control: Other forms of support or to 'no-intervention' (which may include unpaid care).</p> <p>Comparisons could have included, either singly or in combination, informal care (which might be delivered by parents or other family members), institutionalisation,</p>		<p>The work that has been done in this area is restricted to gathering descriptive statistics on number of hours provided by one type of service, number of consumers, staff, and expenditures'. While one study was included in a related review, few studies have compared directly personal assistance and other services and further evaluations are required to determine the relative merits of different ways of organising assistance for children and adolescents with both physical and intellectual impairments. It would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to different models of personal assistance in locations with long-standing personal assistance services.</p> <p>Services for children and adolescents with impairments are organised differently</p>
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		<p>service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups were eligible even if other services received were not described.</p> <p>Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Global quality of life, both (a) Generic measures (e.g., the Pediatric Quality of Life Inventory and (b) Specific measures designed for people with particular impairments. Though well-validated measures for the general population were considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired</p>		<p>around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine: (i) What marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today?) (ii) At what total relative cost? And (iii) Which models of personal assistance are most effective and efficient for particular people?"</p>
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		<p>respondents' or for people with both physical and intellectual impairments. Other measures were included.</p> <p>2. User satisfaction. Direct reports were preferred, though proxies might have been used if users were unable to communicate.</p> <p>3. Participation, including social activities, ability to participate in spontaneous activities, time outside the home, and mobility.</p> <p><i>Secondary outcomes:</i></p> <p>1. Unmet needs, particularly the inability to perform activities of daily living.</p> <p>2. Developmental outcomes, including cognitive milestones, acquisition of skills, and school attendance.</p> <p>3. Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as nutrition, emergency room visits or need for hospitalisation or institution-alisation.</p>		
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		<p>4. Psychiatric outcomes, including self-harm, pica (eating non-food substances), and outwardly directed challenging behaviour. Measures might have included items from the externalising scale of the Behaviour Problem Inventory.</p> <p>5. Impact on others, including parental (maternal) employment, satisfaction, and quality of family life. For example, measures might have included the Short-Form Health Survey or General Health Questionnaire.</p> <p>6. Direct and indirect costs, both immediate and long-term.</p> <p>Study design: Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with</p>		
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		<p>intervention group outcomes.</p> <p>Settings: Community.</p> <p>Other criteria: Outcome intervals, outcomes are planned to be grouped by length of follow-up.</p> <p>No language restrictions were imposed on any results from any search attempts, although most databases were searched in English.</p> <p>No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Studies published: Up to 2005.</p>		
<p>Mayo-Wilson et al 2008 UK [29]</p>	<p>Objectives: To assess the effectiveness of personal assistance for adults (19-64) with physical impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.</p>	<p>Population: Adults (19-64) living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) due to permanent physical impairments.</p> <p>With the exception of people living in student accommodation (e.g. residential schools or dormitories), adults</p>	<p>Characteristics of included studies: 1 study.</p> <p>Country of origin: USA.</p> <p>Participants: Participants had to be current users of the state's personal care benefit.</p> <p>Overall, 66 % were female, 50 % white and 30 % hispanic (regardless of race). Few had attended</p>	<p>Conclusions: "This review identifies some evidence that personal assistance recipients may express greater satisfaction and fewer unmet needs than participants receiving other services, with possible benefits in physical health. Further data would be required to draw conclusions about</p>

		<p>living in institutions for people with impairments were excluded.</p> <p>Adults with intellectual impairments were excluded because these impairments affect activities and participation differently.</p> <p>Interventions: Personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., <i>not</i> rehabilitation or respite care).</p> <p>Personal assistance is paid support given adults with impairments in various settings to enable them to participate in mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance may aim to improve mental and physical health, but it differs from services by</p>	<p>college (17 %) and many (43 %) were in poor health. The majority (65 %) lived with at least one other person and few (10 %) lived in a rural area. Most participants were dependent in several ADLs: 66 %, 69 % and 86 % were not independent in transferring, toileting and bathing and 74 % expressed a need for more help with personal care.</p> <p>DSM/ICD/Disability: Physical impairments.</p> <p>Comorbidity or factors that may affect the outcome: After assignment, the intervention enrolment process was described as complex and discouraging, only 31 % of participants received cash assistance within 3 months, 30 % never received assistance, and 33 % disenrolled during the following year (of whom, 70 % withdrew before the assistance started).</p> <p>Of those participants who dropped out of the intervention, the most common reasons for leaving were dissatisfaction with the amount of cash assistance, difficulty acting as an employer,</p>	<p>mental health and cost.</p> <p>The substantial amount of paid assistance received by participants in the control group underscores the fact that people receive both unpaid and paid assistance without external intervention. These data suggest that providing personal assistance is likely to raise government or insurance costs by paying for work that users would otherwise hire themselves and by paying for time that people would otherwise spend providing assistance for free.”</p> <p>“This review included 817 participants in one U.S. state (Carlson, 2007). More trials would be required to demonstrate if these results generalise to other countries and populations. Furthermore, the follow-up period was short and this review does not provide information about the long term impacts of personal assistance. The study compared a very large amount of personal assistance</p>
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		<p>professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.</p> <p>Comparison/control: Other forms of support or to 'no-intervention' (which may include unpaid care).</p> <p>Comparisons could have included, either singly or in combination, informal care (which might be delivered by partners or other family members), institution-alisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance.</p> <p>'No-treatment' and 'waiting list' groups were eligible even if other services</p>	<p>and satisfaction with traditional agency care.</p> <p>Intervention: The included study randomised participants to personal assistance or usual care.</p> <p>Eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003.</p> <p>Participants in the intervention group or their representatives were contacted by a counsellor who helped them develop spending plans, provided advice and monitored services.</p> <p>Participants received a monthly allowance that could be used to hire caregivers. Intervention participants received approximately 19 hours of paid care per week compared to 17 hours of paid care per week in the control group.</p> <p>Personal assistance participants received more paid care than control participants,</p>	<p>(e.g., 90 hours per week) to another form of service. Large amounts of assistance are increasingly common in Europe, particularly in Scandinavia. As a result, the conclusions of this review may not extend to users with very severe impairments or to more intense models of personal assistance. Cost data have limited generalisability. Data from Carlson 2007 are not comprehensive and implications for different stakeholders may be quite different, the relative costs of personal assistance and other services may be contextually dependent, varying from country to country."</p> <p>"Carlson 2007 has high internal validity, but low uptake and nonresponse raise questions about the external validity of these results. Dropout may suggest that some people who wish to try personal assistance eventually determine they prefer other services or it may indicate</p>
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		<p>received were not described.</p> <p>Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Global quality of life, both (a) Generic measures (e.g., the Short-Form Health Survey and (b) Impairment specific measures. Generic QoL measures are often appropriate for people with physical impairments.</p> <p>2. User satisfaction. For example, measures might have included the Client Satisfaction Inventory.</p> <p>3. Participation, including sense of control, employment, social life, sexual participation, ability to engage in spontaneous activities, time outside the home, and mobility. For example, measures</p>	<p>who often paid for care out of pocket (38.8 versus 33.2 hours over two weeks).</p> <p>The average monthly payment at enrolment was \$1069. Of those still living in the community, 61% of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 92% and 78% of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 145 hours and 150 hours in total ($p = 0.28$), 39 and 31 of which was paid ($p < .01$).</p> <p>Comparison/control: Usual care.</p> <p>Outcome: <i>Primary outcomes:</i> Quality of life User satisfaction The study measured participation, but these data are not yet reported.</p> <p><i>Secondary outcomes:</i> Unmet needs Physical health Mortality Morbidity and Medical Care Impact on others Abuse and Neglect Costs</p>	<p>that they become unable to manage personal assistance. For this reason, Nosek suggests that personal assistance be offered to some individuals on a trial basis for a limited time so that 'both consumers and providers of services could assess the feasibility of management arrangements and mutually define the parameters of management responsibilities'. When intervention participants can choose to return to other models of support rather than receive personal assistance, it may not be surprising that consumers select the option that leads to the best outcomes for them. Consequently, it is difficult to separate the benefits of personal assistance per se and the benefits of consumer choice."</p> <p>"There have been relatively few controlled studies of personal assistance for adults who require a great deal of assistance. Existing evidence suggests that personal assistance</p>
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		<p>might have included the Craig Handicap Assessment and Reporting Technique.</p> <p><i>Secondary outcomes:</i></p> <ol style="list-style-type: none"> 1. Unmet needs, particularly the inability to perform activities of daily living. 2. Health outcomes, including direct measures of muscle strength, disease, injuries, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institution-alisation. 3. Functional status measured using either generic or impairment specific tools. Measures might have included the Functional Independence Measure. 4. Psychological outcomes, including psychological disorders (e.g., anxiety and depression), self-harm, suicide and substance abuse. Generic measures are likely to be appropriate for adults with physical impairments and might have included the Beck Depression 	<p>Study design: RCT</p> <p>Follow-up time: 9 months.</p> <p>Number of participants: 817 participants. 404 in the intervention group and 413 in the control group.</p>	<p>is generally preferred over other services by consumers and their representatives who agree to participate in research, however some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients, their friends and families, however the relative total costs to recipients and society are unknown.</p> <p>This review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive.”</p> <p>“While several studies have been conducted since the 1980s, few studies have compared directly personal assistance and other services and further evaluations are required to determine the relative merits of different ways of organising assistance. It would be possible to compare personal assistance to other services or to</p>
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		<p>Inventory or the State Trait Anxiety Inventory.</p> <p>5. Impact on others, including family (spousal and parental) employment, satisfaction, and quality of family life.</p> <p>6. Direct and indirect costs, both immediate and long-term.</p> <p>Study design: Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance compared to other forms of support or to 'no-intervention' (which may include unpaid care) in which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes.</p> <p>Settings: Community</p> <p>Other criteria: Outcomes were grouped by length of follow-up.</p> <p>No language restrictions were</p>		<p>different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to different models of personal assistance in locations with long-standing personal assistance services. Services for adults with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine (i) What marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) At what total relative cost and (iii) Which models of personal assistance are most effective and efficient for particular people."</p>
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		<p>imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages.</p> <p>No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Studies published: Up to 2005.</p>		
<p>Mayo-Wilson et al 2008 UK [30]</p>	<p>Objectives: To assess the effectiveness of personal assistance for adults (19-64) with both physical and intellectual impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.</p>	<p>Population: Adults (19-64) with both physical and intellectual impairments living in the community who require assistance to perform tasks of daily living (bathing, eating, getting around, etc.) due to varying levels of permanent physical and intellectual impairments (learning disability or acquired brain injury). With the exception of people living in student accommodation (e.g.</p>	<p>Characteristics of included studies: 2 studies.</p> <p>Country of origin: 2 studies were conducted in the USA.</p> <p>Participants: <u>In the first study:</u> Participants had to be current users of the state's personal care benefit.</p> <p>Overall, 45 % were female, 78 % white and 21 % hispanic (regardless of race).</p> <p>Few (11 %) lived in a rural area.</p>	<p>Conclusions: "There have been relatively few controlled studies of personal assistance for adults with both physical and intellectual impairments who require a great deal of assistance. Existing evidence suggests that personal assistance may be preferred over other services by consumers and their representatives who agree to participate in research, however</p>

