



Online support programmes for family carers of people with intellectual disabilities: Systematic review of the international evidence base.

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Abstract:	<p>Background: This systematic literature review examines the evidence-base for use of online support programmes for family carers of people with intellectual disabilities. Methods: Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines were followed. Databases ERIC, Medline, PsycINFO & CINAHL were searched for studies published between 2011 and 2021. Inclusion criteria were applied to all studies resulting in the inclusion of 19 empirical articles. The research team performed data extraction and quality appraisal using standardised appraisal tools. Results: The quality of the included studies were rated as strong (n=6), moderate (n=11) and weak (n=2). Barriers to using online programmes included access to technology and technical difficulties while facilitators related to accessibility to treatments, reduced costs and flexibility. The majority of included papers (n=14) sought to work with family carers to support their family member with disabilities, rather than to address the specific needs of carers. Conclusions: Online programmes offer the potential to provide great benefit to family carers of people with intellectual disabilities. However, the majority of research has not sought to directly address the needs of carers nor has it sought their views in creating these programmes. A collaborative approach to programme development that engages family carers offers the opportunity to tailor supportive interventions which directly address their needs.</p>

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Introduction

Family carers of people with intellectual disabilities provide ongoing care for their family members which may include medication management, monitoring a physical condition and behaviour management (Yannamani et al., 2009). As approximately 77% of people with intellectual disabilities in England were living with their families in 2017/2018 (Nuffield Trust 2021) family carers play a crucial role in supporting their health and well-being. Family carers report positive experiences of having a family member with an intellectual disability. A systematic review of 22 studies detailed positive increased personal growth, strength and development of parents, while acknowledging that distress and stress may still be present for some (Beighton & Wills, 2019). In a study on family quality of life with a member with an intellectual disability, a number of factors were identified that impacted positively, including, informal supports from family and friends, access to formal professional supports, social relationships, and for some, spiritual and religious support (Boehm & Carter, 2019). There is growing recognition of the need to promote and support the mental and physical health of family carers of children with intellectual disabilities. A range of factors were found to effect family carers health and ability to provide care and support, including, the characteristics of the child, family characteristics and access to support and advice (Marquis et al., 2019).

While recognising the positive effects of having a family member with an intellectual disability, some family carers experience significant and ongoing stress and mental health difficulties (Cook et al., 2019; Totsika et al., 2011). A UK based study interviewed 18 mothers who cared for children with intellectual disabilities and challenging behaviours finding they experienced social isolation, conflict, limited lifestyle and self-blame (Johnson et al., 2006). Mothers discussed the feeling that they were surviving day to day and described conflict with professionals over a lack of service provision (Johnson et al., 2006). Mothers have also been shown to possess higher levels of anxiety and depression than a comparison group of those with typically developing children (Abasiubong et al., 2006). The demands of caregiving and the lack of appropriate support also make participation in employment difficult, especially for mothers (Shearn & Todd, 2000). There is less available research on the impact of caregiving on fathers, however, a qualitative study described how fathers' identity changed following diagnosis from that of 'father' to 'father with a child with intellectual and developmental disability'; this unanticipated change would affect their relationship across the child's lifespan (Marsh et al., 2020b). A systematic review and meta-analysis has suggested that fathers have lower mental health difficulties possibly due to their more limited caring role (Dunn et al., 2019). A second review identified the emotional consequences of a diagnosis of intellectual disability finding that fathers experienced feelings of grief, loss, denial and blame (Marsh et al., 2020a).

Programmes and interventions which provide training to family carers have been shown to have a positive impact on: levels of stress and feelings of confidence (Hudson et al., 2003); child

socialisation (MacDonald & Hastings, 2010); and quality of life (Masulani-Mwale et al., 2018). However, parents face barriers in taking part in such interventions including time, family pressures, cost and availability of services (Davis et al., 2020). Online programmes offer greater flexibility of delivery and have been shown to offer comparable outcomes to more traditional treatment approaches in areas such as parenting styles (Sanders et al., 2014), knowledge and self-efficacy (Corralejo & Domenech Rodríguez, 2018). **By online programme we refer to any intervention or training delivered via the internet for the purposes of improving the lives of carers and their families.**

The COVID-19 pandemic made access to face to face support difficult for families with attempts being made by some services to offer online alternatives (Monaghesh & Hajizadeh, 2020; Webster, 2020). While this has created challenges for family carers (e.g. access to reliable technology), it has also provided opportunities (e.g. reduced travel and delivery costs, improved access to programmes). **In one study, mothers reported the need to stay healthy and how they made the changing pandemic situation work for their child with intellectual disabilities, bringing home the significance of their position as family carers (Embregts et al., 2021). Families reported increased levels of stress and burden of care because of the lockdowns, in part due to the closure and changes to service provision, resulting in significant additional family pressures (Navas et al., 2022). Family carers of adults with intellectual disabilities also reported receiving limited support from services and experienced a feeling of powerlessness. However, support from family and friends was helpful and resulted in resilience (Patel et al., 2021). A recent scoping review evidenced the importance of learning from the Covid-19 pandemic from the perspective of people with intellectual disabilities and their family carers. The review identified three core themes related to ensuring that preventative information is quickly available and accessible regarding prevention and spread of the virus, that reasonable adjustments are made in response to the distinct needs of people with intellectual disabilities, such as access to technology to facilitate the provision of care and support and that treatment and management needs are identified and enabled such as access to acute hospitals and lifesaving interventions (Taggart et al., 2022).**

This paper sought to review and synthesise the current evidence base for the perceived benefits and challenges of online programmes from the perspective of family carers of people with intellectual disabilities.

