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RESEARCH ARTICLE

REVISED **Parenting, family interventions and sibling support offered by local authority services for families of children with intellectual disabilities**

[version 2; peer review: 1 approved with reservations, 1 not approved]
Previously Titled: "Support as usual in local authority services for families of children with intellectual disabilities"

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Abstract

Background

Families of children with intellectual disabilities often experience increased adversity. Despite this, parent-reported data suggest that these families experience significant barriers in accessing appropriate supports. Less research has characterised what service providers offer to families. Understanding usual support for these families is important when considering comparators in evaluation research. This study aimed to describe support as usual, in terms of parenting, family, and sibling intervention support, for families of children with intellectual disabilities as reported by professionals and service providers to inform the design of future research trialling new

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parenting and sibling interventions, respectively.

Methods

Data on supports available to parents, siblings, and young carers, were extracted from the Local Offer websites of 100 randomly selected English Local Authorities. Survey data were also collected from 66 professionals, either working in UK Local Authority services and/or services commissioned by Local Authorities, about what programmes or interventions are currently offered to parents of children with intellectual disabilities. Data were analysed using content analysis and descriptive statistics.

Results

A wide range of support programmes or interventions were described as being available to parents of children with intellectual disabilities, with most primarily designed for parents of non-disabled children or parents of children generally with special educational needs and disabilities. Data extracted from Local Offer websites led to the identification of six broad categories of programmes for parents; relatively few Local Authorities provided supports for siblings or young carers.

Conclusion

Our findings offer researchers and professionals insights into usual support offered by Local Authorities to families of children with intellectual disabilities. Future research may draw upon these findings when designing evaluations of health and social care interventions in the UK. Additional research is needed to examine the relationship between what might be on offer for families in theory and what they are able to access.

Plain Language Summary
Families of children with intellectual disabilities often experience more challenges compared to families of non-disabled children. However, parents of children with intellectual disabilities have described difficulties in accessing appropriate support. As such, there may be a difference between the support that is offered and the support these families are able to access.

UK Local Authorities must provide information about the different types of support available to families of disabled children, known as the Local Offer. However, little research has described what supports are typically available to families of children with intellectual disabilities as part of this Local Offer from the perspective of a professional or from official documents.

This study aimed to describe usual support for parents, siblings, and young carers in families of children with intellectual disabilities. We did this in two ways: 1) we collected data from 66 professionals, either working in a Local Authority service and/or service is contracted by Local Authorities, using an online survey; and 2) we extracted information from the Local Offer websites of 100 randomly selected Local Authorities in England.

We found that Local Authorities offered a lot of different programmes and/or interventions to parents of children with intellectual disabilities. Most of these supports were designed for families of non-disabled children or families with children generally with special educational needs and/or disabilities. We identified six categories of supports for parents. For siblings and young carers, we found very few Local Authorities provided supports.

The findings provide researchers and professionals insights into what support is usually offered to families of children with intellectual disabilities. Additionally, they could help the government and other organisations consider national standards for the support available to these families. Further research is needed to consider the relationship between what is offered in theory and what families can access.

Keywords
Families, Intellectual Disabilities, Local Offer, Support as Usual, Local Authorities

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REVISED **Amendments from Version 1**

In line with the reviewers' comments, several revisions have been made to this manuscript. First, the title and abstract have been updated to reflect that 'support as usual' in the context of this study refers specifically to parent, family and sibling interventions, rather than the broader range of support that might be available to these families (e.g., education, financial, and housing support). This update has similarly been included throughout the manuscript in addition to adding definitions of 'usual support' and 'parenting programmes or interventions'. Second, the purpose of this study, which was to inform the design of future research trialling new parenting and sibling interventions, respectively, has been made clearer to contextualise the background of this study and thus justify decisions made in relation to chosen methods. Third, further details relating to development of the online survey, and the procedures followed during the extraction and analysis of data from the 100 Local Authority Local Offer websites, have been added. In addition, justifications for the use of a dual-method approach when collecting data on parent support programmes or interventions have also been outlined. Fourth, we clarified that the search for sibling intervention support was broadened due to the limited availability of supports that fitted within the scope of our study. Fifth, although the aim of this study was not to directly compare the findings from the online survey and the Local Authority Local Offer websites, we have highlighted areas of similarities and discrepancies between these two data sources within the discussion. Finally, additional references to previous literature have been included in both the introduction and discussion.

Any further responses from the reviewers can be found at the end of the article

Introduction

In any randomised controlled trial (RCT) of social care or health intervention, it is important to specify the intervention as well as the comparator (Hoffmann *et al.*, 2014). Often, the comparator in an evaluation is the usual support, which is defined as the support (e.g., interventions) that the study population with the condition being studied would receive as part of a service's typical provision. Describing "support as usual" is crucial for several reasons. First, given that RCTs are experimental designs, each condition or independent variable must be clearly described, as any observed differences can only be interpreted with reference to the difference(s) between conditions (Hoffmann *et al.*, 2014). Second, any intervention condition needs to be different enough from the control condition or other comparator such that different outcomes might be hypothesised to occur (Freedland *et al.*, 2019). Third, and especially in the context of RCTs, those receiving an intervention might also receive or experience support as usual (if they continue to have access to it) differently, or the intervention condition might systematically change support as usual. Unless the nature of support as usual is already clear, any changes to its receipt related to the intervention will be unknown (Yorganci *et al.*, 2020). Fourth, understanding support as usual can offer data to inform the design of health economic evaluations (i.e., what health and care services use should be measured), which is important when evaluating the cost-benefits of the intervention condition compared to usual support (Skivington *et al.*, 2021).

Families of children with intellectual disabilities experience significant mental health problems and inequalities. For example, parents of children with intellectual disabilities may be twice as likely as other parents to report mental health problems (Hastings, 2016), families of children with intellectual disabilities are 1.5 times more likely than other families to be living in poverty (Emerson & Hatton, 2007), and siblings of children with intellectual disabilities are 1.6 times more likely than other siblings to have elevated levels of behavioural and emotional problems (Hayden *et al.*, 2019). As a result, families of children with intellectual disabilities have high levels of support needs.

Despite the high levels of need, families of children with intellectual disabilities often describe significant challenges in accessing support. Parents and other family carers describe a constant battle to get suitable support for themselves and for the person with intellectual disabilities for whom they care (Griffith & Hastings, 2014), and a range of barriers to accessing diagnosis/identification of needs, interventions, and support (Sapiets *et al.*, 2021). In a non-representative survey of 673 families of children with intellectual disabilities and/or autism up to seven years of age in the UK before the COVID-19 pandemic (Sapiets *et al.*, 2023), fewer than 30% reported receiving any intervention for their child or themselves in the preceding 12 months. Of the surveyed parents, 10.5% reported receiving a parenting programme, family support, or individual psychological support for their own needs in the preceding 12 months (Coulman *et al.*, 2022). We were not able to find existing research describing the support that siblings of children with intellectual disabilities receive in the UK.