		<p>residential schools or dormitories), adults living in institutions for people with impairments were excluded. People with physical impairments only and people with intellectual impairments only will be excluded because these impairments affect activities and participation differently.</p> <p>Interventions: Personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., <i>not</i> rehabilitation or respite care).</p> <p>Personal assistance is paid support given adults with impairments in various settings to enable them to participate in mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance</p>	<p>Most participants were dependent in several ADLs: 52 %, 64 % and 78 % were not independent in transferring, toileting and bathing and 54 % expressed a need for more help with personal care.</p> <p><u>In the second study:</u> There were 44 adults in each group. Few details were provided about their characteristics. Most participants and assistants were white. 13 % of program applicants and 30 % of assistants were black</p> <p>DSM/ICD/Disability: Participants with both physical and intellectual impairments.</p> <p>Comorbidity or factors that may affect the outcome: In the first study the intervention enrolment process was described as complex and discouraging. Only 14 % of participants received cash assistance within 3 months, 42 % never received assistance, and 34 % disenrolled during the following year (of whom, 91 % withdrew before the assistance started). The average</p>	<p>some people prefer other models of care. This review indicates that personal assistance may have some benefits for some recipients, their friends and families however the relative total costs to recipients and society are unknown. This review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive.”</p> <p>“In 1986, Ratzka noted that 'there has been surprisingly little in the way of policy evaluation. The work that has been done in this area is restricted to gathering descriptive statistics on number of hours provided by one type of service, number of consumers, staff, and expenditures'. While several studies have been conducted since the 1980s, few studies have compared personal assistance and other services directly, and further evaluations are required to determine the relative merits of different ways of</p>
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		<p>may aim to improve mental and physical health, but it differs from services by professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.</p> <p>Comparison/control: Other forms of support or to 'no-intervention' (which may include unpaid care).</p> <p>Comparisons could have included, either singly or in combination, informal care (which might be delivered by partners or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance. 'No-treatment' and 'waiting list' groups</p>	<p>monthly payment at enrolment was \$1641. Of those still living in the community, 54 % of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 76 % and 64 % of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 188 hours and 189 hours in total ($p = 0.88$), 39 and 29 of which was paid ($p < 0.01$). Of those who hired a worker in the first 9 months, 42 % hired a worker who lived with them. No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages. No filters based on methodology were applied because test searches indicated that such filters might</p>	<p>organising assistance. It would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to new models of personal assistance in places with long-standing personal assistance services. Services for adults with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine:</p> <p>(i) What marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) At what total relative cost and (iii) Which models of personal assistance are most effective and efficient for particular people."</p>
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		<p>were eligible even if other services received were not described. Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Global quality of life, both (a) Generic measures (e.g., the Short-Form Health Survey) and (b) Specific measures designed for people with particular impairments. Though well-validated measures for the general population were sought, a review of global health measures found that 'very few measures have been validated specifically, for cognitively impaired respondents' or for people with both physical and intellectual impairments. Other measures were included.</p> <p>2. User satisfaction. Direct reports will be preferred, though</p>	<p>eliminate relevant studies.</p> <p>Intervention: <u>In the first study:</u> Participants received a monthly allowance that could be used to hire caregivers. Eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003.</p> <p>Intervention participants received approximately 20 hours of paid care per week compared to 14 hours of paid care per week in the control group.</p> <p>Participants in the intervention group or their representatives were contacted by a counsellor who helped them develop spending plans, provided advice and monitored services. Personal assistance participants received more paid care than control participants, who often paid for care out of pocket (39 versus 29 hours over two weeks).</p> <p>After assignment, the authors describe the intervention</p>	
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		<p>proxies were eligible if users were unable to communicate.</p> <p>3. Participation, including social life, employment, sexual participation, ability to engage in spontaneous activities, time outside the home, and mobility.</p> <p><i>Secondary outcomes:</i></p> <p>1. Unmet needs, particularly the inability to perform activities of daily living.</p> <p>2. Health outcomes, including direct measures of muscle strength, disease, injuries, nutrition, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institutionalisation. Measures might include the Health of the Nation Outcome Scales for People with Learning Disabilities.</p> <p>3. Functional status measured using either generic or impairment specific tools. Measures might have included the FIM Instrument or the Patient Evaluation and Conference System.</p>	<p>enrolment process as complex and discouraging.; Only 14 % of participants received cash assistance within 3 months, 42 % never received assistance, and 34 % disenrolled during the following year (of whom, 91 % withdrew before the assistance started). The average monthly payment at enrolment was \$1641. Of those still living in the community, 54 % of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 76 % and 64 % of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 188 hours and 189 hours in total ($p = 0.88$), 39 and 29 of which was paid ($p < .01$). Of those who hired a worker in the first 9 months, 42 % hired a worker who lived with them.</p> <p><u>In the second study</u> participants in the intervention group lived with an assistant, 41 % of whom spent more than 8 hours per day giving assistance in household tasks, activities of daily living and participating in</p>	
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		<p>4. Outwardly directed challenging behaviour. Measures might include items from the externalising scale of the Behaviour Problem Inventory.</p> <p>5. Psychological outcomes, including psychological disorders (e.g. depression), self-harm, pica (eating non-food substances), suicide and substance abuse. For example, measures might have included the PAS-ADD.</p> <p>6. Impact on others, including family (e.g. parental) employment, satisfaction, and quality of family life.</p> <p>7. Direct and indirect costs, both immediate and long-term.</p> <p>Study design: Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance in which participants were prospectively assigned to study groups and in which control group outcomes were</p>	<p>activities. Assistants provided help with laundry (97 %), personal shopping (83 %), cleaning clients' rooms (80 %), transportation to social activities (77 %), handling money (65 %), grooming (49 %), bathing (37 %), dressing (26%), and preparing special diets (21 %). Most did not work outside the home, they typically earned \$6000 to \$7000 excluding program payments.</p> <p>Comparison/control: Usual care.</p> <p>Outcome: <u>Study 1:</u> <i>Primary outcomes:</i> Quality of life User satisfaction Participation were measured, though these data were not reported</p> <p><i>Secondary outcomes:</i> Unmet needs Physical health Impact on others Abuse and neglect Costs</p> <p><u>Study 2:</u> <i>Primary outcomes:</i> User satisfaction Participation</p> <p><i>Secondary outcomes:</i> Unmet needs Physical health Functional status Mental health</p>	
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		<p>measured concurrently with intervention group outcomes.</p> <p>Settings: Community</p> <p>Other criteria: Outcomes were grouped by length of follow-up.</p> <p>No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages.</p> <p>No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Studies published: Up to 2005.</p>	<p>Impact on others Costs</p> <p>Study design: Study one was randomised.</p> <p>Follow-up time: In study one most follow-up occurred nine months later.</p> <p>Number of participants: The included studies involved 1 002 participants. 456 in the personal assistance group and 458 in the control group.</p>	
<p>Montgomery et al 2008 UK [31]</p>	<p>Objectives: To assess the effectiveness of personal assistance</p>	<p>Population: Older adults (65+) living in the community who require assistance to</p>	<p>Characteristics of included studies: 4 studies.</p> <p>Country of origin:</p>	<p>Conclusions: “There have been relatively few controlled studies of personal assistance</p>

<p>programmes for older adults with impairments, and the impacts of personal assistance on partners, families and carers, compared to other interventions.</p>	<p>perform tasks of daily living (bathing, eating, getting around, etc.) and to participate in normal activities due to permanent impairments. Older adults living outside their own homes (e.g., in nursing homes) were excluded. Studies in which the majority (51 % or more) of participants had been diagnosed as suffering from dementia at baseline were excluded as their reasons for receiving assistance and goals might differ from other older adults.</p> <p>Interventions: Personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time (i.e., <i>not</i> rehabilitation or respite care).</p> <p>Personal assistance is paid support given adults with impairments in various settings to enable them to participate in</p>	<p>USA.</p> <p>Participants: <u>Study 1:</u> Participants had to be current users of the state’s personal care benefit.</p> <p>Overall, 45 % were female, 78 % white and 21 % Hispanic (regardless of race).</p> <p>Few (11 %) lived in a rural area.</p> <p>Most participants were dependent in several ADLs: 52 %, 64 % and 78 % were not independent in transferring, toileting and bathing and 54 % expressed a need for more help with personal care.</p> <p><u>Study 2:</u> There were 44 adults in each group. Few details were provided about their characteristics. Most participants and assistants were white. 13 % of program applicants and 30 % of assistants were black.</p> <p>DSM/ICD/Disability: Not reported.</p> <p>Comorbidity or factors that may affect the outcome: In the first study the intervention enrolment process was described as</p>	<p>for older adults who require a great deal of assistance. Existing evidence suggests that personal assistance is generally preferred over other services by consumers and their representatives who agree to participate in research, however, some people prefer other models of care. This review indicates that personal assistance probably has some benefits for some recipients, their friends and families. Paid assistance probably substitutes for informal care and may cost government more than alternative arrangements, however the relative total costs to recipients and society are unknown. Decisions to provide or not to provide and to take-up or not to take-up personal assistance will be informed by personal values and preferences in addition to evidence of its effectiveness. This review indicates that personal assistance is safe for older adults, though it may be difficult to manage. People who choose to receive</p>
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		<p>mainstream activities. Assistants might help with bathing, dressing, moving around during the day, shopping, etc. Personal assistance may aim to improve mental and physical health, but it differs from services by professional healthcare providers (e.g., nurses) with whom users have very different relationships. Personal assistance is designed for people with permanent impairments and differs from rehabilitative services and from services provided for fixed periods of time in that it is indefinite and ongoing.</p> <p>Comparison/control: Comparisons could have included, either singly or in combination, informal care (which might be delivered by partners or other family members), institutionalisation, service housing (cluster housing), on-demand services, night patrols, transportation services, and other alternatives to personal assistance.</p>	<p>complex and discouraging. Only 14 % of participants received cash assistance within 3 months, 42 % never received assistance, and 34 % disenrolled during the following year (of whom, 91 % withdrew before the assistance started). The average monthly payment at enrolment was \$1641. Of those still living in the community, 54 % of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 76 % and 64 % of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 188 hours and 189 hours in total ($p = 0.88$), 39 and 29 of which was paid ($p < 0.01$). Of those who hired a worker in the first 9 months, 42 % hired a worker who lived with them. No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were</p>	<p>personal assistance may prefer it to other services, particularly services over which users have little control. However, this review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive. Personal assistance appears to benefit informal caregivers as well. Individuals considering personal assistance may wish to discuss their options with family and friends.”</p> <p>“In 1986, Ratzka noted that ‘there has been surprisingly little in the way of policy evaluation. The work that has been done in this area is restricted to gathering descriptive statistics on number of hours provided by one type of service, number of consumers, staff, and expenditures’. While several studies have been conducted since the 1980s, few studies have compared directly personal assistance and other services and further evaluations are</p>
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		<p>'No-treatment' and 'waiting list' groups were eligible even if other services received were not described. Studies examining different forms of personal assistance (e.g., assistance organised by users compared to assistance organised by others) were included. These were treated as separate comparisons.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Global quality of life, both (a) Generic measures (e.g., the Short-Form Health Survey and (b) Impairment specific measures. Though well-validated measures for the general population were considered, a review of global health measures found that 'very few measures have been validated specifically for cognitively impaired respondents'.</p> <p>2. User satisfaction. Direct reports were preferred, though proxies were eligible if users were unable to communicate.</p> <p>3. Participation, including social life,</p>	<p>searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages. No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Intervention: In the first study participants received a monthly allowance that could be used to hire caregivers. Eligible Medicaid beneficiaries were randomly assigned to receive a monthly payment (personal assistance) in lieu of other Medicaid services or to receive usual care from 1999 to 2003.</p> <p>Intervention participants received approximately 20 hours of paid care per week compared to 14 hours of paid care per week in the control group.</p> <p>Participants in the intervention group or their representatives were contacted by a counsellor who helped them develop spending plans, provided advice and</p>	<p>required to determine the relative merits of different ways of organising assistance. Personal assistance is expensive and difficult to organise, especially in places that do not have such services in place already. In locations with personal assistance, recipients may resist being assigned to other services. Nonetheless, it would be possible to compare personal assistance to other services or to different forms of personal assistance in locations implementing new programmes. Similarly, new users might be assigned to new models of personal assistance in places with long-standing personal assistance services."</p> <p>"Services for older adults with impairments are organised differently around the world. While advocates may support personal assistance for myriad reasons, this review demonstrates that further studies are required to determine</p>
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		<p>membership in community groups, sexual participation, ability to engage in spontaneous activities, time outside the home, and mobility.</p> <p><i>Secondary outcomes:</i></p> <ol style="list-style-type: none"> 1. Unmet needs, particularly the inability to perform activities of daily living. 2. Health outcomes, including direct measures of muscle strength, disease, injuries, nutrition, abuse or pain and indirect measures such as hospitalisation, emergency room visits or need for institutionalisation. 3. Functional status measured using either generic or impairment specific tools. Measures might have included the FIM Instrument or an index of activities of daily living. 4. Outwardly directed challenging behaviour (e.g., the Cohen- Mansfield Agitation Inventory.) 5. Psychological outcomes, including dementia, psychological 	<p>monitored services. Personal assistance participants received more paid care than control participants, who often paid for care out of pocket (39 versus 29 hours over two weeks).</p> <p>After assignment, the authors describe the intervention enrolment process as complex and discouraging. Only 14 % of participants received cash assistance within 3 months, 42 % never received assistance, and 34 % disenrolled during the following year (of whom, 91 % withdrew before the assistance started). The average monthly payment at enrolment was \$1641. Of those still living in the community, 54 % of the personal assistance group was receiving cash at 9-month follow-up. At 9 months, 76 % and 64 % of participants in the personal assistance and control groups reported receiving paid care in the previous two weeks ($p < 0.01$). They received 188 hours and 189 hours in total ($p = 0.88$), 39 and 29 of which was paid ($p < .01$). Of those who hired a worker in the first 9 months, 42 %</p>	<p>(i) What marginal benefits are gained from personal assistance (i.e. the added value compared to other services that exist today), (ii) At what total relative cost and (iii) Which models of personal assistance are most effective and efficient.”</p>
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		<p>disorders (e.g., anxiety and depression), challenging behaviour, self-harm, suicide and substance abuse. For example, measures might have included the Geriatric Depression Scale, the Mini-Mental State questionnaire, or the PAS-ADD.</p> <p>6. Impact on others, including family (spouse and child) employment, satisfaction, and quality of family life. For example, measures might have included the Dysfunctional Behaviour Rating Instrument, the Short-Form Health Survey or the General Health Questionnaire.</p> <p>7. Direct and indirect costs, both immediate and long-term.</p> <p>Study design: Randomised controlled trials, quasi-randomised controlled trials and nonrandomised controlled studies of personal assistance compared to other forms of support or to 'no intervention' (which may include unpaid care) in</p>	<p>hired a worker who lived with them.</p> <p>In the second study participants in the intervention group lived with an assistant, 41 % of whom spent more than 8 hours per day giving assistance in household tasks, activities of daily living and participating in activities. Assistants provided help with laundry (97 %), personal shopping (83 %), cleaning clients' rooms (80 %), transportation to social activities (77 %), handling money (65 %), grooming (49 %), bathing (37 %), dressing (26 %), and preparing special diets (21 %). Most did not work outside the home, they typically earned \$6,000 to \$7,000 excluding program payments.</p> <p>Comparison/control (n studies): Usual care (2), Nursing homes (1), Cluster care (1).</p> <p>Outcome:</p> <p><u>First study:</u> <i>Primary outcomes:</i> Quality of life User satisfaction Participation were measured, though these data were not reported.</p>	
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		<p>which participants were prospectively assigned to study groups and in which control group outcomes were measured concurrently with intervention group outcomes.</p> <p>Settings: Community.</p> <p>Other criteria: Outcomes were grouped by length of follow-up.</p> <p>No language restrictions were imposed on any results from any search attempts, although most databases were searched in English. Latin American and Caribbean Health Sciences Literature (LILACs) were searched using Spanish and Portuguese terms and Scandinavian databases were searched in appropriate languages.</p> <p>No filters based on methodology were applied because test searches indicated that such filters might eliminate relevant studies.</p> <p>Studies published: Up to 2005.</p>	<p><i>Secondary outcomes:</i> Unmet needs Physical health Impact on others Abuse and neglect Costs</p> <p><u>Second study:</u> <i>Primary outcomes</i> User satisfaction Participation</p> <p><i>Secondary outcomes:</i> Unmet needs Physical health Functional status Mental health Impact on others Costs</p> <p>Study design: One study was an RCT, three studies were non-randomised.</p> <p>Follow-up time: In study one most follow-up occurred nine months later.</p> <p>Number of participants: The four studies involved 1642 participants.</p>	
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<p>Patterson et al 2012 USA & Canada [32]</p>	<p>Objectives: Examine research utilizing single subject research designs (SSRD) to explore the effectiveness of interventions designs to increase parents' ability to support communication and social development on children with autism spectrum disorders (ASD).</p>	<p>Population: Children diagnosed with autistic disorders, pervasive development disorders or Asperger syndrome including comorbid diagnose.</p> <p>Intervention: Training programs for parents of children with autism to increase their ability to support their child with ASD.</p> <p>Comparison/control: No.</p> <p>Outcomes: <i>Primary outcomes:</i> Children's social and /or vocational communication skills as primary outcome. At least one measure of parental behaviour. Numeric graphical data that could be used to calculate the improvement rate differences (IRD) for at least one child and one adult participant.</p> <p><i>Secondary outcomes:</i> If any of the outcomes above considered secondary not clearly stated.</p> <p>Study design: Studies that utilized an SSRD.</p>	<p>Characteristics of included studies: 11 studies</p> <p>Country of origin: Not clear.</p> <p>Participants: Preschool children (n=26), age range 10-112 months (median 43 months). Primary care givers were seldom described, usually the mother.</p> <p>DSM/ICD/Disability: ASD (n=44). Mental retardation, Down syndrome or 'autistic like symptoms' (n=3).</p> <p>Intervention: Interventions designed to increase the social and/or communication skills of children with ASD.</p> <p>Manualized programs used in four studies: Pivotal Response Treatment (PRT), Natural Language paradigm (NLP), Early Denver Model (ESDM). Not manualized programs were used in 9 studies.</p> <p>Comorbidity or factors that may affect the outcome: No comparisons.</p> <p>Comparison/control: No.</p> <p>Outcome:</p>	<p>Conclusions: "Different degree of positive effects on both parents and children's' outcomes were demonstrated for a variety of interventions. Overall the studies were of moderate quality. The studies reveal that parents can learn to accurately implement the program strategies for a short period of time. The parent's ability to use the skills in their everyday life as their child develops is not well understood."</p>
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		<p>Settings: Not stated.</p> <p>Other criteria: No</p> <p>Studies published: Up to 2009.</p>	<p>Several parent and child outcomes.</p> <p>Study design: SSRD.</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: 47 children and their primary care giver. The data from the 44 children with ASD and at least one primary care giver is analyzed in the review.</p> <p>Setting: Not reported.</p>	
Patterson et al 2010 Canada [33]	<p>Objectives: To examine the quality of conduct of experimental studies contributing to our experimental understanding of functional based behavioural interventions for stereotypic and repetitive behaviours (SRB) in individuals with autism spectra disorders (ASD).</p>	<p>Population: Participants of any age diagnosed with autistic disorders, pervasive development disorders or Asperger syndrome including comorbid diagnose.</p> <p>Intervention: Behavioural interventions.</p> <p>Comparison/control: No.</p> <p>Outcomes: Reduce stereotypic and repetitive behaviours (SRBs) in individuals with ASD.</p> <p>Study design:</p>	<p>Characteristics of included studies: 10 studies (9 peer reviewed articles and 1 dissertation).</p> <p>Country of origin: USA.</p> <p>Participants: 17 participants (median n=1), Male (n=13) School age (n=10), toddler (n=1), adolescents (n=2) and adults (n=4).</p> <p>DSM/ICD/Disability: Autism (n=15), pervasive development (n=1), high function autism (n=1). Comorbid diagnosis of mental retardation (n=5) and</p>	<p>Conclusions: “The 17 participants involved in these studies demonstrated high baseline levels of SRBs. These high frequencies, along-side the teacher and parent reports, indicated that these behaviours were interfering with the individuals’ ability to engage appropriately in their environment. Overall, positive effects were reported for behavioural interventions to reduce SRBs maintained by a variety of identified functions displayed</p>