Methods

The review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021).

Search strategy

A systematic search was conducted on literature published between June 2011 and June 2021 using the electronic databases ERIC, Medline, PsycINFO and CINAHL. Database choices and search terms were refined through an iterative process including consultation with a subject specialist librarian. Searches used a combination of MeSH (Medical Subject Headings) terms and free text terms, organised into categories representing: online delivery, programme, carer and disability. These categories related to the key interest of the review and research question which sought to explore online delivery of programmes or interventions for carers of people with intellectual disability. Each category was broken down into search terms which represented key words and phrases used in our searches. The search terms are presented in Table 1.

Insert table 1 about here

Eligibility Criteria

Inclusion criteria specified that the included studies were required to explicitly address the views and experiences of family carers of people with intellectual disabilities and their participation in online programmes. Publications reporting on empirical studies were included. Only publications available in English language versions were included, due to resource restrictions. Criteria also restricted inclusion to publications appearing between June 2011 and June 2021, in a peer-reviewed format.

The review excluded studies that did not explore online programmes or those which failed to focus on carers of people with intellectual disabilities. Reviews, protocols and discussion articles were also excluded. Empirical studies published in languages other than English were excluded due to resource limitations.

Study Selection

The online platform Rayyan (Ouzzani et al., 2016) was utilised for organising and selecting literature for the review, based on the criteria outlined above. One reviewer (TF) independently screened each search result, while a second reviewer (ML) examined 20% of these. Rayyan software detected 895 duplicates amongst the 5,732 search results. After screening the titles and abstracts, the search results were reduced from 4,837 to 45 articles. The full text of the remaining 45 articles were examined against the inclusion criteria, resulting in 19 studies included in the review. The process is outlined in Figure 1 PRISMA diagram (Page et al., 2021).

Insert Figure 1 about here

Data extraction

Data were extracted on country, study aim(s), design, sample, methods, findings and barriers and facilitators to online programmes. Each member of the project team performed data extraction and quality appraisal using standardised data extraction and quality appraisal tools.

Quality assessment

The mixed-methods appraisal tool (MMAT) was independently employed by all authors in order to assess the quality of included studies (Hong et al., 2018). The MMAT assesses five study designs including qualitative, quantitative randomized controlled trials, quantitative nonrandomized, quantitative descriptive and mixed methods. Two screening and five design specific questions are answered for all included studies. For example, questions for quantitative descriptive designs include 'Is the sampling strategy relevant to address the research question?' and 'Is the sample representative of the target population?' To determine quality, the appraisal questions were systematically applied to each article and a category of 'strong', 'moderate' or 'weak' was assigned based on the evidence regarding specific criteria in agreement with MMAT guidance (Hong et al., 2018).

Data analysis

Due to the variety of included methodological approaches it was not possible to conduct meta-analysis. A narrative synthesis was chosen as the most appropriate approach to summarise data from the included studies (Popay et al., 2006). This allowed key concepts to be identified and grouped together for ease of comparison. Concepts were grouped under subject headings or themes which were then discussed by members of the research team for verification.

Results

Study characteristics

Details of the 19 studies that met the aim of the review are displayed in Table 2. Of the 19 included studies, 16 adopted quantitative designs, 2 used qualitative methods and 1 utilised a mixed-methods design. The largest number of studies were conducted in the United States (n=9). The other research was undertaken in Canada (n=3), Italy (n=2), Australia (n=1), Finland (n=1), Hong Kong (n=1), Turkey (n=1) and the United Kingdom (n=1). The study samples ranged in size from 2 to 110 participants.

Insert table 2 about here

Quality Appraisal

Of the final 19 studies, set out in Table 3, 6 were assessed as 'strong', 11 scored 'moderate' and 2 scored 'weak.' A paper was only deemed to be 'strong' in terms of quality if the answer was 'yes' to all five of the methodological quality criteria on the MMAT (Hong et al., 2018). Two of the studies that were found to be of 'strong' quality were quantitative randomised controlled trials (RCTs) (Antonini et al., 2014; Vismara et al., 2018). These papers described appropriate randomisation; comparable groups at baseline; complete outcome data; blinding of assessment and adherence of participants to the intervention. Other papers rated as 'strong' were Cankaya and Kuzu (2018), which utilised a multiple probe research design, Davis et al., (2020), who employed a non-concurrent multiple-baseline design, Heitzman-Powell et al., (2014), pre and post design, and Lee et al., (2019), exploratory qualitative design.

Two quantitative studies employing non-randomised quasi experimental designs without controls (Lindgren et al., 2016; Siracusano et al., 2021) were found to be 'weak' in relation to the following five areas; representativeness of the population; appropriateness of measures for outcome and intervention; completeness of outcome data; control of confounding variables; administration of the intervention as intended.

Insert table 3 about here

Areas of intervention

While all studies met the aim of this systematic review, there were clear differences and nuances between their programmes. One of the clearest distinctions was that some of the interventions (n=4) offered support directly to the parent/carer, whilst the majority of the articles (n=14) discussed interventions that supported carers, who in turn, supported their family members. The remaining study (Siracusano et al., 2021) covered both; the intervention described in this paper aimed to significantly improve the adaptive functioning of young people with Autistic Spectrum Disorder, while also reducing stress among parents.