Data from parents suggest that there is a considerable unmet need for support in the UK – a mismatch between support needs and support received. In the Sapiets *et al.* (2023) survey, for example, three-quarters of the respondents identified at least one unmet need for support. Thus, existing data from parents suggest that support as usual for families of children with intellectual disabilities in the UK might consist of a few specific interventions. In this context, any parent(ing) or family support intervention to be evaluated may be quite different from the comparator, if the comparator is support as usual.

Data from a parent perspective are typically the primary source for characterising support as usual. However, parents are not the only source of information about support as usual for families of children with intellectual disabilities. Professionals could be an alternative source of information, as might be a formal statement of services available by a statutory organization such as an NHS Trust or UK Local Authority/Council. As such, this could offer a more holistic understanding of what usual support in relation to parent or family intervention support may look like for these families.

The overall purpose of this study was to describe what usual support, in terms of parenting, family and sibling support programmes or interventions, is available for families of children with intellectual disabilities, as reported by social care professionals and/or in a formal document describing available support published by English Local Authorities, in order to inform the design of future parenting and sibling intervention research trials, respectively.

Methods

Patient and public involvement
Patients and the public were not directly involved in the design of this study. However, this project was completed as part of broader preparatory work for a RCT of a parent-support programme, in which all authors were involved. This preparatory work included a co-production group of family carers and consultation with Local Authority professionals. We discussed the nature and experiences of Local Authority support for parent carers with these groups which helped us to contextualise and interpret the findings described here.

Study design
To address the first aim of this study, which was to characterise what parenting and family support programmes or interventions are currently being offered to families of children with intellectual disabilities, we used a dual-method approach. These methods were: a) a brief, anonymous online survey for professionals; and b) extracting information from 100 randomly selected Local Authority Local Offer websites. The use of these two methods enabled the inclusion of the perspectives of both professionals themselves and information that is publicly available to families as communicated by organisations responsible for providing support services. Together, these sources provide a more complete picture of supports available and complement existing data directly from families. Given that siblings of children with intellectual disabilities may also be young carers, we also extracted information from Local Offer websites to characterise support as usual for young carers.

Online survey. Professionals supporting parents of children with intellectual disabilities, either as part of a UK Local Authority or a service that worked with or was commissioned by one or more Local Authorities, were invited to participate in a brief anonymous online survey. In the context of the current study, parent support programmes or interventions were defined in our survey as "an organised or structured resource that aims to enhance parent knowledge and skills and/or share helpful practical parenting strategies to overcome parenting challenges or concerns. These supports may be self-directed or delivered by a trained professional". The online survey included 14 questions about the service within which the professional worked (e.g., the geographical location of the service, whether the service had a parenting team), the support programmes or interventions offered by the service to parents of children with intellectual disabilities, and some details about these programmes or interventions (e.g., the mode of delivery, location of delivery, and professional(s) who typically deliver the programmes or interventions). The survey consisted of questions with fixed options and free-text responses. The initial list of parent support programmes or interventions included in the survey as close-ended responses was derived using the Early Intervention Foundation (EIF) guidebook (Early Intervention Foundation, 2024); however, participants could describe 'Other' parent support programmes or interventions using open ended responses. Due to time and resource constraints, we did not have a specific target sample size and instead aimed to recruit as many participants possible within the timeframe of the study.

Local authority local offer websites. Under the Children and Families Act 2014 and the Special Educational Needs and Disability (SEND) Regulations 2014, Local Authorities in England publish a Local Offer of services. Local Authorities include in this offer parenting and family support (including siblings). In England, the Care Act 2014 and accompanying care and support statutory guidance also requires Local Authorities to provide support for the well-being of carers and to provide young carers' needs assessments (Children and Families Act, 2014).

As the statutory requirement for Local Offers applies to England only, we extracted information on support programmes or interventions that are currently offered to parents, siblings of children with intellectual disabilities and young carers, from the Local Offer websites of a randomly selected sample of 100 English Local Authorities (from a total sample of 153 Local Authorities). Whilst considering available time and resources, we adopted a pragmatic sampling approach, with two thirds of English Local Authorities deemed sufficient to understand what support is currently offered to in each local area.

Table 1. Participant-Reported Characteristics of Local Authority Services in the UK.

Variable	n (%)
Location of service (N=98)	
England	92 (94%)
Wales	5 (5%)
Scotland	1 (1%)
Northern Ireland	0 (0%)
Region of England (N= 89)	
London	26 (29%)
South East	22 (25%)
East of England	13 (15%)
South West	7 (8%)
West Midlands	7 (8%)
North West	7 (8%)
Yorkshire and Humber	4 (5%)
East Midlands	2 (2%)
North East	1 (1%)
Does the service have a parent support team? (N=87)	
Yes	45 (52%)
No	42 (48%)

Participants

A total of 103 participants consented to participate in the online survey. Most participants worked in services geographically located in England (94%) within the London (29%) and South East (25%) regions (see Table 1). There was attrition throughout the survey. Ninety-eight participants provided data on the geographical location of their service, while 87 answered the question about whether their service had a parent support team. Only 66 participants answered questions regarding whether their service offered support programmes or interventions for parents. Data from these 66 participants are reported in this paper.

Procedure

Participants were recruited to participate in the online survey through social media, third (voluntary, charity) sector organisations mailing lists/newsletters/fora, and by contacting professionals or Local Authority services directly via email. The research team shared a flyer containing brief information and a QR code link to the survey. For those who were contacted via email, a copy of the flyer and a direct link to the survey were included. Given the distribution method, we have no information about the reach of the invitation or response rate. The online survey was conducted between April and July 2024.

The online survey was hosted on Qualtrics©. Prior to accessing the survey, participants were presented with an information sheet and completed a consent form in Qualtrics©. Since the survey was completed anonymously, no personal data were collected from the participants. Research ethics approval for the online survey was obtained from the Humanities and Social Sciences Research Ethics Committee of the University of Warwick (REF: HSSREC 143/23-24; date of approval: 19th April 2024).

To randomly select 100 English Local Authorities, we obtained a list of all 317 local councils from the UK government website. We excluded district councils (n=164), as they do not deliver services that meet the scope of this research. One hundred Local Authorities were randomly selected from the remaining 153 using the sample function in R (version 4.3.0).

ET and DS compiled a list of the 100 Local Authorities using Microsoft Excel © (version 2409; Microsoft Corporation, n.d.), and reviewed and extracted information on support as usual from each Local Offer website. Extracted information focused on programmes and interventions available to parents of children with intellectual disabilities, as well as programmes and interventions offered to parents of children with special educational needs and/or other disabilities more

generally, as these would likely also be available to families of children with intellectual disabilities. Information was also extracted about support for siblings of disabled children (including those with intellectual disabilities) and young carers. However, as little intervention or programme support was available for siblings and young carers, the research team expanded the scope of this search to explore generally what support is usually offered to siblings and young carers as part of the Local Offer. Data were extracted between June and September 2024.