		<p>Experimental design including RCT, quasi-group designs, or single participants designs.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2008.</p>	<p>chronic conditions (n=2).</p> <p>Comorbidity or factors that may affect the outcome: All of the intervention studies included in the review were single-participant research designs. "Although single-case research is a rigorous, scientific methodology used to define basic principles of behaviour and establish evidence-based practices, it is often seen as a starting point for formulating and understanding how to apply new interventions systematically."</p> <p>Intervention: Response interruption and redirection, NCR and prompting procedures, NCR and response blocking, NCR and response interruption, Antecedent-based visual cue card strategy, Functional communication training, Matched stimulation and NCR, Differential reinforcement and extinction, Non-contingent access, Schedule thinning of response blocking.</p> <p>Comparison/control: No.</p>	<p>by individuals with ASDs, however, there are several limitations to these findings. This evidence is preliminary in nature because of the small number of participants in the 10 studies and the heterogeneity of both the population and the interventions themselves. Caution should be used in choosing and implementing interventions to ameliorate SRBs in order to reduce the use of ineffective treatment, thus wasting valuable resources. Further research is required to examine the array of Sens01Y, pharmaceutical, and developmental, interventions for SRBs based upon the function of the behaviour."</p>
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			<p>Outcome: Decreases in SRB: s such as stereo-typed movements, repetitive object manipulation, circumscribed interests.</p> <p>Study design: Single-case research designs.</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: 17 participants.</p> <p>Setting: Not reported.</p>	
Reichow et al 2012 USA [34]	<p>Objectives: To systematically review the evidence for the effectiveness of social skills groups for improving social competence, social communication, and quality of life in individuals with ASD.</p> <p>To identify the characteristics of the social skills training that are most effective.</p> <p>To identify those subsample(s) of children with ASD for whom social skills groups are most successful.</p>	<p>Population: Children and young adults aged 6 to 21 with ASD (that is, autistic disorder, Asperger’s disorder, PDD-NOS, Rett’s syndrome, childhood disintegrative disorder), defined by diagnosis according to DSM-IV-TR or ICD-10.</p> <p>Interventions: Social skills groups, delivered by professional personnel in groups of at least two individuals, in any setting at any frequency and for any duration. Participants may or may not have</p>	<p>Characteristics of included studies: 5 studies.</p> <p>Country of origin: All studies were conducted in the USA.</p> <p>Participants: Four of the five studies examined social skills groups in children between the ages of eight to 11 years, one study examined social skills groups in adolescents between the ages of 11 and 17 years. 86 % were male.</p> <p>DSM/ICD/Disability: All studies had an inclusion criterion that the participants have IQs that were above</p>	<p>Conclusions: “The results of the meta-analyses in this review suggest that participants in social skills groups may make modest gains in social competence, have better friendships, and experience less loneliness. To put these gains in more concrete terms, if measuring everyday social skills using the Vineland, for example, an average participant from these studies would increase their repertoire of social skills from 123 to 147 after participating in the social skills group,</p>

		<p>received standard treatment in addition to the social skills group intervention. We did not include studies evaluating support group and psychodynamic group therapies in this review.</p> <p>Comparison/control: Eligible comparison groups were standard treatment groups or wait list control groups.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Social Competence This outcome was typically measured through parent report on a standardized assessment scale, for example, Vineland Adaptive Behaviour Scale or the Social Skills Rating System.</p> <p><i>Secondary outcomes:</i> 1. Social communication. 2. Quality of life. 3. Emotion recognition. 4. Individual specific behaviours. 5. Adverse effects.</p>	<p>the cut-off for intellectual disability, which was typically the only inclusion criteria. Across studies, all samples reported mean full scale IQ to be in the average range (range of mean full scale IQ 84.8 to 106.9).</p> <p>Comorbidity or factors that may affect the outcome: No adverse events were reported as a result of treatment in any study.</p> <p>Intervention: The duration of the social skills groups across studies was five to 20 weeks or 12 to 125 sessions. Four of the five studies had one session per week with a duration of 60 or 90 minutes, one study had 25 weekly sessions that were 70 minutes each. Multiple social skills group curricula were used across studies, all of which focused on a broad array of social skills that were taught and rehearsed during the sessions. Four of five studies included a parent component to the social skills group.</p> <p>Comparison/control: Four of the five studies used a randomized wait list control trial. Method,</p>	<p>which is a clinically significant increase.”</p> <p>“This review is not without limitations, however. It includes only five studies with relatively small sample sizes that evaluated different social skills group curricula and assessed effects using different measures of social competence and a narrow range of additional outcomes. Given these limitations, we cannot formulate specific practice guidelines on the characteristics of the most successful social skills groups.”</p> <p>“The results of this review suggest much work remains to be done in establishing the efficacy of social skills group interventions. Although many quasi-experimental studies of social skills group interventions have been conducted (for example, pre-/post-treatment comparison, non-randomized group comparison), we located only five RCTs. Future research should be conducted using true experimental designs</p>
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		<p>Social communication, quality of life, and emotion recognition were measured using standardized assessments and/or parent- or teacher-rated scales.</p> <p>Study design: Randomized controlled trials of social skills groups.</p> <p>Settings: Not reported.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2011.</p>	<p>one study used a randomized controlled trial design with a no treatment control. All five studies compared the treatment group with a group not partaking in a social skills group. Individuals with autism typically receive many treatments, thus we did not have an included study in which participants were receiving no treatment.</p> <p>Outcome: Social competence, Social communication, Emotion recognition, Quality of life</p> <p>Follow-up time: If data had permitted, the plan was to group outcome time points as follows: immediately post-intervention, one to five months postintervention, six to 11 months post-intervention, 12 to 23 months post-intervention, 24 to 35 months post intervention, etc.</p> <p>Only post-intervention scores were reported, and this is the time point included in this review.</p> <p>Outcome measures were assessed immediately following</p>	<p>with adequate power to detect clinically important effects. Research should also focus on expanding the participant age range (that is, also including participants under 7 years of age and participants above 13 years of age) and cognitive functioning levels (that is, including individuals with below average cognitive abilities) to increase the generalizability of findings. Finally, although non-randomized studies have been conducted outside of the US, well designed RCTs are needed in settings outside of the US to evaluate how well social skills group interventions work in different social and cultural contexts.”</p>
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			<p>treatment, no long-term outcome data were reported</p> <p>Number of participants: 199 participants.</p>	
<p>Schrank et al 2015 UK & Austria [35]</p>	<p>Objectives: To systematically establish:</p> <p>1. What interventions, for parents with SMI after the post-partum period, have been evaluated in the scientific literature, and</p> <p>2. What is known on their effectiveness. It focuses on interventions for parents with psychotic or bipolar disorders and includes all available outcomes reported for both parents and their children.</p>	<p>Population: Parents (16-65 years old) with severe mental illness, past or present diagnosis of a psychotic or bipolar disorder based on ICD or DSM, who had at least one dependent child aged over 1 year and below 18 years of age.</p> <p>Intervention: A range of interventions for parents with SMI, after the post-natal period (child over 1 year).</p> <p>Comparison/control: With or without control.</p> <p>Outcomes: Not reported.</p> <p>Study design: RCT, experimental cohort studies with or without control group, intervention studies.</p> <p>Settings: Home, community residential homes.</p> <p>Other criteria: No.</p>	<p>Characteristics of included studies: 18 publications reporting on 15 intervention studies.</p> <p>Country of origin: 10 articles from USA, 2 from Australia 1 each in Germany, Netherlands and UK.</p> <p>Participants: Parents 16-65 years with severe mental illness with children between 1 to 18 years.</p> <p>DSM/ICD/Disability: Not reported.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: The most frequent intervention components were</p> <p>1. Parenting skills training, mainly focusing on managing child behaviour and</p> <p>2. Educating parents on the impact of SMI on parenting.</p> <p>Home based programmes, complex community-based programmes, online programmes.</p>	<p>Conclusions: “This review establishes the evidence base and identifies areas for development. Based on the heterogeneity of the interventions and their findings, future interventions might offer a combination of different strategies covering a wide range of areas, such as online and face-to-face techniques or a combination of trans-diagnostic and more diagnosis specific aspects. Flexible application of these strategies will accommodate the complex and varying needs of parents with SMI. Rigorous trials should include a direct assessment of both parents and children, relevant public health outcomes, and establish long-term effects ideally until children have reached 18 years of age. More understanding is also needed about intervention components and the</p>