Of those studies that addressed interventions which supported the parents/carers directly, two adopted mindfulness techniques (Flynn et al., 2020; Lunskey et al., 2021) to improve the well-being of the parents/carers. De Luca et al., (2021) examined the impact of an Online Skype Therapy programme and was interested primarily in reducing the levels of carer anxiety, while Lappalainen et al's., (2021) study was interested in increasing parental well-being through the internet-delivered Acceptance and Commitment Therapy (iACT). Those parents in the iACT group (i.e. the intervention group of an RCT) had three online meetings with a clinical psychologist, as well as participating in a 10-week online programme, which comprised of 5 modules, each 2-weeks in duration. Lappalainen et al., (2021) described how the modules were centred around the ACT approach: (1) What is important to you? (2) meaningful actions; (3) present moment; (4) distance to thoughts and feelings; and (5) acceptance and self-compassion.

It may be worth noting that of those interventions primarily interested in supporting the carer directly, all (n=4) were recently published (i.e. 2020/2021). This might suggest that the online delivery of carer wellbeing has only come to the fore in recent years.

The 14 papers which focused on supporting family carers to support their family members with disabilities employed a range of approaches. Two of the interventions offered technology to assist parents in teaching their children to perform certain household tasks, for example cooking an omelette (Cankaya & Kuzu, 2018; Davis et al., 2020). Other papers addressed problematic behaviours and the positive impact that online carer programmes can have on such negative behaviours (Antonini et al., 2014; Benson et al., 2018; Siracusano et al., 2021). Three papers discussed the communication needs of the individuals being cared for (Douglas et al., 2017, 2021; Simacek et al., 2017). Douglas et al. (2017; 2021) both employed single-case multiple-probe designs to investigate online delivery of training to improve the language modelling of family carers in children with complex communication needs. The intervention described by Simacek et al., (2017) was founded on Functional Communication Training, which is a reinforcement-based approach aiming to replace inappropriate or challenging behaviour with an appropriate communicative response, with coaching via telehealth. Two of the papers focused on online training for parents to enable them to implement Applied Behaviour Analysis (ABA) techniques (Heitzman-Powell et al., 2014; Lindgren et al., 2016). Most of the included studies sought to deliver therapeutic training to address a need identified by the researchers (e.g. problematic behaviours, communication, mindfulness). Only Hinton et al. (2017) sought to consult with parents, through focus group interviews, regarding their preferences and further supports as part of their TPOL-D programme. No studies sought to include the perspective of family carers in the design, conduct or analysis of their work so that it might better address their needs.

Benefits of online programmes

The majority of papers (n=15) identified and discussed the benefits of using online programmes. The most predominant facilitator of online programmes was that they enhanced

accessibility and reduced the impact of geographical barriers (Lindgren et al., 2016; Siracusano et al., 2021). This implies that individuals/families who live in remote, rural or isolated settings can participate in programmes that may otherwise not be a possibility for them (Antonini et al., 2014; Lunskey et al., 2021). Online programmes also reduce the cost of transportation (Douglas et al., 2017; Heitzman-Powell et al., 2014; Lunskey et al., 2021) and allows families without access to transport to participate (Antonini et al., 2014). Other ways in which costs of online programmes are lower than in-person approaches include savings made on facilities and childcare costs (Douglas et al., 2017; Lunskey et al., 2021).

The flexible nature of being able to access the content provided by online programmes was emphasised, in terms of when and where one can access the resources (Hinton et al., 2017). Lunskey et al., (2021) also highlighted the benefit of how online programmes enable individuals to view recordings of the sessions at a later stage. In addition, the use of various types of technology (e.g. telehealth connection, video recording of interventions and conferencing technology) were deemed to be useful in terms of enabling caregivers to interact with their children in different situations and care settings (Davis et al., 2020). Recent research by De Luca et al., (2021) emphasised that since the COVID-19 pandemic, video conferencing interventions tend to reduce levels of anxiety and distress in remote caregivers, with the use of technology having the capability to provide a meaningful connection between absent caregivers and their family member.

Challenges of online programmes

Most (n=10) papers also discussed potential challenges of the online nature of the programmes. It was highlighted that online programmes are clearly limited to those families who own the necessary technology and have an internet connection (Antonini et al., 2014; Davis et al., 2020; Vismara et al., 2018). It was acknowledged by Antonini et al., (2014) however, that at that time, internet and technology access was increasing and free web-conferencing technology was straight-forward and easy to download. Heitzman-Powell et al., (2014) reiterated this challenge around online programmes, by highlighting that some parents living in rural areas may have limited access to the necessary telemedicine technology.

Another issue discussed by the selected studies was around the potential for technical difficulties to arise when using online programmes, such as web-browser issues and logging in problems (Douglas et al., 2017; Heitzman-Powell et al., 2014) It was proposed that these types of technical difficulties might disrupt the fluidity of collecting and observing data (Davis et al., 2020). One of the more recent studies emphasised that online resources could be offered as complementary to in-person programmes, and not simply a replacement (Siracusano et al., 2021).

For Review Only

Discussion

This review brought together the latest research regarding family carers of people with intellectual disabilities who were provided with support via online platforms. Included studies sought to address areas including anxiety reduction, mindfulness, activities of daily living, problem behaviour and communication. Few studies (n=4) focused on directly supporting family carers whilst the majority (n=15) sought to help their family member through upskilling the carer. This suggests that further efforts are required to support family carers themselves, particularly due to their poor mental health (Cook et al., 2019; Totsika et al., 2011).