Analysis

Data gathered from the fixed options were analysed using descriptive statistics. For free text responses, we coded the raw data in Microsoft Excel© (version 2409; Microsoft Corporation, n.d.) using content analysis so that they could also be summarised using descriptive statistics.

To analyse the data obtained from the Local Offer websites, we coded the raw data again in Microsoft Excel© (version 2410; Microsoft Corporation, n.d.) using content analysis to obtain a descriptive summary of support as usual offered by Local Authorities to parents, siblings, and young carers. For supports offered to parents, we first reviewed the raw data as a whole to identify any emerging patterns or categories. Drawing upon our definition of parent support programmes and interventions (e.g., whether the support is self-directed and/or delivered by a trained professional), the EIF guidebook (Early Intervention Foundation, 2024), our existing knowledge of parent support programmes and interventions, and the focus of the support (e.g., workshops on diet/eating, programmes focused on building positive relationships between family members), we iteratively categorised data into these emerging categories which led to the initial development of seven broad codes. However, following a discussion amongst the research team, these seven broad codes were further refined to six and were based around interventions included in the EIF guidebook (Early Intervention Foundation, 2024), online programmes/interventions, and those most commonly delivered. The initial coding of the raw data concerning support as usual for siblings and young carers highlighted the limited available support. Hence, we present a relatively raw descriptive summary of our findings.

Results

We present the findings for both aims of this study and using both methods/data sources. First, we report the results from the online survey (i.e., perspective of professionals) and extraction of information from 100 Local Authority websites to further understand what parenting or family interventions are available as usual support for parents of children with intellectual disabilities as communicated by organisations responsible for providing support services. These perspectives are different, but in combination provide more complete information about what might be available to families. We did not seek to compare these sources of information, recognising that they represent quite different perspectives. Second, we present the findings of what supports are available for young carers and siblings of children with intellectual disabilities as communicated by organisations with responsibility for providing supports.

Support for parents of children with intellectual disabilities

Online survey. **Support Programmes or Interventions for Parents of Children with Intellectual Disabilities.** A total of 48 of the 66 survey participants responded that their service currently offers support programmes or interventions for parents of children with intellectual disabilities. The remaining 18 participants reported that their service did not offer any support programmes, so they did not provide any further data.

As shown in Table 2, participants reported that a variety of support programmes and interventions were offered to parents of children with intellectual disabilities. Triple P programmes (35%) – particularly, the Triple P Parenting Program – and the Solihull Approach programmes (25%) were identified as the most frequently offered programmes for these parents.

Thirty survey participants also reported that their service offered other parent support programmes or interventions beyond those listed in the survey (see Table 3). Open-ended responses suggested that other commonly offered parent support programmes or interventions included Riding the Rapids (n=3), Family Links – Nurturing programme (n=3), Cygnet (n=2), EarlyBird (n=2), Talking Teens (n=2), Time Out for Parents (n=2), Who's in Charge (n=2), and Non-Violent Resistance (n=2). Sixteen other support programmes or interventions were also reported to be offered to parents by individual Local Authorities. Moreover, four participants reported delivering workshops to families of children with intellectual disabilities focused on topics such as helping parents understand their child's emotions, PECS/Makaton, and themes identified as important for parents accessing the service.

Further details of these support programmes or interventions can be found here: https://osf.io/zytx5/

Table 2. Professional-Reported Support Programmes/Interventions for Parents of Children with Intellectual Disabilities.

Parent Support Programme	N (%)
Any Triple P	17 (35%)
Triple P Parenting Program	16 (33%)
Stepping Stones Triple P	11 (23%)
Triple P Online	5 (10%)
Solihull Approach programmes	12 (25%)
Incredible Years	10 (21%)
Strengthening Families, Strengthening Communities (SFSC)	6 (13%)
Empowering Parents, Empowering Communities (EPEC)	5 (10%)
Parents Plus	3 (6%)
Circle of Security	2 (4%)
ParentChild+	2 (4%)
New Forest Programme	2 (4%)
Multisystemic Therapy	2 (4%)
Other	16 (33%)

Table 3. Professional-Reported Other Support Programmes/Interventions for Parents of Children with Intellectual Disabilities in the UK.

Type of Support	N (%)
Programme or intervention	**16 (33%)**
Helping Hand Project	1
Learning How to Communicate with your Child and Understanding Behaviours	1
Transition training for parents and teachers	1
Care for the Family	1
Blossom Group	1
House Sleep	1
Connective Parenting Courses	1
Confident Parenting Behaviour Programme	1
Sensory Processing and Profiling	1
Tree of Life	1
SPACE programme	1
Sleep programme	1
Autism Spectrum Disorder Psychoeducation	1
NHS webinars	1
Therapies (e.g., Video Interaction Guidance, Theraplay, Life Story work)	1
Post-Autism Diagnosis Programme	1
Workshops	**4 (8%)**
Understanding Emotions	1
PECS/Makaton	1
Workshops delivered depending on parental needs	1
Workshops from professionals (e.g., speech and language therapist, occupational therapist)	1

Note. NHS= National Health Service, PECS = Picture Exchange Communication System; SPACE = Supportive Parenting for Anxious Childhood Emotions.

Table 4. Professionals Delivering Parent Support Programmes/Interventions in Local Authority Services in England.

Professional Type	N (%)
Family Support Worker	31 (62%)
Parenting Team/Practitioner/ Co-Ordinator	10 (20%)
Social Worker	7 (14%)
Learning Disability Nurse	4 (8%)
Counsellor/Psychotherapist	4 (8%)
Family Hub Practitioner	3 (6%)
Educational Psychologist	3 (6%)
Clinical Psychologist	2 (4%)
Early Intervention Worker	2 (4%)
Young People's Worker	2 (4%)
School	2 (4%)
Health Visitor	1 (2%)
Early Years Practitioner	1 (2%)

Note. These categories are not mutually exclusive.

Most of the programmes offered were originally developed for parents of children with disabilities, or for parents of non-disabled children, rather than bespoke for families of children with intellectual disabilities, as determined through existing knowledge of these programmes and desk research to confirm the nature of the initial development of the programmes.

Implementation and delivery of parent support programmes or interventions. Participants provided information about the implementation and delivery of some of the parent support programmes or interventions listed in the online survey by responding to a series of multiple response questions.

Professionals involved in the delivery of support programmes or interventions for parents of children with intellectual disabilities (Table 4) were mainly family support workers (62%). Other professionals frequently involved in the programme or intervention delivery were parenting specialists (team/coordinator/practitioner) (20%) and social workers (14%).

As summarised in Table 5, participants reported that most parent support programmes or interventions were implemented online (via Zoom, Microsoft Teams, WhatsApp) (59%), while 39% were delivered in-person. Additionally, 22% of the programmes were delivered using a hybrid approach (i.e., combining both online and face-to-face elements). Professionals most frequently delivered these in-person programmes in community centres (39% of in-person programmes), family homes (37%), education settings (i.e., school) (20%), or in local family hubs (20%).