		<p>Studies published: Up to 2014.</p>	<p>Outcome: Different outcomes which were either child related, parents related, family related, or intervention related.</p> <p>Study design: 4 RCT, 2 experimental cohort studies, 5 simple cohort studies without a control group, 1 retrospective chart review, 3 intervention with outcomes without specifying the methods of data collection. Three articles were publications of different stages of a single trial.</p> <p>Follow-up time: Differed from 6 months to 1-2 years.</p> <p>Number of participants: Reported in different ways: Parents, families.</p>	<p>processes underlying the interventions. Integrating qualitative and quantitative evidence on processes and outcomes will improve our understanding on the effectiveness of complex interventions for parents with SMI.”</p>
<p>Sharp et al 2014 UK [36]</p>	<p>Objectives: Evaluate the effectiveness of dance in comparison to other exercise interventions and no intervention for people with Parkinson’s disease (PD).</p>	<p>Population: Participants of any age or gender with a diagnosis (as defined by the study author’s) of PD.</p> <p>Intervention: Any form of dance.</p> <p>Comparison/control: No intervention and other exercise interventions.</p>	<p>Characteristics of included studies: 8 studies (10 articles) included in qualitative synthesis, 5 studies (7 articles) included in quantitative synthesis.</p> <p>Country of origin: Not reported.</p> <p>Participants: The mean age was between 63.3 years</p>	<p>Conclusions: “Dance demonstrates short term clinically meaningful benefits in Parkinson’s disease. Future RCT’s should be well designed and determine the long-term effects of dance, which dose and type of dance is most effective and how dance compares</p>

		<p>Outcomes: <i>Primary outcomes:</i> Motor disability, physical function, gait, balance and quality of life.</p> <p><i>Secondary outcomes:</i> Not specified.</p> <p>Study design: RCT.</p> <p>Setting: Not reported.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2014.</p>	<p>and 71 years in four of the studies</p> <p>DSM/ICD/Disability: Participants of any age or gender with a diagnosis, as defined by the study author's, of PD were included in the analysis regardless of duration of PD, type of drug or surgical therapy, duration of treatment or level of impairment.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Dance.</p> <p>Comparison/control: No intervention, exercise.</p> <p>Outcome: Balance, gait, velocity, 6MWT, PDQ-39.</p> <p>Study design: RCT.</p> <p>Follow-up time: Baseline and final outcome week 10-13, 3 months and 6 months.</p> <p>Number of participants: Dance vs. no intervention, 100 participants.</p>	<p>to other exercise therapies.”</p>
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			<p>Dance vs. exercise, 38-43 participants.</p> <p>Two studies contributed 68 participants regarding PDQ-39.</p>	
<p>Shilling et al 2013 UK [37]</p>	<p>Objectives: The review addressed the following research questions:</p> <ol style="list-style-type: none"> 1. Is peer support for parents of children with disabling conditions perceived as beneficial to their health, well-being, and family functioning? 2. Are these effects measurable and long-lasting? 3. What are the economic implications of this support, and how does it affect service use and relationships with health care professionals? 	<p>Population: Parents and caregivers of children with chronic disabling conditions including disabled, chronically, or seriously ill children and young people.</p> <p>Interventions: Informal or formal support offered to parents by parents in the form of one-to-one or group meetings.</p> <p>Internet or telephone support was excluded, as were professionally led or parenting skills training interventions.</p> <p>Comparison/control: Studies comparing peer support with no peer support, those comparing between different types of support, and those with no comparator group at all were eligible for inclusion.</p> <p>Outcomes: Psychological health of parents. Experience of the person offering or</p>	<p>Characteristics of included studies: 17 studies.</p> <p>Country of origin: 11 studies were conducted in the USA, 3 in UK and 3 in Canada.</p> <p>Participants: Parents of children with mixed conditions, parents of children with specific conditions including dyslexia, limb deficiency, and diabetes.</p> <p>DSM/ICD/Disability: Not applicable.</p> <p>Comorbidity or factors that may affect the outcome: The systematic review is part of a pilot programme evaluation of a one-to-one peer support service offered to parents by Face 2 Face, 11 a UK organization that provides peer support for parents of children with disabling conditions.</p> <p>Intervention: Peer-support.</p> <p>Outcomes/Themes:</p>	<p>Conclusions: “The qualitative synthesis highlights important characteristics of peer support that appear to be generic across different types of support and medical conditions. These include the benefits of finding a shared social identity, the opportunity to learn practical information and be inspired by others, going through a process of personal growth, and finally, finding the ability to support others. The chronology to these stages of support is an overriding theme, thus an important feature of peer support would seem to be its potential for self-sustainability. The qualitative findings are consistent with the growing awareness of the positive and ‘protective’ psychological and physical health effects of sharing a social identity with others..., and the benefits derived by a</p>

		<p>receiving peer support, Economic implications of peer support programmes, Family functioning, Accessing services and information, Relationships with health professionals, Long-term impact of peer support.</p> <p><i>Primary outcomes:</i> Which one of the outcomes above considered primary not clearly stated.</p> <p><i>Secondary outcomes:</i> Which one of the outcomes above considered secondary not clearly stated.</p> <p>Study design: The authors did not limit study inclusion by study design.</p> <p>Settings: The authors did not limit study inclusion by setting.</p> <p>Other criteria: The authors did not limit study inclusion by language, date, or child's condition.</p> <p>Studies published: Up to 2011.</p>	<p><u>Qualitative data (themes):</u> Social identity Learning from the experience of others Personal growth Supporting others When peer support does not work</p> <p><u>Quantitative data (outcomes):</u> Psychological health Family function The experience of parents receiving support Accessing services and information</p> <p>Study design: Seven randomized controlled trials, nine qualitative studies, and one mixed-methods evaluation.</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: 680 participants in the intervention groups (17 studies) and 341 participants in the control groups (7 studies).</p>	<p>person being able to offer support, known as the helper-therapy principle. However, quantitative studies did not substantiate these perceived benefits. Although the general trend on measures of psychological health favoured peer support, few studies reported strong evidence and, in the only study to measure it, no difference in the use of community or health care resources was observed.”</p> <p>“Overall it was not possible to answer the review questions fully.”</p> <p>“This review has identified the need for more robust evaluation of peer support services and identified several methodological challenges. More rigorous evaluation is necessary to help parents and service commissioners make informed decisions about the potential benefits and costs of peer support services.”</p>
Spain et al 2017 UK	Objectives: To evaluate the clinical effectiveness	Population: Families that have at least one person -	Characteristics of included studies:	Conclusions: “In spite of uncertainty about

[38]	and acceptability of family therapy as a treatment to enhance communication or coping for individuals with Autism spectrum disorders (ASD) and their family members. If possible, we will also seek to establish the economic costs associated with family therapy for this clinical population.	<p>Child or adolescent (aged 17 years and under) or adult (aged 18 years and over) – diagnosed with an ASD.</p> <p>ASD was defined according to clinical criteria of either the International Classification of Diseases, WHO or the Diagnostic and Statistical Manual of Mental Disorders, and ideally (but not necessarily) diagnosed using standardised methods of assessment (e.g. the Autism Diagnostic Interview-Revised, or the Autism Diagnostic Observation Schedule).</p> <p>Family members were defined as individuals from multi-generations (parents, grandparents, siblings, children, or spouses), either biologically related to the individual with ASD or related through marriage or cohabitation.</p> <p>Also included were non-professional carers (e.g. individuals providing foster or respite care) and significant others such as friends.</p>	No studies met the inclusion criteria for this review.	<p>effects, it may be that family therapy is deemed clinically appropriate, either in conjunction with other prescribed treatments or as a stand-alone intervention. Decisions to use family therapy should be made in consultation with suitably qualified multidisciplinary professionals. Also, the use of family or systemic therapies should be informed by best practice guidance for clinical work with this population”.</p> <p>“There are several implications for research. Building on the literature to date, there is a need for further intervention studies that employ methodologically rigorous trial designs (i.e. RCTs). This may include studies that examine the clinical utility and effectiveness of psychoeducation for family members, couples’ therapy to strengthen relationships and coping when one parent has ASD, and family or systemic therapy for parents, siblings, grandparents and</p>
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		<p>Studies that described interventions delivered to participants residing in the same dwelling, or interventions offered to family members living separately were included.</p> <p>Interventions: Family therapy interventions delivered by at least one suitably qualified clinician, derived from systemic theories, and specifically focusing on understanding, enhancing and improving aspects of relationships between individuals with ASD and at least one family member, or between two or more members of the family of an individual with ASD (e.g. parents, or parents and siblings).</p> <p>Following modalities of family therapy were included: Systemic therapy, structural family therapy, strategic family therapy, Milan approaches, solution-focused therapy, narrative therapy, and behavioural family therapy.</p>		<p>children of people with ASD, and dyads (e.g. members of two generations and young people or adults with ASD and members of the immediate and extended family). Whether particular systemic approaches glean more favourable outcomes is yet to be established, but this warrants further investigation. Similarly, consideration of treatment mediators and moderators would prove beneficial. As a secondary objective, intervention studies should undertake process evaluations to establish satisfaction and acceptability of these interventions for family members.”</p>
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		<p>The intervention had to have been offered either face-to-face or via web-based real-time sessions.</p> <p>Comparison/control:</p> <ol style="list-style-type: none"> 1. No treatment. 2. Provision of standard clinical care (i.e. treatment as usual). 3. A wait-list control (e.g. a delayed-start intervention). 4. An active comparator (e.g. an alternative psychological intervention such as applied behavioural analysis or cognitive behavioural therapy). <p>Outcomes:</p> <p><i>Primary outcomes:</i></p> <ol style="list-style-type: none"> 1. Quality or quantity of social interaction and communication (e.g. Social Responsiveness Scale by Constantino 2003; Autism Diagnostic Observation Schedule by Lord 2000). 2. Mental health morbidity, including stress, anxiety or depression (e.g. Hospital Anxiety and 		
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		<p>Depression Scale by Zigmond 1983).</p> <p>3. Quality of life (e.g. EQ-5D by Szenda 2007), including quality of relationships with family members (e.g. Family Questionnaire by Wiedemann 2002).</p> <p>4. Adverse effects or events (e.g. increased mental health morbidities, as measured by the Hospital Anxiety and Depression Scale (Zigmond 1983); or an increase in challenging behaviour).</p> <p><i>Secondary outcomes:</i></p> <p>1. Confidence in, or attributions about, coping (e.g. Attributional Style Questionnaire by Seligman 1984).</p> <p>2. Satisfaction with treatment (e.g. Client Satisfaction Questionnaire by Attkisson 1982).</p> <p>3. Dropout from treatment.</p> <p>4. Health economic outcomes, including direct costs (e.g. treatment costs) and indirect costs (e.g. use of clinical services or work</p>		
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		<p>absence due to stress).</p> <p>Study design: Randomised controlled trials (RCTs) and quasi-RCTs (in which participants were allocated by alternate allocation, for example according to days of the week).</p> <p>Settings: Not reported.</p> <p>Other criteria: We included studies in which participants had a comorbidity or were receiving other treatments concurrently to the family therapy, although the intention was to clarify this level of detail from reports or by contacting trial authors.</p> <p>Studies published: Up to 2017.</p>		
<p>Storebo et al 2011 Denmark [39]</p>	<p>Objectives: To assess the effects of social skills training in children and adolescents with Attention Deficit Hyperactivity Disorder (ADHD).</p>	<p>Population: Children and adolescents between five and 18 years diagnosed with ADHD according to DSM-IV or hyper-kinetic disorders from ICD-10, WHO. The main term in DSM-IV is ADHD 314, which is divided into three sub diagnoses:</p>	<p>Characteristics of included studies: 11 studies.</p> <p>Country of origin: Eight of the 11 studies were carried out in the USA, one in Canada, one in the Netherlands, and one in Hong Kong (China).</p> <p>Participants:</p>	<p>Conclusions: “It is not possible to recommend or refuse social skills training for children with ADHD at the moment. Parent and participant satisfaction with the treatment is rated as high and most teachers would recommend the treatment to others,</p>