The quality of included papers varied with six being described as strong (Antonini et al., 2014; Cankaya & Kuzu, 2018; Davis et al., 2020; Heitzman-Powell et al., 2014; Lee et al., 2019; Vismara et al., 2018) and two described as weak (Lindgren et al., 2016; Siracusano et al., 2021). Both of these scored poorly on three out of the five design specific questions included in the MMAT. These were in relation to accounting for confounding variables, appropriateness of measurement, completeness of outcome data and representativeness of the target population. The majority (n=11) were assessed as possessing moderate quality. These papers scored poorly on one or two out of the five MMAT questions. These questions related to accounting for confounding variables, representativeness of the target population and divergence between quantitative and qualitative findings. There appears to be a dearth of high quality evidence in this field. Research councils and other funding bodies should prioritise the development and testing of high quality interventions to support family carers given their crucial role in providing care to their family members. If the only focus of concern were the economic benefits of 'informal' care, then a study in Sweden (Ekman et al., 2021) suggests providing programmes or interventions to better support carers makes sound economic sense. In Sweden, where 15% of the population have caregiving roles, it was estimated that savings to the economy of approximately 14.5 billion Euros or 16.3 billion USD were made annually (Ekman et al., 2021). Therefore, investing in research and evidence-based programmes to support the vital role of carers may be cost effective.

The benefits of directly supporting carers were also highlighted by the UK's Cabinet Office, as part of their 'Think Family' policy initiative (Morris et al., 2008; Social Exclusion Task Force, 2009) which recognised the importance of services and supports that address the specific and independent needs of family members providing care, so as to maintain or enhance the support they are then able to provide. This includes supports that only indirectly relate to their caring role, for example, to maintain their paid employment or address their mental wellbeing. Such services and supports therefore perceive the carer as a service user in their own right (Hughes, 2010).

The systematic review highlights the benefits of using online approaches including accessibility in relation to travel, childcare costs, reduced cost of delivery, greater opportunity for participation, flexibility and connecting families. One study showed that online delivery had the

effect of reducing anxiety and burden in carers and could be useful as a complimentary approach to traditional approaches (De Luca et al., 2021). Whether this was due to contact with a therapist or the delivery mechanism itself is unclear. However, if carers have difficulties with arranging and or paying for care when they need to attend appointments or can receive remote advice and reassurance from a professional this could reduce their anxiety.

The downside of online approaches focused on access to and difficulties with technology. However, as we become increasingly used to mobile devices and have better access to reliable digital networks many of these difficulties will be overcome. To these we might also suggest the distancing from full spectrum of human contact. For example, the nuances of body language may be missed when using online communication which only displays carers from the shoulders up.

There is growing recognition of the utility of online approaches for addressing the needs of family carers which may partly be due to the increasing digital literacy of carers and the ubiquity of technology. The COVID-19 pandemic has significantly increased familiarity with online platforms (Webster 2020) and demonstrated that many services can be delivered online. Of course some services will always need to be delivered face to face and online platforms should be used where they can be most effective in addressing the needs of carers.

Implications for policy

Arising from the findings of this review are implications for policy that need to be considered for the future, notably in relation to long COVID. As the full implications and long-term effects of the COVID-19 pandemic are realised, policy makers need to ensure that the needs of families caring for people with intellectual disabilities are fully recognised and included. This is important due to the impact on the health and well-being and quality of life of families when caring for a family member with an intellectual disability (Arora et al., 2020; Totsika et al., 2017). There is scope for policy makers to ensure that specific needs of families of people with intellectual disabilities are included in post-pandemic responses, thereby seeking to ensure there is on-going access to social support networks (Willner et al., 2020). As the full extent of the effects of COVID-19 and lockdown restrictions during the pandemic on physical and mental health of family carers become apparent, primary care and mental health policies need to reflect the needs and concerns of families and their family member with intellectual disabilities (McBride et al., 2021; Theis et al., 2021). **Online** programmes for families may be one approach for inclusion in future post-pandemic health policies. Failure to recognise and respond to the needs of this population will impact negatively on their long-term health and capacity and capability to continue to care and provide support for their family members (Lorenz-Dant & Comas-Herrera, 2021).

Potential biases in the review process

We reduced bias in this review by following predetermined data extraction and quality appraisal questions and ensured our search terms were appropriate through consultation with

a subject specialist librarian. However, we did not seek to include studies published in languages other than English. This was due to limitations in the availability of translation services and means that we may have missed some aspects of the international evidence-base.

Conclusions

More research focusing on online support programmes for carers of those with intellectual disabilities is needed. This work should be co-designed with carers so that it addresses issues which directly impact on their lives. Much of the work included in this review was conducted in high income countries, however, the ubiquity of online platforms and mobile technology would mean that people living in low income countries could also benefit from inclusion in such work. It may not be appropriate to deliver all types of support and services online, however, such programmes offer a low cost opportunity to deliver care and support which is convenient and open to all who wish to avail of it.

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Table 1: Search terms employed in this review.

Online delivery	Programme	Carer	Disability
online; internet; e-learning; web*; virtual; computer-based; electronic; tech*; telemedicine	program*; intervention; training; education*	care*; parent*; famil*	"intellectual disab*"; "mental retard*"; "mental handicap"; "developmental disab*"; "learning disab*"; "cognitive functioning"; "cognitive impairment"; "intellectual impairment"