Some programmes were delivered exclusively using a group-based format (45%), individually (10%), or self-directed (2%). Other programmes were delivered using a combination of one-to-one and group-based formats (25%), with 4% of programmes delivered using either group-based or self-directed formats. A further 4% of the programmes were implemented using all three delivery formats (i.e., group-based, one-to-one, and self-directed).

Local authority local offer websites

Nearly all Local Authorities (96%) listed support for parents of children with intellectual disabilities as part of their Local Offer. Table 6 presents the six broad categories of support developed through the coding of individual programmes. Sixty-two percent of Local Authorities listed programmes identified in the EIF guidebook, meaning that they have some evidence supporting their effectiveness (Early Intervention Foundation, 2024). Just over half of the Local Authorities (55%) listed any Triple P programme, while 53% listed any online, self-directed programme, and 63% listed other parenting programmes. Forty-four percent of Local Authorities listed parenting programmes that were identified as being bespoke or local to a particular Local Authority. In addition to parenting programmes, 52% of Local Authorities listed other types of support (e.g., workshops and drop-in sessions).

Table 5. Implementation and Delivery Characteristics of 51 Parent Support Programmes/ Interventions in English Local Authority Services.

Variable	n (%)
Delivery of intervention	
Online	30 (59%)
Face-to-face	20 (39%)
Hybrid	11 (22%)
Telephone	0 (0%)
Location of face-to-face element	
Community centre	20 (39%)
Family home	19 (37%)
Education setting	10 (20%)
Family hubs	10 (20%)
Child and family centres	5 (10%)
Local health centre	3 (6%)
Early childhood and family service base	3 (6%)
Local Authority office	2 (4%)
Libraries	1 (2%)
Format of delivery	
Group-based	23 (45%)
One to one	5 (10%)
Self-directed	1 (2%)
Combination of group-based and one to one	13 (25%)
Combination of group-based, one to one and self-directed	2 (4%)
Combination of group-based and one to one	2 (4%)
Missing information	5 (10%)

Note. These categories are not mutually exclusive.

Data extracted from Local Authority Local Offer websites also highlighted that identified programmes are not necessarily designed specifically for parents of children with intellectual disabilities. Rather, these programmes were generally designed for, and then available to, parents of children with SEND, and/or were developed initially for parents of typically developing children.

Support for siblings of children with intellectual disabilities
A minority (18%) of the Local Authorities listed some kind of support to siblings of children with intellectual disabilities as part of their Local Offers. However, in only three of these Local Authorities, this support was targeted specifically for siblings of children with intellectual disabilities.

Fourteen of these 18 Local Authorities offered sibling groups for siblings of disabled children (including siblings of children with intellectual disabilities) to participate in fun activities and to connect and share experiences with other siblings. Some of these sibling groups were organised by external organisations, including third-sector organisations (n=6) or a Child and Adolescent Mental Health Service Disability Team (n=1). Six of the 18 Local Authorities also provided information on sibling support programmes and/or workshops. Of these, three Local Authorities listed a support programme for adult siblings of autistic individuals (including children) delivered by *Sibs* (https://www.sibs.org.uk/).

Just over half of the 100 Local Authorities (52%) signposted families and/or siblings to third-sector organisations for information, advice, and/or support – all of these provided website links and/or contact details for *Sibs*. Furthermore, six Local Authorities signposted families and siblings to other charities.

Table 6. Categories of Support Programmes Offered by Local Authorities as Part of their Local Offer.

Support as Usual	Number of Local Authority services	Number of Programmes	Description
Triple P Programmes	55	16	Programmes that have been developed by Triple P such as Triple P Parenting Programme, Stepping Stones Triple P, Triple P Fearless, Triple P Baby, Triple P Teen, Triple P Family Transitions, Triple P Online.
Online, self-directed parenting programmes	53	33	Programmes that parents complete online and are also self-directed (i.e., parents complete programmes on their own and at their own pace). These online programmes include, Triple P, the Solihull Approach (including *Understanding your Child with Additional Needs*), Family Lives, and OnePlusOne.
Programmes identified in the Early Intervention Foundation Guidebook (EIF, 2024)	61	14	Programmes identified in the Early Intervention Framework Guidebook as having some emerging evidence supporting the effectiveness of the programme in improving child outcomes. Examples of programmes in this category include the Incredible Years programmes, Empowering Parents, Empowering Communities (EPEC), PEEP, the Circle of Security, HENRY, ParentChild+, Strengthening Families, and ParentsPlus. Triple P programmes that are included in the EIF guidebook have not been included in this category.
Other parenting programmes	63	32	Programmes that are commonly delivered across Local Authority services but are not identified in the Early Intervention Framework Guidebook, as a Triple P programme, nor identified as online, self-directed programmes. Some of these programmes are specifically for parents of disabled or autistic children who may also have an intellectual disability (e.g., Time Out for Parents – Children with Additional Needs, Cygnet, EarlyBird, The Incredible Years), or for parents of typically developing children (e.g., Family Links, 123Magic, Who's in Charge, and Strengthening Families, Strengthening Communities).
Bespoke/local parenting programmes	44	70	Programmes which are bespoke to or local to a particular Local Authority. These programmes may focus on children's behaviour, child development within the early years, building positive relationships between family members, and domestic violence.
Other miscellaneous support (e.g., workshops, unstructured peer support groups, drop-in parent support)	52	87	These supports mainly consist of workshops which are accessible to all parents (e.g., sleep, toileting, diet/eating, emotional well-being, school avoidance) or parents of a disabled child (e.g., autism and sensory processing, supporting a child with ADHD, stand-alone sessions on Down Syndrome, Foetal Alcohol Syndrome). Some Local Authorities offer one to one or group drop-in parent support sessions to address any concerns parents may have relating to their child, with a small number of these sessions specifically for parents with an autistic child or SEND. In addition, a small number of webinars are also available for parents to attend.

Support for young carers

The majority (86%) of the Local Authorities listed support for young carers as part of their Local Offers. Just over half of all Local Authorities (55%) listed social opportunities for young carers in the form of social activities, clubs, and meetups to connect with other young carers. Other common types of support included individual and/or group support, information and advice (26%), respite/short breaks (18%), school support or activities (e.g., after-school clubs) (15%), residential trips and outings (10%), counselling/listening support (5%), advocacy (3%), signposting to other agencies/organisations (8%), training and educational opportunities (7%), and assessments (8%). Moreover, 10 Local Authorities listed workshops for young carers to build self-confidence or to help manage their emotions, support in career planning, and learn more about the role of being a young carer. Some Local Authorities listed specific support, such as home visits (10%), practical and emotional well-being support (6%), and therapeutic support (1%).