		<p>predominantly inattentive type (314.00), predominantly hyperactive/impulsive type (314.01), and combined type (314.02). The DSM-IV diagnosis ADHD unspecified (314.9) may also be used, as well as diagnostic categories from earlier DSM systems (DSM- 111 and DSM- III-R) and from hyperkinetic disorders in ICD-9. In addition, we included participants with a diagnosis of ADHD based on a cut-off score from a validated diagnostic assessment instrument, for example, Conners' parent rating scales. We also included participants with different kinds of co-morbidity such as conduct or oppositional disorders, depression, attachment disorder, or anxiety disorders.</p> <p>Interventions: All forms of social skills training where training focused on behavioural and cognitive-behavioural efforts to improve social skills and emotional competence. This means behavioural</p>	<p>Children between five and 12 years old.</p> <p>In four of the studies, the number of girls compared to boys was 1:3 or 1:4, and in three studies, the number of girls compared to boys was nearly 1:2. In three trials, the number of girls compared to boys was as low as between 1:7 and 1:10.</p> <p>In seven of the studies, the participants were between 80 % and 90 % caucasians. In two studies, the ethnicity was more mixed, with 49 % to 61 % caucasians and the majority being of another ethnicity, i.e., 4 % to 20 % Afro-American and 5 % to 16 % Asian. In one study, the participants were all Chinese.</p> <p>DSM/ICD/Disability: All participants were diagnosed with ADHD using tools that had been accepted for inclusion in this review. All these diagnostic tools were based on the international DSM or ICD diagnostic systems, or a cut-off score from the Conners' Rating Scale.</p>	<p>but in two trials there was no difference in this outcome between the social skills training groups and the control group.”</p> <p>“This review highlights the need for more standardised treatment interventions that can be investigated in more high-quality trials, with low risk of bias and with sufficient numbers of participants, investigating the effects of social skills training versus no training for children as well as adolescents with ADHD. There is a need for pre published protocols, which could help with the problem with multiple outcomes and the difficulty of identifying the primary outcomes and the secondary outcomes.”</p>
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		<p>and cognitive treatments focusing on reaching the children how to 'read' the subtle cues in social interaction, such as learning to wait for their turn, knowing when to shift topics during a conversation, and being able to recognise the emotional expressions of others, social 'rules', and expectations of others.</p> <p>Comparison/control: No intervention or wait list control. These control groups were considered equal, and therefore did not distinguish between the control groups, but analysed the trials with relevant outcomes together in the same comparison.</p> <p>Comorbidity or factors that may affect the outcome: Trials with concurrent medical treatment were included if the medication was administered equally in both groups.</p> <p>Outcomes: <i>Primary outcomes:</i> 1. Social skills and emotional competences in</p>	<p>Comorbidity or factors that may affect the outcome: In 10 studies, the children had different types of comorbidities, for example, oppositional defiant disorder, conduct disorder, anxiety disorder, in addition to the ADHD diagnosis.</p> <p>Intervention: The 11 studies had comparable treatment interventions. The interventions were named social skills training, cognitive behavioural intervention, multimodal behavioural/psychosocial therapy, behavioural therapy/treatment, behavioural and social skills treatment, and psychosocial treatment.</p> <p>Five studies had child social skills training and parent training plus medical treatment in the experimental treatment versus medical treatment alone. Another one of these studies also administered academic organisational skills training and individual psychotherapy. Two studies had child social skills training, parent</p>	
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		<p>school or at home, measured at post-treatment and longest follow-up, by well-established and validated instruments, for example, Social Skills Rating System (SSRS) or Conners' CBRS.</p> <p>2. General behaviour in school or at home, measured at post-treatment and longest follow-up, by well-established and validated instruments, for example, the Achenbach Child Behaviour Checklist.</p> <p><i>Secondary outcomes:</i></p> <p>1. Core ADHD symptoms of inattention, impulsivity, and hyperactivity, measured at post-treatment and longest follow-up, by well-established and validated instruments, for example, Conners' parents' rating scales.</p> <p>2. Performance and grades in school, measured at post-treatment and longest follow-up.</p> <p>3. Participant and/or parent satisfaction with the treatment, measured as continuous</p>	<p>training, and teacher consultations in the experimental treatment. The MTA study used child social skills training, parent training, teacher consultations, and classroom behavioural intervention in the experimental treatment. Two studies used child social skills training and parent training plus teacher consultation in the experimental treatment. All of the interventions in the studies were group interventions except one.</p> <p>Comparison/control: Eight studies used medications in both the experimental treatment and as the only treatment in the control treatment and therefore it is comparable with a no treatment control group. One of these studies also included a no treatment control group.</p> <p>Three trials used a wait list control group, without medication in any of the groups.</p> <p>The duration of the intervention was comparable in eight of the included studies and was between eight weeks and 10</p>	
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		<p>outcomes by psychometrically validated instruments such as the Client Satisfaction Questionnaire.</p> <p>4. Adverse events: a) Severe and</p> <p>b) non-severe. The severity was assessed according to the International Committee of Harmonization guidelines (ICH I 996). Serious adverse events are defined as any event that leads to death, is life threatening, requires inpatient hospitalisation or prolongation of existing hospitalisation, results in persistent or significant disability, and any important medical event that may have jeopardised the patient's health or requires intervention to prevent it. All other adverse events will be considered non-serious.</p> <p>Study design: Randomised controlled trials investigating social skills training alone or as an adjunct to pharmacological treatment in comparison with no</p>	<p>weeks. In one study, the intervention lasted for 24 weeks; in one trial for 14 months, and in one trial the intervention lasted for two years.</p> <p>Outcome: <i>Primary outcomes:</i> Social skills competences General behaviour.</p> <p><i>Secondary outcomes:</i> ADHD symptoms Performance in school Satisfaction with the treatment. Adverse events (none of the studies reported on this outcome).</p> <p>Study design: 11 randomised trials.</p> <p>Follow-up time: Not clear.</p> <p>Number of participants: The 11 randomised studies included a total of 747 participants. The number of participants randomised per study ranged from 27 to 576 participants.</p>	
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		<p>intervention or wait list control. We included trials where the children were taking concurrent medication as long as it was in both arms of the trial.</p> <p>Settings: School, home.</p> <p>Other criteria: No</p> <p>Studies published: Up to 2011.</p>		
<p>Sukhodolsky et al 2013 USA [40]</p>	<p>Objectives: To systematically appraise the evidence for using cognitive-behavioural therapy (CBT) to treat anxiety in children and adolescents with higher-functioning autism spectrum disorder (ASD).</p>	<p>Population: Patient population with a primary diagnosis of an ASD.</p> <p>Interventions: CBT.</p> <p>Theoretical underpinnings of CBT assume that pathologic anxiety is the result of an interaction between excessive physiologic arousal, cognitive distortions, and avoidance behaviour. The core components of CBT include teaching emotion regulation skills aimed at reducing physiologic arousal and maladaptive thinking, followed by systematic exposure to feared situations to eliminate avoidant behaviour.</p> <p>Comparison/</p>	<p>Characteristics of included studies: 8 studies</p> <p>Country of origin: Not reported.</p> <p>Participants: Children and adolescents.</p> <p><u>Study 1-8</u> N = 71, 65 boys, age range 10–12 y</p> <p>N = 47, 35 boys, mean age = 10.8 y, SD = 1.4 y, range 8–13 y</p> <p>N = 40, 27 boys, mean age = 9.2 y, SD = 1.5 y, range 7–11 y</p> <p>N = 70, 66 boys, mean age = 11.2 y, SD = 1.8 y, range 9–16 y</p> <p>N = 22, 21 boys, mean age = 11.3 y, SD = 1.5 y, range 8–14 y</p> <p>N = 50, 48 boys mean age = 10.4 y, SD = 1.7</p>	<p>Conclusions: “Eight randomized controlled studies of CBT for anxiety in children and adolescents with ASD were located and yielded significant effects of CBT relative to waitlist or TAU control conditions. Parent ratings and clinician assessments of anxiety but not child self-reports of anxiety were sensitive to treatment change. Future studies should evaluate CBT for anxiety against attention control conditions in samples of children with ASD that are well characterized with regard to ASD diagnosis and co-</p>

		<p>control: No treatment control group or waitlist control group.</p> <p>Comorbidity or factors that may affect the outcome: Comparison groups in which patients receive an alternative treatment will not be included.</p> <p>Outcomes: <i>Primary outcomes:</i> Anxiety. <i>Secondary outcomes:</i> None.</p> <p>Study design: Randomized controlled trials. Case studies, single case designs, and qualitative case reports were not considered for the meta-analysis.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2012.</p>	<p>y, range 7–14 y N = 45, 36 boys, mean age = 8.9 y, SD = 1.3 y, range 7–11 y N = 30, 23 boys, mean age = 14.6 y, SD = 1.5 y, range 12–17 y DSM/ICD/Disability: ASD. No inclusion criterion for the children’s level of cognitive functioning, but all studies included in the meta-analysis were conducted with subjects who had high functioning ASD, defined as IQ above 70. No published studies to the authors knowledge have evaluated CBT in children with ASD and IQ below 70. Comorbidity or factors that may affect the outcome: Most children with ASD receive psychoeducational services or pharmacotherapy (according to the authors), therefore subjects randomized to waitlist (as well as subjects randomized to CBT) were allowed to continue their ongoing treatments. Thus, the waitlist-controlled studies were combined with studies that used TAU-</p>	<p>occurring anxiety symptoms.”</p>
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			<p>controlled conditions because these 2 types of control conditions in studies of children with autism appear to be essentially the same. There was considerable heterogeneity among the studies in describing concomitant treatments including providing no information, reporting a number of subjects receiving concomitant medication, and reporting medication, psychological, and school-based services.</p> <p>Intervention: CBT.</p> <p><u>Study 1-8</u> 6, two-hours group sessions of CBT with child only or with child and parent.</p> <p>12, two-hours group sessions using the Cool Kids manual.</p> <p>15, one-and-a-half hour individual sessions using modular format.</p> <p>16, one-and-a-half hour group sessions using in-house curriculum.</p> <p>16, one-and-a-half hour individual sessions using the Coping Cat manual.</p>	
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			<p>12, one-and-a-half hour group sessions using Face Your Fears curriculum.</p> <p>16, one to one-and-a-half hour sessions using the Behavioural Intervention for Anxiety in Children with Autism Program.</p> <p>13, one hour and fifteen minutes to one-and-a-half hour sessions of individual CBT plus 7 group sessions of social skills training.</p> <p>Comparison/control: 5 studies compared CBT for anxiety with waitlist, 2 with TAU, and 1 with an attention control condition.</p> <p>Subjects randomized to waitlist (as well as subjects randomized to CBT) were allowed to continue their ongoing treatments. Thus, waitlist-controlled studies were combined with studies that used TAU-controlled conditions because these 2 types of control conditions in studies of children with autism appeared to be essentially the same.</p> <p>Outcome: Parent-Rated Anxiety, Clinician-Rated Anxiety,</p>	
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			<p>Child-Reported Anxiety</p> <p>Follow-up time: Not reported.</p> <p>Number of participants: 469 participants (252 treatment, 217 comparison).</p>	
<p>Tate et al 2014 Australia [41]</p>	<p>Objectives: Community-based, leisure/social activity intervention programmes for people with TBI and the efficacy of such interventions.</p> <p>Results of the searches and other literature to provide detailed description of a varied selection of pertinent programmes that aim to increase leisure/social activity after TBI with a view to highlighting future research directions.</p>	<p>Population: Adults with TBI.</p> <p>Intervention: Community-based, leisure-specific (including social activity) intervention programme community-based, leisure-specific (including social activity) intervention programme.</p> <p>Comparison/control: Not reported.</p> <p>Outcomes: Meaningful activity.</p> <p>Study design: All research methodologies involving primary research studies, including uncontrolled studies as well as single-case studies. Review articles excluded.</p> <p>Settings: Not clear.</p> <p>Other criteria: Peer-reviewed articles.</p>	<p>Characteristics of included studies: 9 studies</p> <p>Country of origin: 4 articles from Australia. 1 from UK, 2 from USA, 2 from Canada.</p> <p>Participants: Adults with TBI, 19-63 years.</p> <p>DSM/ICD/Disability: Not reported.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Active leisure programmes, social peer mentoring, individually brokered leisure services, therapeutic recreation model, leisure education programmes in the stroke population, The Clubhouse model.</p> <p>Comparison/control:</p>	<p>“In summary, this systematic review identified nine studies evaluating interventions to increase leisure/social activity in people with TBI. But only two studies (one RCT and one controlled but nonrandomised clinical trial) had sufficient scientific rigour to provide a valid evaluation of the intervention. Although the studies evaluated different interventions (Tai Chi Qigong vs. outdoor adventure experience and goal setting), both studies showed significant between-group differences in mood (Tai Chi Qigong) and quality of life (outdoor adventure and goal setting) favouring the experimental group. They therefore provide support for the conclusion that active leisure programmes improve</p>

		<p>Studies published: 1994-2014.</p>	<p>Alternative intervention or no intervention.</p> <p>Outcome: Mood, quality of life, community integration etc.</p> <p>Study design: Four were controlled studies.</p> <p>Settings: Community day setting, research clinic, community, group home.</p> <p>Follow-up time: None, or 1-3 months.</p> <p>Number of participants: 126 with TBI.</p>	<p>psychological wellbeing in people with TBI. In spite of these positive studies, the evidence base is limited and there is a need for a larger number of better-designed studies.</p>
<p>Tsang et al 2016 Hong Kong [42]</p>	<p>Objectives: Unraveling the existence of different therapeutic interventions and the effectiveness internalized stigma reduction in people with severe mental illness (SMI).</p>	<p>Population: People with SMI, defined as mental illness having a chronic course and leading to significant social and occupational dysfunction such as Schizophrenia, Psychotic disorder, Psychosis, Delusional disorder, Schizoaffective, Bipolar disorder and Personality disorder.</p> <p>Interventions: Community or hospital based therapeutic interventions.</p> <p>Comparison/control:</p>	<p>Characteristics of included studies: 14 studies included in the review and 5 in the meta-analysis.</p> <p>Country of origin: The studies originated from nine countries across Americas, Europe, and Asia.</p> <p>Participants: Not reported.</p> <p>DSM/ICD/Disability: Participants were given a diagnosis of schizophrenia, schizophrenia spectrum disorder, bipolar disorder, or major mood disorder. Participants were mostly given a</p>	<p>Conclusions: “Most programs we reviewed showed significant effects in reducing internalized stigma. As an emerging area, studies were still limited. The programs are implemented by professionals including clinicians, psychiatric nurse, social worker, and non-professionals who are trained according to the program manuals. Among different intervention approaches, psychoeducation seems to be more promising and two</p>