For Review Only

Table 2: Characteristics of included studies

Author and Country of Origin	Aim(s)	Design	Sample	Methods	Findings	Barriers and facilitators to online programmes
Antonini et al. (2014) USA	To compare the efficacy of an online positive parenting skills intervention program focused on young children with Traumatic Brain Injury (TBI) (Internet-based interacting together every day: recovery after childhood TBI; I-InTERACT) with access to Internet resources (Internet Resource Comparison; IRC) in increasing positive parenting behaviours and reducing child behaviour problems.	Pilot RCT.	37 families of children with TBI provided informed consent and were randomized to I-InTERACT (n = 20) or IRC (n = 17).	The Dyadic Parent–Child Interaction Coding System (Eyberg, Nelson, Duke, & Boggs, 2005) coded recordings of parent–child interactions and determined changes in parenting skills. Child Behaviour Checklist (Achenbach & Rescorla, 2000, 2001) measured emotional/behavioural functioning. Eyberg Child Behaviour Inventory (Eyberg & Pincus, 1999) assessed behavioural functioning.	Participants using I-InTERACT improved their positive parenting skills relative to those in the IRC group. Parents in the low-income I-InTERACT group and high-income IRC group reporting the greatest improvements in behaviour.	Web-based videoconferencing technology removed the need for families to travel. Online programs disadvantage families who lack internet access. However, the technology is increasingly available and is widely used.
Benson et al. (2018) USA	To employ tele-supported live homebased parent coaching Functional Analysis (FA) + Functional Communication Training (FCT) to assess and intervene for Self-Injurious Behaviour (SIB).	ABAB single-case experimental design.	No demographics on carers. Two boys. One had cerebral palsy (8 years old) and one had Autism Spectrum Disorder (ASD) (5 years old).	Parent fidelity of implementation.	Parents successfully implemented the FA and FCT protocol with 95% overall fidelity via telehealth-supported coaching.	The results provide additional evidence that parents can implement FA and FCT procedures for their child with SIB when supported by live coaching via telehealth.

Cankaya et al. (2018) Turkey	To identify the effectiveness of mobile skill teaching software (Independent Life Education, ILE) for use by parents of children with intellectual disability.	Multiple Probe research design.	4 adults with intellectual disabilities (n=3 male, 2 with Down syndrome) (n=1 female) and their parents.	Parents taught their children to cook a cheese omelette with use of the software. 32 teaching activities and 20 data collection practices related to baseline and follow-up phases were carried out. 52 videos recorded were viewed by a special education expert, and the performances of the individuals with Intellectual Disability were determined.	Parent activities with use of the software were found to be effective.	Not discussed in full, although the online nature of the support given to parents is expected to have a positive impact.
Davis et al. (2020) USA	To evaluate the effectiveness of using technology for remote caregiver training of a token economy used during routine non-preferred activities.	Non-concurrent multiple-baseline design	1 male and 1 female carer, each with a child with an ASD diagnosis.	Surveys and interview schedules designed for the study.	Caregivers were able to implement the fixed interval schedule of reinforcement required to effect behaviour change within the token economy. Caregivers reported greater positive experiences and interactions with their children.	Remote carer training increased desired interactions between the child and caregiver. Telehealth and video recording of interventions and conferencing offers tools for caregivers to interact with their children in different situations and care settings.
De Luca et al. (2021) Italy	To evaluate a systematic online therapy (online Skype therapy, OLST) to support global	Pre-post pilot study (no control group).	Carers of 25 participants affected by severe ABI aged between 24 and 70 years.	Caregivers were evaluated before and after the treatment using the Zung Self-Rating Anxiety Scale	Significant results included a reduction in caregiver's	Video conferencing interventions reduce anxiety and distress in remote caregivers and using

	cognitive and sensory-motor recovery in severe Acquired Brain Injury (ABI) patients and reduce caregiver distress.			(Zung, 1965) and the Zarit Burden Interview (Zarit et al., 1980).	anxiety and burden.	technology helps absent caregivers connect with ill loved ones in meaningful ways.
Douglas et al. (2017) USA	To determine the effectiveness of online parent training to support children with complex communication needs (CCN).	Single-subject multiple-probe.	Parents and their children (with CCN) (n=4 dyads)	Video recorded sessions (X3 points) (15 minutes). Clips analysed using Datavyu software (Datavyu Team, 2014).	Online parent training showed higher levels of communication opportunities. Parents found the programme beneficial.	Minor challenges identified by some parents: web browser issues and logging in problems. Online training reduced the cost of transportation, training facilities and childcare.
Douglas et al. (2021) USA	To investigate whether telepractice is an effective and socially valid means for teaching multiple family members to implement aided language modelling with fidelity in the home.	Single-case multiple-probe design across 4 dyads.	Four family members (mother, father, sister and brother) of one child with Phelan-McDermid Syndrome.	Implementation of aided language modelling using the speech generating device	Telepractice-based training and coaching increased family members' high-fidelity models and rate of modelling	Telepractice was effective and socially valid.
Flynn et al. (2020) UK	To examine whether an online mindfulness programme can be delivered successfully to family carers of individuals with Intellectual Disability and determine the feasibility of conducting a full Randomised Controlled Trial (RCT).	Feasibility RCT.	Family carers (n=60; 55 female and 5 male).	Feasibility questions (recruitment, retention, adherence and acceptability). Randomised to complete Be Mindful (online intervention) Semi-structured process evaluation interviews conducted (n=18)	Possible to recruit and retain 88% of participants to a full RCT. Study design and intervention are acceptable. Guided telephone support was perceived as motivating.	Feasible to deliver mindfulness with ongoing telephone guided support to family carers of people with Intellectual Disability . Some benefits over receiving mindfulness alone.