Forty-three Local Authorities listed support through either a Young Carers Service/Hub/Centre/Team (n=36) or as part of a Young Carers Programme/Project (n=7), with most of them delivered by third-sector organisations (n=36). An additional six Local Authorities listed supports delivered by third-sector organisations. Furthermore, support listed by five Local Authorities solely consisted of signposting young carers to third-sector organisations to access support.

Discussion

The first aim of the current study was to describe parent support programmes or interventions available to families of children with intellectual disabilities, as part of usual support included in English Local Authorities' Local Offers, to inform the planning of a new parenting intervention study. In addition, we aimed to describe supports available for siblings of children with intellectual disabilities, in Local Offers, to inform the design of a future sibling intervention study.

While parents of children with intellectual disabilities mainly report not receiving interventions supporting their own needs (Sapiets *et al.*, 2023), data from professionals and Local Authorities suggest that a variety of interventions are offered to at least some families. It is not clear whether all social care professionals working with families of children with intellectual disabilities work in services that offer interventions for these families. However, the findings from both the Local Offer websites and the survey of professionals working in services that offer at least some interventions suggest that a variety of different intervention approaches were in use – although, both sets of findings highlighted that the majority of programmes on offer were not bespoke for families of children with intellectual disabilities. Programmes were typically delivered by family/parenting practitioners, with most being delivered digitally or in hybrid formats (likely accelerated by the COVID-19 pandemic; Fang *et al.*, 2024; Rodi *et al.*, 2024).

In terms of Local Offers, just over 60% of Local Authorities included evidence-based parenting programmes. Similar to the survey findings, Triple P programmes were commonly offered, and just over half of the programmes included in Local Offers were self-directed programmes (typically online). Likely reflecting their statutory responsibility to offer support, Local Offers usually listed some supports for young carers (which should also be available to sibling young carers of children with intellectual disabilities). However, other forms of support for siblings of children with intellectual disabilities were rare: only 14% of Local Offers included support groups for siblings of disabled children, and only 3% of Local Offers included targeted support for siblings of children with intellectual disabilities.

Survey data from social care professionals provide an important additional perspective on support as usual for families of children with intellectual disabilities in the UK. However, the sample size is small and thus not representative of services from the whole of the UK, but the data reflect what professionals report as being available to these families from their services. The proportion of families that receive these supports and programmes is unknown. Given the existing data from a parent perspective (e.g., Sapiets *et al.*, 2023), we might speculate that the reach of these supports is limited. It is also striking that, even with such a small sample, the number of different options provided by services is broad. We might speculate that it seems unlikely for programme delivery to be offered with a high degree of fidelity with resource constraints faced by providers of services currently. Thus, the quality of any delivered programmes and support is unknown but may be compromised by attempting to deliver too many options.

Local Authority official descriptions of services offered to families of disabled children, including those with intellectual disabilities (i.e., Local Offers), also provide an important additional perspective on support as usual for these families. Similar to our findings from the online survey, a wide variety of parenting programmes and family support are on offer, with a large number being evidence-based. However, the majority of programmes and supports on offer did not appear to have an established evidence base; thus, contrasting what was reported by professionals in the online survey. One reason for this difference in finding may be due to the inclusion of close-ended response options informed by the EIF guidebook, although the opportunity to provide details of 'Other' interventions was available. Moreover, these data suggest a

significant reliance on self-directed/online support, which presumably requires fewer personnel resources. This suggests a considerable role for online support in practice, if not a growing reliance on technology, and trends could be monitored over time. Support as usual for siblings of children with intellectual disabilities is relatively rare. Given that Local Offers were sampled randomly for analysis in this research, we have a high degree of confidence that there is very little support for siblings.

As with the social care professionals' survey data, although Local Offers describe suitable and a wide range of potentially available supports, it is not clear what proportion of parents and families in a local area access the available support nor the method for accessing these supports. Unless there are limits on available access codes or similar, one might expect that given that there is a considerable reliance on online self-directed support, most families would be able to access some support. However, this assumption assumes that families know about and look at the Local Offers. Additionally, there are considerable digital access barriers that may be more pronounced for families of disabled children, who are at an increased risk of living in 'digital poverty' (Ruiu *et al.*, 2023).

The current data can be used by researchers to further understand what parenting, family and sibling/young carer support is available as usual support for families of children with intellectual disabilities from the perspective of social care professionals and statutory organisations. These data cannot replace data from parents' perspectives, but they provide context for what families might receive and can be used to inform the design of data collection tools in RCTs where new data are required on support as usual, and can inform tools for service use data needed for health economic evaluations. Even though the current data represent what might be in theory on offer to families, they clearly show that support for siblings of children with intellectual disabilities is rare in England, so this may be a priority for the development of services and research. Nonetheless, this study only focused on parenting and family support programmes and interventions for families of children with intellectual disabilities. It is acknowledged, however, that these families require a wide range of supports and services, including educational, practical and financial support, which future research could explore to provide a more holistic understanding of available supports.

Ethics and consent
Ethics approval was obtained from the Humanities and Social Sciences Research Ethics Committee of the University of Warwick (REF: HSSREC 143/23-24; date of approval: 19th April 2024). This study adheres to the Declaration of Helsinki.

Participants were provided with an information sheet and a consent form in Qualtrics© before completing the online survey. All participants were asked to read the information sheet and provide written consent prior to participating in the study.

Data availability
Underlying data
We were unable to share raw data collected through the online survey due to ethical considerations, as some data may be personally identifiable. This project received ethics approval from the Humanities and Social Sciences Research Ethics Committee of the University of Warwick under the condition that these data would not be shared.

Data extracted from the Local Offer websites is publicly available and can be accessed online.

Extended data
Open Science Framework: 'Support as Usual in Local Authority Services for Families of Children with Intellectual Disabilities'. https://doi.org/10.17605/OSF.IO/ZYTX5 (Taylor, 2025)

This project contains the following extended data:
Document 1 – The document contains the supplementary material for the current study. This supplementary information includes further information about the programs discussed in the main body of text.

Document 2 – This document includes a pdf copy of the online survey we invited professionals to take part in.

Document 3 – This document contains the weblinks to the Local Offer websites of the 100 randomly selected Local Authority services.

Extended data are available under the term of the Creative Commons Attribution 4.0 International Public License (CC BY 4.0 license).

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Open Peer Review

Current Peer Review Status: ✗ ?

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Version 1

Reviewer Report 12 June 2025

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? **Carlo Schuengel** (iD)

[1] Vrije Universiteit Amsterdam, Amsterdam, The Netherlands
[2] Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

This paper describes which support programmes and interventions were available for families with a child with intellectual disability in England. It did so on the basis of a survey among support professionals in the UK and by extracting website information from a random sample of local authorities in England. The results are that a variety of programs is on offer, with part of these offering enjoying some research based support. Programs for siblings are limited.