		<p>Conventional treatment.</p> <p>Outcomes: Validated instruments for screening and assessing the severity of internalized stigma.</p> <p><i>Primary outcomes:</i> Not clearly stated.</p> <p><i>Secondary outcomes:</i> Not clearly stated.</p> <p>Study design: Randomized clinical trials, clinical trials, and experimental studies.</p> <p>Qualitative studies and literature reviews were excluded.</p> <p>Settings: Community or hospital-based interventions.</p> <p>Other criteria: There were no limitations in the follow-up period.</p> <p>Studies published: Up to 2014.</p>	<p>diagnosis by psychiatrists according to DSM IV or ICD-10. Two studies recruited participants according to their self-reported diagnosis. One study reported the use of the structured interview procedure in verifying the diagnosis of the research participants.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: Psychoeducation approach with inclusion of a combination of other components such as CBT, social skills training, goal attainment program, and narrative therapy. The duration of these programs ranged from 10 to 40 sessions.</p> <p>Coming Out Proud, a group discussion focusing on topics of secrecy and disclosure of own mental illness. Photovoice: individuals photograph objects or events in their daily lives were used to generate narratives for group discussion.</p> <p>Comparison/control: Controlled group design was employed in ten studies.</p>	<p>novel techniques (i.e., coming out proud and photovoice) deserve more attention. In future, more innovative approaches to reducing internalized stigma should be developed and more RCTs on particular intervention components using standard outcome measure should be conducted so that meta-analysis could be conducted, and effects of the intervention could be compared. All of the above adds to evidence-based practice in internalized stigma reduction.”</p>
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			<p>Treatment as usual (TAU) was applied in seven studies, conventional treatment group (i.e., newspaper reading) in one study, no active treatment in one study, and waitlist control in one study.</p> <p>Outcome: Internalised stigma was assessed as the primary outcome in all the included studies except one which treated internalized stigma as a mediator of dysfunctional beliefs.</p> <p>The internalized stigma scales applied in the studies included Internalized Stigma of Mental Illness (ISMI), short form of Self-stigma of Mental Illness Scale (SSMIS), Chinese Selfstigma of Mental Illness Scale (CSSMIS), Link Perceived Stigma Questionnaire (LPSQ), and Japanese version of Social Distance Scale (SDS-J). Other outcome measurements were also applied to assess the intervention effect, for examples, the Positive and Negative Syndrome Scale (PANSS) and the Rosenberg Self-Esteem Scale (RSES). These outcome measures varied</p>	
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			<p>substantially across studies.</p> <p>Study design: Seven RCTs, three controlled clinical trials and four uncontrolled studies without a control group.</p> <p>Follow-up time: Thirteen studies examined the effect of internalized stigma reduction and one examined the effect of negative symptoms immediately following the internalized stigma reduction intervention. In addition, seven studies examined the sustainability of intervention effect after follow-up periods ranging from three weeks to six months.</p> <p>Number of participants: Sample size of the studies varied from 21 to 205 participants, with a total of 1 131 participants including 879 participants in the experimental groups and 452 participants in the control groups.</p>	
Vanderkerken et al 2013 Belgium [43]	<p>Objectives: To perform a meta-analysis of single-case experiments (SCEs) on the effectiveness of psychosocial</p>	<p>Population: Individuals with autistic disorder exhibiting VCB.</p> <p>Interventions: Psychosocial interventions</p>	<p>Characteristics of included studies: 52 studies.</p> <p>Country of origin: Not clearly reported.</p> <p>Participants:</p>	<p>Conclusions: “...We conclude that the psychosocial interventions reported in the included SCEs were on average highly effective in reducing</p>

	<p>interventions for vocal challenging behaviour (VCB) in individuals with autistic disorder.</p> <p>The aim was to answer four questions:</p> <ol style="list-style-type: none"> 1. What is the overall effect of psychosocial interventions for VCB in individuals with autistic disorder? 2. Are there differences in intervention effects between studies? 3. Are there differences in intervention effects between participants? 4. What characteristics at the level of the participant, at the level of the intervention and the intervention context, and at the level of the study have a moderating effect on the intervention effect? 	<p>directed to the individual and/or the environment.</p> <p>Comparison/control: No.</p> <p>Outcomes: Not stated.</p> <p>Study design: Single-case experiments (SCE). Studies had to offer repeated baseline and treatment data points and had to present raw data for each participant separately (i.e., neither mean scores, nor aggregated data for multiple subjects). Both baseline and treatment condition had to contain at least two data points.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2011.</p>	<p><u>Age:</u> M = 10.1; SD = 7.80; range = 4–52</p> <p><u>Gender:</u> N (men) = 53; n (women) = 20</p> <p>DSM/ICD/Disability: Autistic disorder. <u>ID (level)</u> 0 = average intelligence 1 = High functioning 2 = Borderline intelligence 3 = Mental retardation 4 = Mild mental retardation 5 = Moderate mental retardation 6 = severe mental retardation 7 = profound mental retardation: n0 = 4; n1 = 3; n2 = 2; n3 = 2; n4 = 3; n5 = 4; n6 = 4; n7 = 1</p> <p>Comorbidity or factors that may affect the outcome: <u>Additional language problem:</u> 0 = no additional language problem 1 = additional language problem: n0 = 6; n1 = 33</p> <p><u>Additional diagnosis:</u> 0 = normal hearing and vision according to school records 1 = not any known sensory or physical deficits 2 = Down syndrome 3 = Tourette's syndrome</p>	<p>VCB in individuals with autistic disorder. These results confirm our hypothesis regarding the overall effect.”</p>
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			<p>4 = Developmental delays 5 = Emotional disturbances and normal hearing and vision according to school records 6 = Major depression 7 = Pervasive developmental disorder 8 = Pervasive developmental disorder not otherwise specified and obsessive-compulsive disorder 9 = Schizophrenia, developmental disabilities, non-organic psychosis 10 = Waardenburg syndrome and severe hearing impairment 11 = Seizures 12 = Hypotonia, chronic otitis media, and congenital scoliosis: n0 = 3, n1 = 4 n2 = 1, n3 = 2 n4 = 2, n5 = 1 n6 = 1, n7 = 1 n8 = 1, n9 = 1 n10 = 1, n11 = 1 n12 = 1</p> <p>Intervention: Duration of treatment (in weeks): M = 6.8; SD = 11.74; range = 1–84.</p> <p>Frequency of treatment (sessions/week): M = 7.2; SD = 9.41; range = 1.5–53.63</p> <p>Comparison/control:</p>	
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			<p>No.</p> <p>Outcome: Reducing VCB.</p> <p>Study design: 1 = AB-design 2 = Reversal design 3 = Multiple baseline design 4 = Alternating treatments design.</p> <p>Follow-up time: Treatment data points: M = 37.6; SD = 48.59; range = 3–280.</p> <p>Settings: 1 = Community environment or treatment facility 2 = Home 3 = School: n1 = 21, n2 = 14 n3 = 36</p> <p>Number of participants: 75</p>	
Westbrook et al 2015 USA [44]	<p>Objectives: To identify and describe the effectiveness of behavioural and social interventions that prepare school-aged youth with ASDs for employment after graduation. In addition, the review intended to serve as guidance for planners of transition programs and as an indicator of where further</p>	<p>Population: Adolescents with ASD who were of secondary school age (14–22 years) and involved in transition from school to work activities. Individuals diagnosed with Asperger syndrome, autism, Rett syndrome, childhood disintegrative disorder, or pervasive developmental disorder—not otherwise specified.</p>	<p>Characteristics of included studies: No eligible studies were found. That is, none of the 85 full-text studies met the inclusion criteria.</p>	<p>Conclusion: “This review intended to identify elements of a school-to-work transition program that implemented interventions designed to meet the specific transition needs of individuals with ASD. The available data for drawing a “what works” conclusion did not serve as a foundation for the authors to determine the effectiveness of</p>

	<p>research would be beneficial.</p>	<p>Intervention: An approach to prepare and/or place transition-aged individuals with ASD in a gainful competitive employment setting earning minimum wage or above. Types of employment targeted for inclusion were competitive, supported, or integrated employment. The intervention under investigation had to be directed toward addressing skills and/or behaviours needed by individuals with ASD for employment. Eligible interventions addressed social, behavioural, cognitive, or specific employment skills.</p> <p>Comparison/control: Not reported.</p> <p>Outcomes: Attainment of an employment placement and specific data about the duration and/or retention of that placement. Eligible gainful employment consisted of competitive, integrated, or</p>		<p>interventions in approaching job searching, job placement, or on-the-job supports such as job coaching to achieve successful employment outcomes for transition program participants with ASD. The scientific quality of the available studies is weak and generally do not utilize comparison group study designs. In addition, as stated earlier, studies do not link transition interventions to successful employment outcomes for subjects.”</p>
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		<p>supported employment, employment at sheltered work or nonintegrated work settings was not considered as an outcome measure for this review</p> <p>Employment encompassed full- or part-time placements.</p> <p>Study design: Experimental or randomized controlled trial design, quasi-experimental design (QED), or single-subject experimental design (SSED) to report the effects of the intervention.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: 1943-2011.</p>		
<p>Weston et al 2016 UK [45]</p>	<p>Objectives: To investigate the effectiveness of cognitive behavioural therapy (CBT) across the lifespan for either:</p> <p>(a) Affective disorders more broadly, while focusing on anxiety disorders as well, or</p>	<p>Population: Participants of any age was with a diagnosis of ASD (or autistic disorder, Asperger’s disorder, childhood disintegrative disorder or pervasive developmental disorder not otherwise specified prior to the publication of DSM-V).</p>	<p>Characteristics of included studies: 50 studies of which 48 studies were included in the quantitative analysis.</p> <p>Country of origin: 26 studies were conducted in the USA, 6 studies were conducted in Australia, 5 in UK, 4 in the Netherlands, 2 in Sweden and 1 in</p>	<p>Conclusions: “The results of the meta-analysis indicated that cognitive behavioural therapy (CBT) is associated with a small to medium effect size when used to treat co-morbid affective disorders with children, adolescents, or adults who have</p>