<p>Heitzman-Powell et al. (2014)</p> <p>USA</p>	<p>To investigate the feasibility of training parents to implement Applied behaviour Analysis (ABA) outreach training with their autistic children. OASIS (Online and Applied System for Intervention Skills) programme (Heitzman-Powell, Buzhardt, Suchowierska, & Morrison, 2003).</p>	<p>Pre-post test design.</p>	<p>Seven parents from 4 families of children with autism living in rural or remote areas.</p>	<p>Pre and post online tests examined: Parent skill assessment- 2 trained observers independently assessed and coded recordings; Parent knowledge assessment- 48 multiple-choice items, with six items from each of the eight online tutorial assessments; Parent satisfaction with training- survey administered to determine the OASIS programme's social validity (Schwartz & Baer, 1991); time and cost savings.</p>	<p>Parents' knowledge of ABA strategies increased. Parents' implementation of ABA strategies increased. Parents saved over 9,000 miles of travel- this was an online programme.</p>	<p>Parents were highly satisfied with the online training and coaching sessions. Those living in rural areas had limited access to technology. Lack of awareness of the technology required for telemedicine. Technical difficulties with equipment. Fees charged for telemedicine and associated IT support. Coaches unable to physically prompt parents due to being online.</p>
<p>Hinton et al. (2017)</p> <p>Australia</p>	<p>To examine the efficacy of Triple P Online – Disability (TPOL-D) a telehealth intervention for parents of children with a disability.</p>	<p>RCT.</p>	<p>98 parents and carers of children aged 2–12 years diagnosed with a range of developmental, intellectual and physical disabilities. 76 = male 22 = female.</p>	<p>Developmental Behaviour Checklist – Primary Carer version (Einfeld & Tonge, 2002); Child Adjustment and Parent Efficacy Scale – Developmental Disability (Emser, Mazzucchelli, Christiansen, & Sanders, 2016); The Parenting and Family Adjustment Scales (Sanders & Morawska, 2010);</p>	<p>Parents receiving the intervention demonstrated significant improvements in parenting practices and parenting self-efficacy. At 3-month follow up intervention gains were maintained and/or enhanced. A significant decrease in parent reported child behavioural</p>	<p>Flexibility in access to content, resources and facilitator support contributed to successful outcomes. Parents were able to decide: a) when and where they accessed the modules; b) when and if they used the additional hardcopy resources; c) the amount of facilitator support they required; and</p>

				The Client Satisfaction Questionnaire (Sanders et al., 2001).	and emotional problems.	d) the medium in which facilitator support was provided.
Lappalainen et al. (2021) Finland	To determine if internet-delivered iACT (Acceptance and Commitment Therapy) with the guidance of student therapists was effective at enhancing the psychological well-being of parents in comparison to self-help ACT intervention without guidance.	RCT.	A total of 110 parents (103 females, 7 males) of children aged 0.8 to 17 years with chronic conditions and developmental disabilities. Children were 76 males, 35 females. 36 children had developmental disabilities.	Shirom-Melamed Burnout Questionnaire (Melamed et al., 1999). Depression; Patient Health Questionnaire-9 (Kroenke et al., 2001). Health-related quality of life measured by the Finnish version of the SF-36 measure (Ware and Sherbourne, 1992) the RAND-36 (Aalto et al., 1999).	Burnout showed a decrease in both groups. Intervention produced significantly larger improvements in depressive symptoms, psychological flexibility and mindfulness compared to control.	Suggestions for future research indicate that support provided via video conference calls could be improved to provide more convenient and adequate support and peer support should be included in the intervention.
Lee et al. (2019) Hong Kong	To gain insight into the experiences of family carers participating in a weight management programme via mHealth (Mobile Health) tools for overweight children and adolescents with intellectual disabilities.	Exploratory qualitative design.	20 family carers of overweight children and adolescents with Mild Intellectual Disability (MID); 4 males and 16 females.	5 focus groups with 4 participants in each.	4 main themes: (a) improving carer-child interactions and communications; (b) gaining useful and practical health information from experts via mHealth tools; (c) supporting each other via the mHealth platform; and (d) appreciating the collaborative effort between school personnel and family carers.	Family carers reported that the intervention had facilitated their motivation to reinforce and monitor their child's behaviours at home. Some found the WhatsApp group very helpful to motivate them to learn new health information and to enhance their role in monitoring and supporting their child's healthy behaviours.

Lindgren et al. (2016) USA	To determine whether challenging behaviour in young children with autism and other developmental disabilities can be treated successfully at lower cost by using telehealth to train parents to implement applied behaviour analysis (ABA).	Quantitative nonrandomized quasi experimental study without controls.	107 young children with autism or other neurodevelopmental disorders aged 21-84 months who were treated between 1996 and 2014 for problem behaviour (data focused on the 94 who completed treatment). Carer data were available for only groups 2 and 3 (i.e. clinic and home telehealth).	Comparison of outcomes and costs associated with 3 different models for delivery of Functional Analysis (FA) and Functional Communication Training (FCT) to treat problem behaviour and replace it with appropriate social communication. 3 groups: 1) in-home therapy 2) clinic telehealth 3) home telehealth Parents were coached to conduct FA and FCT during weekly sessions, and later by telehealth at home. Behavioural outcomes and treatment acceptability (Treatment and Acceptability Rating Form – Revised; Reimers et al., 1991)	Parents successfully used FA and FCT to treat moderate to severe behaviour problems regardless of whether treatment is directed by behaviour consultants or via remote coaching. No statistical or clinically significant differences in outcomes related to service delivery method. Costs were lowest for home telehealth. Treatment and acceptability were high for all groups.	Facilitators – geographical barriers can be minimised using telehealth. ABA telehealth can treat problem behaviour at a lower cost compared with in-home therapy. Barriers – timing and dose issues warrant careful study.
Lunsky et al. (2021) Canada	To evaluate the feasibility, acceptability and preliminary outcomes of a manualised mindfulness-based group intervention delivered virtually to parents of young	Pre-post pilot study (no control group).	39 parents, primarily mothers (89.7%) and English speaking (89.7%), of adolescent and adult-aged autistic sons and daughters from seven provinces in Canada.	Depression, Anxiety & Stress Scale (Henry and Crawford, 2005); the Five-Facet Mindfulness Questionnaire (Baer et al., 2006); the Bangor Mindfulness Parenting Scale (Jones et al., 2014); the Self-	It was feasible to deliver the Intervention-i.e. the technology worked, parents were recruited, and a good proportion of people completed (21/39). Parents	Facilitators of online support include: being accessible to people who live remotely, ability to mute oneself or take a break, time and cost saved not having to travel to a group or arrange