The manuscript is clearly and concisely written. The authors are explicit in making readers aware that the primary purpose of this study was to prepare for an upcoming RCT of a parent-support intervention. Still, the authors convincingly argue that the study has scientific and practical value beyond that. Variation in the comparator are an achilles heel of RCTs and are an issue that is often papered over. It is therefore commendable that the authors take methodical steps to tackle this. Furthermore, the current study could provide valuable context to the planned RCT or any other RCT for that matter. It is therefore a good thing that the authors decided to publish their work.

That said, there are a number of areas that could be improved to increase the value of the work.

1. Definition of support: It is not clear from the report how the authors defined support programs or interventions. How was it described to the survey participants and what did the researchers look for on the local authority websites? Families with children with intellectual disability require a range of supports and services, including medical, education, mental health, parenting, housing, etcetera. A conceptual framework of needs and supports might be helpful to be able to position the type of support that was the focus of this study and to be able to gauge the extent to which the supports on offer match the needs of families.

2. Rationale for study approach: the authors are correct in outlining the limits of information obtained from parents about support services that they received or have access to and therefore, for their RCT, it is very wise that they collect this information from professionals and websites as

well. However, for the current study to be able to stand on its own, an argument is needed for why the survey and the website coding were both done to collect data for this study. Furthermore, the results from both approaches are presented alongside each other without a formalized method of comparison, making it difficult to integrate these results in answering the research questions. Given that such comparisons would be very complicated, it might be better to write out the distinct research questions that the survey sought to answer and the research questions that the website coding sought to answer and treat the findings for these research questions separately.

3. Rationale for sampling frames: The sampling frame for the survey appeared to have been UK (although with a preponderance of participation from professionals in England) but for the local authorities, only those in England were sampled. This difference complicates the interpretation somewhat. Would it perhaps be better to just focus both methods on England?
Also, what was the target sample size of the survey (and was the achieved number above or below that) and what was the rationale for the number of 100 local authorities to be investigated?

4. Background of the methods: It would be helpful to explain the background of the survey questions and of the coding system for the websites (theories, earlier empirical work).

5. On page 7, the authors state that most of the programmes offered were originally developed for families of children with disabilities. How did the authors determine this?

6. On page 9, the authors write: "It seems unlikely that it is possible to offer programme delivery with a high degree of fidelity with resource constraints. Thus, the quality of any delivered programmes and support is unknown and may be compromised by too many options." This conclusion rests on a number of implicit assumptions and reads now as very speculative. Can the authors make their argument more explicit, using, perhaps, findings from other research? Or would the authors formulate this point rather as a question than as a conjecture?

7. Evidence for statements: The literature on which the paper is based is rather limited. Factual statements do require a reference to evidence. One example is on page 10: "Additionally, there are considerable digital access barriers that may be more pronounced for families of children with intellectual disabilities, who are at an increased risk of living in 'digital poverty'." What evidence is there to support this statement?

Is the work clearly and accurately presented and does it cite the current literature?
Partly

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

If applicable, is the statistical analysis and its interpretation appropriate?
Yes

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Parenting and parent-child relationships; intervention research; effectiveness

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

> Author Response 11 Feb 2026
>
> **Emma Taylor**
>
> We would like to thank the reviewer for taking the time to review our manuscript and for providing helpful and constructive comments. We have responded to each of their points below:
>
> **1. Definition of support: It is not clear from the report how the authors defined support programs or interventions. How was it described to the survey participants and what did the researchers look for on the local authority websites? Families with children with intellectual disability require a range of supports and services, including medical, education, mental health, parenting, housing, etcetera. A conceptual framework of needs and supports might be helpful to be able to position the type of support that was the focus of this study and to be able to gauge the extent to which the supports on offer match the needs of families.**
>
> **Response:** We have included our definition of support programmes or interventions as outlined in the survey in the main manuscript:
>
> "In the context of the current study, parent support programmes or interventions were defined in our survey as "an organised or structured resource that aims to enhance parent knowledge and skills and/or share helpful practical parenting strategies to overcome parenting challenges or concerns. These supports may be self-directed or delivered by a trained professional". (p.4)
>
> This definition was similarly used in our search of Local Authority websites.
>
> We have edited the manuscript throughout to clarify that the focus of this study was parenting and family support programmes and interventions. However, we have added some text to the Discussion to highlight that families of children with intellectual disabilities do require a wider range of support, which might be important for future research to explore.
>
> "Nonetheless, this study only focused on parenting and family support programmes and

interventions for families of children with intellectual disabilities. It is acknowledged, however, that these families require a wide range of supports and services, including educational, practical and financial support, which future research could explore to provide a more holistic understanding of available supports." (p.10)

2. Rationale for study approach: the authors are correct in outlining the limits of information obtained from parents about support services that they received or have access to and therefore, for their RCT, it is very wise that they collect this information from professionals and websites as well. However, for the current study to be able to stand on its own, an argument is needed for why the survey and the website coding were both done to collect data for this study. Furthermore, the results from both approaches are presented alongside each other without a formalized method of comparison, making it difficult to integrate these results in answering the research questions. Given that such comparisons would be very complicated, it might be better to write out the distinct research questions that the survey sought to answer and the research questions that the website coding sought to answer and treat the findings for these research questions separately.

Response: We have added the following text to the Study Design section of the Methods to clarify why we chose two methods:

"The use of these two methods enabled the inclusion of the perspectives of both professionals themselves and information that is publicly available to families as communicated by organisations responsible for providing support services. Together, these sources provide a more complete picture of supports available and complement existing data directly from families." (p.4)

To make it clearer, we have added the following paragraph at the beginning of the Results section so that structure is clearer:

"We present the findings for both aims of this study and using both methods/data sources. First, we report the results from the online survey (i.e., perspective of professionals) and extraction of information from 100 Local Authority websites to further understand what parenting or family interventions are available as usual support for parents of children with intellectual disabilities as communicated by organisations responsible for providing support services. These perspectives are different, but in combination provide more complete information about what might be available to families. We did not seek to compare these sources of information, recognising that they represent quite different perspectives. Second, we present the findings of what supports are available for young carers and siblings of children with intellectual disabilities as communicated by organisations with responsibility for providing supports." (p.5)

We have also added headings to clearly distinguish which sections focus on parenting/family interventions and sibling and young carer support.

We did not seek to make direct comparisons between the survey and website local offer review as data sources on support for parents/families – as these were quite different

sources. In the Discussion, we have added some text throughout to discuss points of connection and divergence between these data sources (p.9-10).

3. Rationale for sampling frames: The sampling frame for the survey appeared to have been UK (although with a preponderance of participation from professionals in England) but for the local authorities, only those in England were sampled. This difference complicates the interpretation somewhat. Would it perhaps be better to just focus both methods on England? Also, what was the target sample size of the survey (and was the achieved number above or below that) and what was the rationale for the number of 100 local authorities to be investigated?

Response: We have added a sentence to the Methods section detailing that Local Offers only exist in England to make this decision clearer for the reader.