	<p>(b) The symptoms and features associated with ASDs.</p> <p>To investigate whether there are differences in outcome for children, adolescents and adults.</p>	<p>Interventions: A clinician-led CBT intervention, either individual or group-based, incorporating both cognitive and behavioural components and based on well-established and theoretically driven principles and techniques.</p> <p>Comparison/control: Control or comparison group design, e.g. waiting list or treatment as usual (TAU), with or without randomisation.</p> <p>Outcomes: <i>Primary outcomes:</i> Included studies will include at least one validated/standardised outcome measure of either core ASD features, i.e. difficulties in social interaction, impaired social communication or restricted or repetitive patterns of behaviour and interests, or co-occurring symptoms of mental disorder, e.g. anxiety, depression, psychosis.</p> <p><i>Secondary outcomes:</i> Not stated.</p>	<p>Canada, Germany, France, Italy, Singapore, Japan and Korea respectively.</p> <p>Participants: Age range 4-64 years. Gender not reported.</p> <p>DSM/ICD/Disability: ASD.</p> <p>Comorbidity or factors that may affect the outcome:</p> <p>Intervention: Group-based and individual CBT.</p> <p>Comparison/control: Treatment as usual, non-CBT group-based treatment, placebo drug, waitlist control.</p> <p>Outcome: <i>Primary outcomes:</i> Anxiety, emotional regulation, insomnia, Obsessive Compulsive Disorder, depression, self-esteem, quality of life and sense of coherence, stress, Theory of Mind, social skills, Social skills, peer relationships, emotion recognition, problem solving, friendship quality, face-emotion recognition, interest expansion, interpretation of non-literal language, affectionate communication, quality of life, social</p>	<p>ASDs, but this varied according to whether the outcome data was taken from self-report, informant-report, clinician-report, or task-based measures. CBT was associated with a small and non-significant effect size, $g = 0.24$, when the analysis was completed using self-report measures, and associated with significant heterogeneity, when studies at risk of bias were excluded, resulting in low heterogeneity, treatment was associated with a small non-significant effect size, $g=0.09$. CBT was superior to control conditions when the analysis was completed with either informant- and clinician-report measures, both being associated with a medium effect size, but there was significant heterogeneity, a sensitivity analyses reduced heterogeneity, and revealed that CBT remained superior, and was associated with a medium effect size of, $g = 0.45$, and, $g = 0.59$, respectively. Turning</p>
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		<p>Study design: Randomised Controlled Trials and Quasi-Experimental studies will be included. Single case studies, case series, single case designs, qualitative studies, meta-analysis and review articles will be excluded.</p> <p>Settings: Not stated.</p> <p>Other criteria: Outcome measures may be self-report, informant-report, clinician-rated or task-based.</p> <p>Studies published: Up to 2016.</p>	<p>reciprocity, social behavioural impairment, social cognition.</p> <p>Study design: Quasi-experimental or non-randomised.</p> <p>Follow-up time: Between non to 57 months.</p> <p>Settings: Not reported.</p> <p>Number of participants: 2099 participants (1081 CBT, 1018 control).</p> <p>There was small sample size across all studies was, contributing to reduced power. The highest number of participants were 101 CBT, 108 control, whilst eight of the studies included in the quantitative synthesis involved less than ten participants per group.</p>	<p>to consider CBT for symptoms associated with ASDs, the findings from the meta-analysis were very similar to that found for CBT when used to treat co-morbid affective disorders. CBT, when used as a treatment for the symptoms of ASDs, rather than affective disorders, was associated with an effect size that ranged from small to medium, again, dependent upon the type of outcome measure used. Using data from self-report measures, CBT was associated with a small non-significant effect size, $g = 0.25$, and while heterogeneity was not significant, excluding studies at risk of bias to reduce heterogeneity reduced the effect size, it remained small and non-significant, $g=0.1$. There was evidence that CBT was significantly beneficial when the analysis was based on informant-report measures, and resulted in a small effect size, $g = 0.48$, which increased to medium following our sensitivity analysis to account</p>
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				<p>for heterogeneity, $g = 0.52$. Considering clinician report measures, CBT was found to be significantly superior, and associated with a medium effect size, $g = 0.65$. Following the exclusion of studies thought to be at risk of bias to reduce heterogeneity, CBT was no longer superior, and associated with a non-significant medium effect size, $g=0.44$. Task-based measures, which are both less subjective and completed by the participant, were also evaluated to determine whether CBT is an effective treatment for symptoms of ASDs. The initial findings were significantly in favour of CBT as an effective treatment, and associated with a small effect size, $g=0.35$, but the exclusion of studies thought to be at higher risk of bias, led to a non-significant treatment effect, falling in the small range, $g = 0.3$.”</p> <p>“Definitive trials are needed to demonstrate that CBT is an empirically validated treatment</p>
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				for use with people who have ASDs.”
Victor 2009 UK [46]	<p>Objectives: The review considered interventions designed to support carers. It seek to answer the questions:</p> <p>What is known about the outcomes of interventions for carers?</p> <p>What explanatory evidence exists about how interventions support carers and the contextual factors which influence outcomes?</p>	<p>Population: Carers. Defined as: People who care for family members, friends or neighbours on an unpaid basis. The carer could be caring for someone with any type of condition, for example, mental health difficulty, terminal illness and so on and could have varying kinds of relationship to them, for example, parent, child or spouse. Studies which focused upon parents or other carers of non-disabled children and which are therefore concerned with general parenting or childcare were not included. Studies focusing upon young carers (those under the age of 18) were also excluded.</p> <p>Interventions: Interventions directly targeted at carers, rather than those aimed principally at the person who is receiving care which may also benefit carers. The interventions covered included those concerned</p>	<p>Characteristics of included studies: 107 studies.</p> <p>Country of origin: UK.</p> <p>Participants: Carers of people with a range of conditions (28 studies): dementia (28), mental health difficulties (14), stroke (11), and of older people (10).</p> <p>DSM/ICD/Disability: Not applicable.</p> <p>Comorbidity or factors that may affect the outcome: A possible limitation of the search strategy is the potential omission of studies which focus upon interventions specifically for parents of disabled or ill children where this group is referred to in this way rather than as ‘carers’.</p> <p>Intervention: Access to services, health, emotional and social support, education and training, employment, breaks.</p> <p>Comparison/control: Not reported.</p> <p>Outcome: Emotional wellbeing (84 studies),</p>	<p>Conclusions: “Little evidence was identified (within the boundaries of the review: post-1990, UK based research) about the following interventions for carers.</p> <p>Support to access services in personalised forms such as direct payments which give control to the person receiving support. Interventions targeted at carers’ physical health. Interventions aimed at helping carers to maintain or access employment... Befriending schemes. Complementary therapies...”</p> <p>“Most of the evidence which measured outcomes was relatively weak in quality. This is unsurprising given the practical and ethical difficulties which may be encountered in using methods such as randomised controlled trials in social research.”</p> <p>“in some cases, quantitative studies recorded little or no effect upon specific</p>

		<p>with supporting carers to access services, those targeted at carers' physical health, interventions focused upon emotional and social support, education and training for carers, employment-related interventions, and carer breaks. Studies concerning interventions for any type of carer were included with the exceptions of young carers and those undertaking childcare (where this was not for a child with specific additional care needs, for example, through disability).</p> <p>Comparison/control: Not reported.</p> <p>Outcomes: Carer's well-being or ability to care.</p> <p>Study design. All types of empirical study designs were included.</p> <p>Settings: The review was restricted to studies conducted in the UK since 1990.</p> <p>Other criteria: No.</p>	<p>Knowledge (42), Satisfaction (40), Social inclusion (27), Ability to care including skills development and coping (23), Service use (20), Achievement of a break (18), Ability to continue caring (10) Physical health (10).</p> <p>Study design: RCT/other controlled longitudinal, uncontrolled longitudinal, cross-sectional survey, qualitative.</p> <p>Follow-up time: Not reported.</p> <p>Settings: UK.</p> <p>Number of participants: Varying, not summarized.</p>	<p>outcomes in contrast to qualitative studies of similar interventions in which carers did report benefits of this kind. This raises questions about the validity and sensitivity of the outcome measurements used. The standardised measures used in quantitative studies may not adequately cover all the dimensions of complex outcomes such as emotional well-being. Qualitative work is helpful in identifying particular benefits, for example, feeling recognised and valued that can be missed in standardised quantitative outcome measurement. However, it may be that carers retrospectively overstate the benefits of interventions through gratitude in qualitative research. In addition, the changes may, in fact, be very small and therefore difficult to detect quantitatively."</p>
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		Studies published: Up to 2008.		
Virues-Ortega et al 2013 Canada & Spain [47]	<p>Objectives: To provide a preliminary and comprehensive summary of the evidence in support of the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) program.</p> <p>The specific purposes of the study were:</p> <p>(a) To conduct a meta-analysis of studies evaluating the TEACCH program effect over a variety of standardized outcomes including perceptual and motor skills, activities of daily living, behavioural adaptive skills, cognition, and language</p> <p>(b) To identify specific characteristics of the sample, the intervention and the study methodology that could be reliably associated with increased</p>	<p>Population: Individuals with autism spectrum diagnosis (ASD).</p> <p>Interventions: TEACCH intervention.</p> <p>Comparison/control: Intervention group was composed of all individuals in the study undergoing TEACCH, while individuals in the control group were those not receiving TEACCH.</p> <p>Outcomes: Not clearly stated. Described as: Studies reporting outcomes that were not present in at least two other studies were used to compute mean effect sizes of the intervention across all studies, but isolated outcomes were not reported individually.</p> <p><i>Primary outcomes:</i> 1. Not stated.</p> <p><i>Secondary outcomes:</i> 1. Not stated.</p> <p>Study design: Between-group and pre-post designs. Intervention group of the study should</p>	<p>Characteristics of included studies: 13 studies</p> <p>Country of origin: 1 study were conducted in Japan, 2 studies in Ireland and 3 in the USA, 3 in Italy, 1 in Sweden, 1 in Germany, 2 in Greece, and 1 in China.</p> <p>Participants: Mean age range between 2.5 to 32.3 years. Male range between 67 %-100 %.</p> <p>DSM/ICD/Disability: Autism, intellectual disability, pervasive developmental disability not otherwise specified.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention: In six studies the intervention was delivered through a center based TEACCH program.</p> <p>In three studies the intervention was delivered by trained parents in their homes.</p> <p>In two additional cases, parental intervention was</p>	<p>Conclusions: “In summary, the present meta-analysis suggests that:</p> <p>(a) TEACCH effects over perceptual, motor, verbal and cognitive skills may be of small magnitude.</p> <p>(b) Effects over adaptive behavioural repertoires including communication, and activities of daily living may be within the negligible to small range.</p> <p>(c) Effects over social behaviour and maladaptive behaviour may be moderate to large.</p> <p>(d) The evidence base currently available does not allow to identify specific characteristics of the intervention (duration, intensity, and setting) and the target population (developmental age) that could be driving the magnitude of effects, and</p> <p>(e) Effects are, in general, replicated across age groups, although the</p>

	<p>intervention effectiveness.</p>	<p>be composed of five individuals or more.</p> <p>Settings: Not stated.</p> <p>Other criteria: No.</p> <p>Studies published: Up to 2012.</p>	<p>supplemented with either specialized staff working at home or with a support teacher at school.</p> <p>On study relied solely on trained teachers at school.</p> <p>One study relied on trained staff at a group home for adults with autism.</p> <p>Finally, one study used a short-duration intervention in a room for pre-vocational and work-related activities.</p> <p>The hours of intervention varied from 1.5 to 30 every week. However, weekly hours of intervention were not always reported. Intervention duration varied from 1 to 36 weeks.</p> <p>Comparison/control: Control groups attended mainstream schools with special education support, or without it, received some form of specialized eclectic treatment for autism, or underwent some form of specialized treatment including physical or speech therapy. One control group reported received a placebo intervention</p>	<p>magnitude and consistency of intervention effects are greater among school-age children and adults. Again, it is important to acknowledge that these preliminary conclusions are grounded in very limited data. Namely, only two of the meta-analyzed studies were randomized controlled trials (RCT), all studies had small samples, only one study monitored treatment fidelity, and only two studies conducted blinded assessments. Moreover, several outcomes showed evidence of excessive heterogeneity and potential for publication bias. Therefore, our conclusions should be considered preliminary.”</p>
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			<p>consisting of home visits (unstructured presentation of toys and instructions).</p> <p>Outcome: The specific outcomes that were part of the meta-analysis were (number of studies in parenthesis):</p> <p>Activities of daily living (ADL) (6), Cognitive functioning (5), Communication skills (5), Developmental/mental age (5), Language/verbal skills (9), Eye-hand coordination (6), Motor functioning (4), Fine motor skills (6), Gross motor skills (6), Imitation (6), Social repertoire (7), Perception (6), Maladaptive behaviour (4), PEP-R total (6), VABS adaptation composite (4).</p> <p>In addition, 31 additional isolated outcomes reported only in one or two studies, were included in the mean effect size meta-analysis. Five studies reported both isolated outcomes and outcomes that were present in at least two other studies.</p> <p>Study design:</p>	
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			<p>Not clearly reported. Based on a preliminary review of study abstracts most studies were controlled trials and included similar number of participants in intervention and control groups.</p> <p>Follow-up time: Not clearly reported.</p> <p>Settings: Center, home, school.</p> <p>Number of participants: The pooled sample of individuals receiving TEACCH across studies was 172. The overall number of participants varied substantially across studies with a typical sample size of about 30 participants.</p>	
Ziviani et al 2012 Australia [48]	<p>Objectives: To systematically review the literature to ascertain current best practices and efficacy of service delivery to children and young people (CYP) with behavioural issues related to or secondary to disability, who are in out-of-home care.</p>	<p>Population: Children and/or young people aged birth to 18 years with complex psychological and/or behavioural issues, and/or a disability living in out-of-home (including kinship) care, or with their foster caregivers/parents</p> <p>Interventions: Various interventions, programs or support services on the child and young person</p>	<p>Characteristics of included studies: 4 studies.</p> <p>Country of origin: Not reported.</p> <p>Participants: <u>Study 1:</u> 7–15 years <u>Study 2:</u> 7-15 years <u>Study 3:</u> 3-17 years <u>Study 4:</u> 2-8 years</p>	<p>Conclusions: “There is emerging evidence that current practices and interventions for CYP with behaviour issues are effective in creating positive outcomes for these CYP. There is some support of improvements in a CYP's behaviour, delinquency, and placement stability and improvement in some educational outcomes. However, benefits for the CYP's foster caregivers/par-ents</p>