	people or adults with autism.			Compassion Scale— Short Form (Raes et al., 2011); the Revised Caregiving Appraisal Scales (Lawton et al., 2000) the Positive Gain Scale (Jess et al., 2020); and a bespoke satisfaction survey.	completing the intervention reported high satisfaction ratings, reduced levels of distress (maintained after 3-months), and increased mindfulness.	childcare, and ability to view recordings.
Marleau et al. (2019) Canada	To conduct a preliminary examination of (a) the effects of Interactive Web Training (IWT) on function identification and intervention selection by parents, (b) its duration, and (c) its social validity	Pre post design.	26 parents of children with developmental disabilities (23 male and 3 female).	Function identification tasks – parents could identify the challenging behaviour; Intervention selection tasks – use of clinical vignettes adapted from Shayne & Miltenberger (2013); Treatment Acceptability Rating Form Revised (Reimers, Wacker, & Cooper, 1991); The Web App recorded time on the module, number of times accessed and correct quiz responses.	Parents were more accurate in identifying behavioural function and selected more adequate interventions following IWT which was rated positively.	Parents found the format and content socially acceptable and reported that the training was easy to follow.
Simacek et al. (2017) USA	To determine the effectiveness of parent-implemented communication assessment and functional communication training (FCT) via telehealth for young children with severe neurodevelopmental disabilities.	Single case experimental design.	Children aged 3-5 years old (n=3) with severe neurodevelopmental disabilities. Number of carers not specified.	Functional assessment interview (O’Neill et al., 1997) and preliminary observations of free play sessions. Structured descriptive assessment (Anderson and Long, 2002) identified responses and potential contexts to embed the communication training	Participants had multiple communication responses across multiple contexts during parent-implemented intervention delivery. Parents were successful at implementing the procedures.	Telehealth is cost effective compared to home-based clinical delivery. Approach could be used as an adjunct to routine interventions. Future research could investigate use of telehealth to train and support

				intervention. A consequent-based functional analysis (Iwata et al., 1982) to identify relations between the challenging behaviour and social reinforcers.		service providers in rural settings.
Siracusano et al. (2021) Italy	To longitudinally evaluate the impact of online parental training on the adaptive functioning, on repetitive and problematic behaviours of Autism Spectrum Disorder (ASD) youth - with and without Intellectual Disability - and on parental stress.	Quantitative nonrandomized quasi experimental study without controls.	A total of 23 participants were included in the study (18 males; 5 females).	Participants' ASD diagnosis was confirmed by Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012). Cognitive functioning: the Leiter International Performance Scale-Revised (Roid & Miller, 1997). The Adaptive Behaviour Assessment System-Second Edition (Oakland, 2011). The Repetitive Behaviour Scale Revised (Bodfish et al., 2000). The Aberrant Behaviour Checklist-Community (Aman & Singh, 1994) The Parental Stress Index Short Form (Abidin, 1995).	After 6 months of training, they found a significant improvement in adaptive functioning of ASD participants and a reduction in parental stress.	While the online approach enhances accessibility for many families, the authors consider it as a complementary intervention and not a replacement of in-person training.
Vismara et al. (2018) Canada	To compare telehealth parent training (Early Start Denver Model parent coaching program, P-ESDM) with a	RCT.	24 parents (5 males, 19 females) of children with ASD.	Primary outcome measures: P-ESDM fidelity-evaluated intervention skills used by therapists	Improved skill usage among parents in the P-ESDM over comparison group. No	While telehealth training was found to be feasible for parents telehealth may not suit all parent

	community treatment-as-usual, early intervention programme.			(Rogers & Dawson, 2010). Programme website use (electronic tracking and recording). Programme satisfaction scale (bespoke 20-item, 6-point questionnaire). Social communication behaviours.	significant change from post to follow-up overall. Telehealth training facilitated higher parent fidelity gains and programme satisfaction.	styles. Limited resources impeded offerings of weekly sessions to both groups.
Zyga et al. (2018) USA	To identify the feasibility and acceptability of a telehealth programme (the PRETEND Program – Parent-focused Remote Education To Enhance Development) delivered remotely to primary caregivers of preschool children with Prader-Willi Syndrome.	Pre post design.	N=15 Preschool children with Prader-Willi Syndrome (n=7 male) (n=8 female) and their parents	Mullens Scales of Early Learning assessment (Mullen, 1995), Modified Behavioural Intervention Rating Scale survey (Elliot & Treuting, 1991)	Telehealth is potentially acceptable in delivering parent training interventions of preschool children. Remote parent training may help caregivers to access resources and support thereby improving child outcomes.	Using and accessing the online software may be challenging for some caregivers. Time to engage in the intervention activities may be difficult for some caregivers and to find time to practice the skills learned through the video session and generalise the learning.