"**As the statutory requirement for Local Offers applies to England only,** we extracted information on support programmes or interventions that are currently offered to parents, siblings of children with intellectual disabilities and young carers, from the Local Offer websites of a randomly selected sample of 100 English Local Authorities (from a total sample of 153 Local Authorities)." (p.4)

Due to time and resource constraints, we did not have a target sample size for the survey. We have clarified this in the Methods:

"Due to time and resource constraints, we did not have a specific target sample size and instead aimed to recruit as many participants possible within the timeframe of the study" (p.4)

Similarly, we selected a sample of 100 Local Authorities due to time and resources available. As only 153 Local Authorities would have been eligible for review, we viewed a random sample of 100 as being sufficient for the purposes of this study. We have updated the manuscript to reflect this:

"Whilst considering available time and resources, we adopted a pragmatic sampling approach, with two thirds of English Local Authorities deemed sufficient to understand what support is currently offered to parents and siblings of children with intellectual disabilities and young carers in each local area." (p.4)

4. Background of the methods: It would be helpful to explain the background of the survey questions and of the coding system for the websites (theories, earlier empirical work).

Response: We have added some further information about the background of the survey questions:

"The survey consisted of questions with fixed options and free-text boxes. **The initial list of parent support programmes or interventions included in the survey as close-ended responses was derived using the Early Intervention Foundation (EIF) guidebook (Early**

Intervention Foundation, 2024); however, participants could describe 'Other' parent support programmes or interventions using open ended responses." (p.4)

We have also included additional descriptions of the coding systems used for the websites:

"For supports offered to parents, **we first reviewed the raw data as a whole to identify any emerging patterns or categories. Drawing upon our definition of parent support programmes and interventions (e.g., whether the support is self-directed and/or delivered by a trained professional), the EIF guidebook (Early Intervention Foundation, 2024), our existing knowledge of parent support programmes and interventions, and the focus of the support (e.g., workshops on diet/eating, programmes focused on building positive relationships between family members), we iteratively categorised data into these emerging categories which led to the initial development of seven broad codes.** However, following a discussion amongst the research team, these seven broad codes were further refined to six and were based around interventions included in the EIF guidebook (Early Intervention Foundation, 2024), online programmes/interventions, and those most commonly delivered." (p.5)

5. On page 7, the authors state that most of the programmes offered were originally developed for families of children with disabilities. How did the authors determine this?

Response: This was based on existing knowledge of these programmes, and also additional desk research for those supports less commonly known. We have added some further information to the manuscript detailing this:

"Most of the programmes offered were originally developed for parents of children with disabilities, or for parents of non-disabled children, rather than bespoke for families of children with intellectual disabilities, **as determined through existing knowledge of these programmes and desk research to confirm the nature of the initial development of the programmes.**"(p.6)

6. On page 9, the authors write: "It seems unlikely that it is possible to offer programme delivery with a high degree of fidelity with resource constraints. Thus, the quality of any delivered programmes and support is unknown and may be compromised by too many options." This conclusion rests on a number of implicit assumptions and reads now as very speculative. Can the authors make their argument more explicit, using, perhaps, findings from other research? Or would the authors formulate this point rather as a question than as a conjecture?

Response: We agree that this point is more speculative. Therefore, we have edited this sentence:

"It is also striking that, even with such a small sample, the number of different options provided by services is broad. **We might speculate that it seems unlikely for programme delivery to be offered with a high degree of fidelity with resource constraints faced by providers of services currently.** Thus, the quality of any delivered programmes and

support is unknown but may be compromised by attempting to deliver too many options." (p.9-10)

7. Evidence for statements: The literature on which the paper is based is rather limited. Factual statements do require a reference to evidence. One example is on page 10: "Additionally, there are considerable digital access barriers that may be more pronounced for families of children with intellectual disabilities, who are at an increased risk of living in 'digital poverty'." What evidence is there to support this statement?

Response: We have added citations for previous research in both the introduction and discussion to support with such statements.

Competing Interests: No competing interests were disclosed.

Reviewer Report 30 May 2025

https://doi.org/10.3310/nihropenres.15142.r35594

❌ **Roy McConkey** (ORCID)
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Based on the ethos of RCTs, the purpose of the study was to describe 'support as usual' for families of children with intellectual disabilities as reported by a self-selected sample of 66 professionals and also by service providers: sourced through the websites of 100 English Local Authority (LA) that describe the 'Local Offer' available to such families, as required by legislation, alongside the offer that is provided to young carers. This modest study contributes few new insights of use to designers of RCTs or the much wider research community.

In the interests of full disclosure I should note that I am not based in England, I have neither wanted to, or ever conducted a RCT but have had a long-standing interest in family support for families of children and adults with intellectual and developmental disabilities in the UK, Ireland as well as internationally. When invited to review this paper, I was sufficiently intrigued by the title to agree but like an attractively wrapped gift, the contents disappointed when the article was opened. The title and abstract do not accurately describe the study.

I was bemused why 15 authors were named in what turned out to be a very modest study and presumably at some considerable cost to NIHR. The term 'support as usual' appeared frequently but was never defined, although the sparse literature review in the introduction rightly emphases the broad health and social needs of families.

I gather a more favoured term in RCTs is 'treatment as usual' but I had thought 'support' would signal a wider appreciation by the authors of the diverse forms of support that were needed and which have been shown to assist such families and their children. Indeed when I read the English Government guidance on Local Offers and see that it covers - as I hoped it might - supports provided by health personnel, schools alongside adjunct educational supports, housing needs and presumably as part of social care, short (respite) breaks as well as domiciliary support. Yet these forms of support (for which there is an evidence base of their benefits to families) feature rarely in the information presented in this paper which instead lists training packages of which Triple P is the most common. To compound matters, no data was gathered of the quantum of English families in receipt of even the very particular supports that are reported, which admittedly the authors do note as a concern.   By contrast, a wider range of supports were identified by the raters in terms of the supports available to young carers in their Local Offers, and these types of supports have also been effective with parent carers which makes their omission all the more puzzling in their analysis of Local Offers to parents.

One possibility for this omission is that the two raters had a more focused definition of support in mind when undertaking their analysis of 100 Local Offers to families but why not share this and defend their rationale for so doing? It is only when I dug deeper into the supplementary files containing the questionnaire sent to professionals that I discovered a much narrower definition of support and here it is. "Parent support programmes or interventions refers to an organised or structured resource that aims to enhance parent knowledge and skills and/or
share helpful practical parenting strategies to overcome parenting challenges or concerns. These supports may be self -directed or delivered by a trained professional".
Could this have been in the mind of the two raters examining LA's Local Offer websites which led them to discounting other forms of support 'programmes' provided through health services, schools or social care, which to my mind could still fall within that definition and that are supported by peer-reviewed articles that I could happily cite. Moreover were any cross-checks undertaken by any of the other 13 authors, who might have probed to see if other forms of support had been overlooked or was any member checking of the raters' analysis performed via telephone calls with a lead person in even a sample of LAs? I fear the information gathered and reported here does not constitute robust evidence for 'treatments as usual' let alone 'support as usual' as it under values the other forms of support being provided by LAs and their independent providers. Admittedly there could be little 'support - of any kind - as usual' for some, perhaps many families in parts of England.   But even within the context of RCTs, surely these wider forms of support by health, education and social care services need to be factored in as 'supports as usual' for the 'experimental' as well as 'control' group. Indeed I suspect that it is the better supported families (who may have received them in the past as well as at present) who will opt to join trials. Moreover if the 'new intervention' proves effective, its implementation beyond the trial will depend on the existing support providers embracing it. Identifying in advance your likely allies would then be an extra bonus from the RCT.