		<p>and/or foster caregivers/par-ents.</p> <p>Comparison/control: Placebo, usual care or different intervention type.</p> <p>Outcomes: Not reported.</p> <p>Study design: Experimental or quasi-experimental longitudinal studies (i.e., randomised, quasi-randomised and non-randomised controlled trials, and cohort studies).</p> <p>Settings: Not stated.</p> <p>Other criteria: Studies were excluded if participants were in treatment foster care as an alternative to residential care or incarceration because the CYP had severe antisocial behaviour, delinquency problems or were chronic juvenile offenders.</p> <p>Studies published: Up to 2010.</p>	<p>DSM/ICD/Disability: <u>Study 1:</u> With, or at risk for emotional and behavioural disorders.</p> <p><u>Study 2:</u> With, or at risk for emotional and behavioural disorders</p> <p><u>Study 3:</u> Challenging behaviour.</p> <p><u>Study 4:</u> Externalising behaviour problems.</p> <p>Comorbidity or factors that may affect the outcome: No studies which included samples of children with a disability were identified. Only studies of children with behaviour issues were found.</p> <p>Intervention: <u>Study 1 and 2:</u> Fostering Individualized Assistance Program (FIAP). Duration = 1.5 years, 3.5 years. Intensity= Variable, however treatment teams generally met monthly.</p> <p><u>Study 3:</u> Small group training on challenging behaviour management.</p>	<p>appear to be somewhat limited. As previously published studies are few in number, and are only of moderate methodological quality, they do not provide conclusive evidence of the effectiveness of these interventions. The authors originally aimed to review studies of CYP with behaviour issues related to, or secondary to, disability, in out-of-home care. As no studies of CYP with disabilities were identified, and given the additional support needs of these CYP, research pertaining to this group would be highly beneficial. Addressing the limitations of previous studies regarding CYP with psychological/behavioural issues will improve the methodological rigour of future studies with CYP who also have disabilities.”</p>
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			<p>Duration= Three days training program Intensity= One-off training and follow-up.</p> <p><u>Study 4:</u> Parent-child interaction therapy (PCIT). Duration= Average number of treatment sessions was 15.95 (SD=6.5). Intensity= Not stated, however, PCIT sessions are typically weekly.</p> <p>Comparison/control: <u>Study 1 and 2:</u> A 'standard practice' group who received care, services and support characteristically provided to CYP in foster care e.g., meeting CYP's welfare needs, developing permanency plans, etc.</p> <p><u>Study 3:</u> No intervention during, and for up to 7 weeks following, the trial.</p> <p><u>Study 4:</u> Two intervention groups were compared, with one group comprising non-relative foster parent/child dyads and the other comprising biological parent/child dyads.</p>	
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			<p>Outcome: Broadly, all interventions aimed to reduce children's behavioural problems, supporting their adjustment, emotional or other mental health issues.</p> <p><u>Study 1 and 2:</u> Reduce the frequency and length of runaway periods, reduce the CYP's risk of incarceration, increase stability of the CYP's foster care placements, develop sustainable permanency plans, to improve school attendance and reduce the number of suspensions and school changes.</p> <p>Caregiver/parent intervention components aimed to equip caregivers/parents with skills necessary to offer children a stable and nurturing home life.</p> <p><u>Study 3:</u> Increase caregivers/parents' knowledge of behaviour management strategies, and enhance their capacity to deal with children's behaviour.</p> <p>Reducing caregivers/parents' stress levels</p>	
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			<p>by altering the meanings (attributions) they attached to CYP's behaviours.</p> <p>Study 4: Increase caregivers/parents' knowledge of behaviour management strategies, and enhance their capacity to deal with children's behaviour.</p> <p>Improvement in caregivers/parents' psychological functioning, a reduction in parenting stress and child abuse potential, and the development of a more positive and fulfilling relationship between foster caregivers/parents and the children they cared for.</p> <p>Study design: Two randomised control trials (RCTs) and two of non-randomised control trials.</p> <p>Follow-up time: <u>Study 1 and 2:</u> Not reported.</p> <p><u>Study 3:</u> Follow-up day 3–4 weeks post-intervention.</p> <p><u>Study 4:</u> Not reported.</p>	
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			<p>Setting: <u>Study 1 and 2:</u> CYP's home and community settings.</p> <p><u>Study 3:</u> Participants recruited from four local foster authority areas.</p> <p><u>Study 4:</u> University outpatient clinic.</p> <p>Number of participants: 539 participants.</p> <p><u>Study 1:</u> 132 (109 with complete data), treated 47 (with complete data), control group 62 (with complete data) (children and young people).</p> <p><u>Study 2:</u> 131, treated 54, control group 77 (children and young people).</p> <p><u>Study 3:</u> 103, treated 49, control group 54 (children and young people) 106, treated 53, control group 53 (Foster caregivers/parents)</p> <p><u>Study 4:</u> 173, treated 75, control group 98 (Parent-child dyad).</p>	
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<p>Zwi et al 2011 UK & Denmark [49]</p>	<p>Objectives: To determine whether parent training interventions are effective in reducing ADHD symptoms and associated problems (for example, disruptive behaviour disorders or specific impairments such as learning difficulties) in children and young people aged five to 18 years with ADHD.</p>	<p>Population: Parents of children and young people aged five to 18 years (or with a mean age above five years), in whom the main problem was ADHD (or hyperkinetic disorder) diagnosed using DSM or ICD operationalised diagnostic criteria. The diagnoses must have been clinical diagnoses by specialists with or without the use of semi-structured or structured interview instruments.</p>	<p>Characteristics of included studies: 5 studies</p> <p>Country of origin: One study was conducted in Canada at The Learning Centre, Calgary, Canada. Three studies were conducted in the USA: one in Memphis, Tennessee; one at The Hofstra University's Centre for Psychological Evaluation, New York; and one at the University of Virginia in Charlottesville, Virginia. The fifth study was conducted in the Netherlands at an outpatient clinic in Groningen.</p>	<p>Conclusions: "There is some indication that parent training may have a positive effect on difficulties experienced by children with ADHD, particularly in terms of general behaviour. Data are more encouraging for the parents and carers of such children (in whom parent training may well be of benefit in reducing parental stress and building a sense of parental confidence). However, data concerning ADHD specific behaviour are more ambiguous. The poor methodological quality of the studies overall makes it likely that there is bias in the results and weakens any conclusions that may be drawn in this review. For many important outcomes, including school achievement and adverse effects, data for this intervention are lacking. Overall, data from this review do not provide sufficiently strong evidence on which to base recommendations for practice."</p>
		<p>Acceptable diagnoses included:</p> <ul style="list-style-type: none"> • Attention Deficit/Hyperactivity Disorder (DSM III-R, DSM-IV). • Attention Deficit Disorder (DSM III). • Hyperkinetic Disorder (ICD-9, ICD-10). 	<p>Participants: Participants included within the review ranged in age from four to 13 years old.</p>	
		<p>Interventions: Parent training programmes where the intervention was designed to train parents in behavioural or cognitive behavioural, or both, interventions to improve the management of their child's ADHD related difficulties.</p>	<p>Ranges, means and standard deviations, where provided, were as follows:</p> <ul style="list-style-type: none"> - Six to 11 years (no other information supplied). - Five to 9 years (means: group 1 = 6.94 (SD= 1); group 2 = 6.56 (SD = 1.03); group 3 = 6.88 (SD = 1.36)). - Six to 10 years (median = 8.0). - Six to 12 years (mean = 8.9). - Four to 12 years (mean = 7.4, SD = 1.9). 	

		<p>The term 'parent training' includes:</p> <ul style="list-style-type: none"> • Group-based interventions • Interventions for individual parents, or for a couple. • The combination of individual or couple and group interventions, and • Parents acting as the main mediators of the intervention with an additional component involving teacher(s) trained in behavioural management. <p>Comparison/control: Not stated.</p> <p>Outcomes: All primary outcomes related to participant children, not to parent outcomes (for example, reduction of parental stress), so studies with only parent outcomes were excluded.</p> <p><i>Primary outcomes:</i></p> <ol style="list-style-type: none"> 1. Change in the child's ADHD symptom-related behaviour in home setting, for example, Conner's or SNAP questionnaires. 2. Change in the child's ADHD symptom-related behaviour in school setting; for example, 	<p>All investigators with the exception of one supplied data on gender. They each reported a majority of male children (179 boys versus 65 girls across the four studies in which this demographic was reported).</p> <p>Most children entered the studies on medication for ADHD symptoms. In general, where reported, participants had to be stabilised on medication throughout the trial and this was established prior to randomisation. It was assumed that medication, where used, was used in the same way across the intervention and control groups.</p> <p>DSM/ICD/Disability: One study used DSM-III-R criteria for ADHD. The children had to demonstrate evidence of ADHD in a wide range of situations and the problems must have been evident before the age of six years.</p> <p>A second study included participants who had to be diagnosed with ADHD using DSM-IV criteria. This study also</p>	<p>"Further well-designed, randomised controlled trials within this population are needed and should be reported clearly in accordance with the principles set out in the CONSORT 2010 Statement (www.consortstatement.org/consort-statement/). Measurement of treatment outcome is often limited to parent and teacher completed questionnaires and could be extended to include, for example, health-related quality of life outcomes (HRQL). Trials need to collect information about adverse events related to any intervention. Researchers should consider child outcomes and not only focus on reduction of parental stress or sense of competence. Child outcomes may also include HRQL, social interactions with peers, family interactions and school achievement.</p> <p>As comorbidity is so common in ADHD, further research with children displaying disruptive behaviour</p>
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		<p>Conner's Teacher Rating Scale.</p> <p>3. Changes in the child's general behaviour; for example, Achenbach Child Behaviour Checklist.</p> <p><i>Secondary outcomes:</i></p> <p>1. Academic achievement of children as measured through school test results or general tests of language or development.</p> <p>2. Adverse events (these could include emotional or psychological trauma of any kind, such as might be suffered by a parent with a history of physical abuse experiencing flashbacks in a discussion about physical chastisement, or parents for whom parent training causes an increase in anxiety or depression about their own skills).</p> <p>3. Changes in parenting skills; for example, The Parenting Clinical Observation Schedule.</p> <p>4. Parental stress, for example, the</p>	<p>required a high level of maternal stress for inclusion in the training programme.</p> <p>Another two studies used DSM-IV criteria.</p> <p>One study reported that DSM-IV criteria were used (that is the proportion of those of Combined type (ADHD-C) and Inattentive type (ADHD-I) were reported). In this study, diagnoses were further reinforced and refined using the Child Symptom Inventory (CSI) and confirmed by parental interview using the K-SADS-PL.</p> <p>One study included participants who met DSM-IV criteria for ADHD, had an IQ > 80 (full scale IQ of the WISCIII-R, for children under the age of six years the Full Scale IQ of the QWPPSI-R) and were four to 12 years old. In addition, both parents (if present) had to be willing to participate in the behavioural parent training program.</p> <p>Comorbidity or factors that may affect the outcome: Not reported.</p> <p>Intervention:</p>	<p>disorders should address these comorbid conditions and not focus on only one area, for example, ADHD or ODD/CD. The effects of gender, both that of the parent and child, should be carefully considered. Many parents and young people wish to limit the exposure of children to psychoactive medication, so it may be useful to explore whether this might be achieved through psychosocial interventions targeted at those most likely to benefit from them.</p> <p>Furthermore, a complementary review of parent training for parents of children under the age of five years who have been assessed as 'at risk' of ADHD would be a timely addition to literature in this area."</p>
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		<p>Parenting Stress Index.</p> <p>5. Parental understanding of ADHD, for example, ADHD Knowledge & Opinion Scale.</p> <p>Study design: Randomised controlled trials (RCTs), including quasi-randomised trials where sequence generation was, for example, by birth date or alternate allocation, that contain at least one measure of ADHD related behaviour.</p> <p>Settings: Not stated.</p> <p>Other criteria: Trials which did not report any outcome data on outcomes relating directly to the child's own behaviour or wellbeing (ADHD-related or not) were not included.</p> <p>Trials in which drug treatments were used alongside parent training interventions (that is parent training plus medication versus medication alone) were included.</p> <p>Studies published: Up to 2010.</p>	<p>In one study two active experimental arms, one for group parent training and one for individual parent training.</p> <p>In a second study two experimental arms, one for behavioural parent training alone, the other for behavioural parent training combined with self-management.</p> <p>In a third study one intervention group received 'Parental friendship coaching' (PFC), a programme that resembled other parent training programmes for the first two sessions then focused on developing social skills in children.</p> <p>The duration of the parent training varied: 12 weekly, two-hour sessions (group treatment), 12 weekly, one-hour sessions (individual treatment).</p> <p>12 two-hour sessions spread over five months.</p> <p>Nine weekly, two-hour sessions.</p> <p>Eight weekly, 50-minute sessions (parent training treatment), and eight weekly one and a half hour sessions (parent</p>	
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			<p>training and self-management treatment).</p> <p>PFC was delivered in eight group sessions of 90 minutes each.</p> <p>One study described efforts to ensure treatment fidelity across all sessions.</p> <p>Comparison/control: Waitlist control group who were offered the group intervention at the end of the study.</p> <p>No treatment control group which at the close of the study received a summary session on the programme content of the intervention.</p> <p>Parent support group as a placebo control.</p> <p>'Treatment as usual'</p> <p>Outcome: <i>Primary outcomes:</i> Change in the child's ADHD symptom-related behaviour in home setting.</p> <p>Change in the child's ADHD symptom-related behaviour in school setting.</p> <p>Changes in the child's general behaviour.</p> <p><i>Secondary outcomes:</i> Changes in parenting skills.</p>	
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			<p>Parental stress.</p> <p>Study design: All included studies were described by the investigators as randomised controlled trials.</p> <p>Four employed a stratified 'block' design and the fifth randomised by individual participants.</p> <p>Two studies involved three arms, the remaining three were, for the purposes of this review, two-armed intervention studies. One study did involve a third group but as it was a normative comparison group of children without a diagnosis of ADHD the study was treated within this review as a parallel group study.</p> <p>Follow-up time: One study had two follow-up assessments at three and six months. No other study reported collecting data at later time points, or planning to do so, and this may be explained by waitlist conditions or financial constraints, or both.</p> <p>Settings: Not clearly reported.</p>	
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			Number of participants: Overall, sample sizes were small, ranging from 24 participants to 96, the remaining studies comprised 54, 48 and 62 participants respectively.	
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