Table 3: MMAT Quality Appraisal Results

First author	Year	Q1	Q2	Q3	Q4	Q5	MMAT Outcome
Antonini	2014	Y	Y	Y	Y	Y	Strong
Benson	2018	Y	N	Y	Y	Y	Moderate
Cankaya	2018	Y	Y	Y	Y	Y	Strong
Davis	2020	Y	Y	Y	Y	Y	Strong
De Luca	2021	CT	Y	Y	Y	Y	Moderate
Douglas	2017	CT	Y	Y	CT	Y	Moderate
Douglas	2021	Y	N	Y	Y	Y	Moderate
Flynn	2020	Y	Y	Y	CT	Y	Moderate
Heitzman-Powell	2014	Y	Y	Y	Y	Y	Strong
Hinton	2017	Y	Y	N	Y	Y	Moderate
Lappalainen	2021	Y	Y	Y	CT	CT	Moderate
Lee	2019	Y	Y	Y	Y	Y	Strong
Lindgren	2016	Y	CT	N	CT	Y	Weak
Lunsky	2021	CT	Y	Y	Y	Y	Moderate
Marleau	2019	Y	Y	Y	CT	Y	Moderate
Simacek	2017	Y	Y	Y	CT	Y	Moderate
Siracusano	2021	N	Y	Y	N	CT	Weak
Vismara	2018	Y	Y	Y	Y	Y	Strong
Zyga	2018	Y	Y	Y	CT	Y	Moderate

Y = yes, indicates a clear statement appears in the paper which directly answers the question;

N = no, indicates the question has been directly answered in the negative in the paper;

CT = can't tell, indicates there is no clear statement in the paper that answers the question.

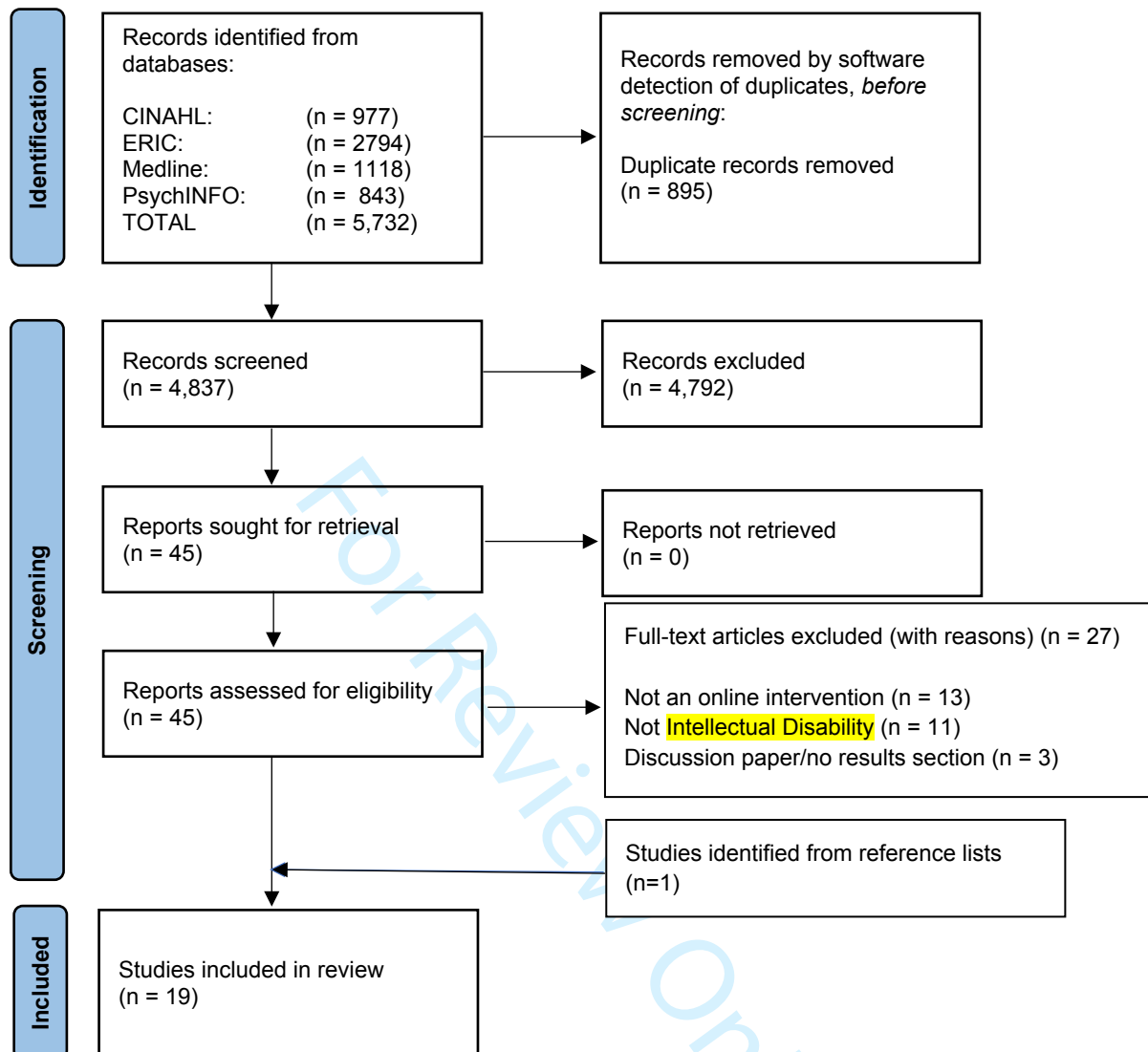


Figure 1: PRISMA Diagram of paper selection process