The second strand in the paper was an online questionnaire sent to an unknown number of persons. The response from busy professionals to the cold-calling approach used by the team was disappointedly small but predictable. The highly structured questions focused on named programmes and thus provided little scope for reporting other forms of support. The self-selected sample (with a bias to responses from more affluent areas of England as per Table 1) adds little robust evidence and could perhaps could charitably be classed as a pilot study.

I fear the authors in their discussion rather over sell the usefulness of their information in relation to RCTs and the setting of national standards. They need to be more upfront about the limitations of their information gathering and more forthright about what should be done. For example, if you want to define 'support as usual' as part of a trial for economic assessments, you need to get the information directly from parents, and find out not just which supports they currently access (and maybe have accessed) but those they found of help to them and why. We know that in any sample of families greater than n=1, there will be variation in their support needs, aspirations and access to and usage of formal and informal supports. In that sense there can be no treatment as usual, as there is in fact no 'usual' when it comes to supporting families who have children with intellectual and developmental disabilities. It's a pity the authors did not end their paper with that conclusion.

Is the work clearly and accurately presented and does it cite the current literature?
No

Is the study design appropriate and is the work technically sound?
No

Are sufficient details of methods and analysis provided to allow replication by others?
No

If applicable, is the statistical analysis and its interpretation appropriate?
Partly

Are all the source data underlying the results available to ensure full reproducibility?
No

Are the conclusions drawn adequately supported by the results?
No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Family support, intellectual and developmental disabilities, inclusive research, service evaluation, Low and middle income countries.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

> Author Response 11 Feb 2026
> **Emma Taylor**
>
> We would like to thank the reviewer for taking the time to provide us with detailed and helpful feedback on our manuscript. We have provided responses to their comments below:
>
> **1. The title and abstract do not accurately describe the study.**

Response: We have updated the title of the study to "Parenting, family interventions and sibling support offered by local authority services for families of children with intellectual disabilities". (p.1)

We have also made some further edits to the Background section of the Abstract to further clarify the purpose of this study:

"Understanding usual support for these families is important when considering comparators in evaluation research. This study aimed to describe support as usual, **in terms of parenting, family and sibling intervention support**, for families of children with intellectual disabilities as reported by professionals and service providers **to inform the design of future research trialling new parenting and sibling interventions, respectively."** (p.1)

2. I was bemused why 15 authors were named in what turned out to be a very modest study and presumably at some considerable cost to NIHR.

Response: We state in the Patients and Public Involvement section of the Methods that this study was conducted as part of "broader preparatory work for a RCT of a parent-support programme". All of the listed authors of this study were involved in this funded broader piece of work. We have endeavoured to make this clearer by adding the following edit to this section:

"However, this project was completed as part of broader preparatory work for a RCT of a parent-support programme, **in which all authors were involved."** (p.4)

3. The term 'support as usual' appeared frequently but was never defined

Response: We have added a definition to the Introduction.

"Often, the comparator in an evaluation is the usual support, **which is defined as the support (e.g., interventions) that the study population with the condition being studied would receive as part of a service's typical provision**" (p.3)

4. Government guidance on Local Offers and see that it covers - as I hoped it might-supports provided by health personnel, schools alongside adjunct educational supports, housing needs and presumably as part of social care, short (respite) breaks as well as domiciliary support. Yet these forms of support (for which there is an evidence base of their benefits to families) feature rarely in the information presented in this paper which instead lists training packages of which Triple P is the most common.

Response: We have updated the manuscript throughout to reflect that the focus of this study was to describe parenting, family and sibling support programmes or interventions, to inform the design of future parenting and sibling intervention research trials, respectively, and not to describe all supports for families.

5. To compound matters, no data was gathered of the quantum of English families in receipt of even the very particular supports that are reported, which admittedly the authors do note as a concern.

Response: As outlined in the Introduction, it was not the purpose nor scope of the current study to collect this type of data. We cite in the Introduction previous research (e.g., Sapiets et al. 2023) that sought to address this question (i.e., what supports families receive). Our focus was to add to existing literature by gathering data on the perspectives of professionals and/or in formal documents describing available supports offered by English Local Authorities. As noted in our discussion, we do highlight that families are likely to provide a different perspective. Our focus though was not on this perspective for the current study

6. By contrast, a wider range of supports were identified by the raters in terms of the supports available to young carers in their Local Offers, and these types of supports have also been effective with parent carers which makes their omission all the more puzzling in their analysis of Local Offers to parents.

Response: As mentioned previously, the scope of this study was to see what support programmes or interventions are available to inform the design of future evaluation trials focussing on new parenting and sibling interventions, respectively. However, we found during this search that little intervention or programme support is available for siblings and young carers thus we broadened our search in this respect to consider if any support at all was available. We have updated the Procedure section of the Methods to make this clearer for the reader:

"However, as little intervention or programme support was available for siblings and young carers, the research team expanded the scope of this search to explore generally what support is usually offered to siblings and young carers as part of the Local Offer" (p.5)

7. One possibility for this omission is that the two raters had a more focused definition of support in mind when undertaking their analysis of 100 Local Offers to families but why not share this and defend their rationale for so doing? It is only when I dug deeper into the supplementary files containing the questionnaire sent to professionals that I discovered a much narrower definition of support and here it is. "Parent support programmes or interventions refers to an organised or structured resource that aims to enhance parent knowledge and skills and/or share helpful practical parenting strategies to overcome parenting challenges or concerns. These supports may be self -directed or delivered by a trained professional". Could this have been in the mind of the two raters examining LA's Local Offer websites which led them to discounting other forms of support 'programmes' provided through health services, schools or social care, which to my mind could still fall within that definition and that are supported by peer-reviewed articles that I could happily cite.

Response: As noted above, we have clarified what data we intended to extract and it was

indeed more focused. We have also included this definition of support in the manuscript for transparency:

'In the context of the current study, parent support programmes or interventions were defined in our survey as "an organised or structured resource that aims to enhance parent knowledge and skills and/or share helpful practical parenting
strategies to overcome parenting challenges or concerns. These supports may be self-directed or delivered by a trained professional".' (p.4)

8. Moreover were any cross-checks undertaken by any of the other 13 authors, who might have probed to see if other forms of support had been overlooked or was any member checking of the raters' analysis performed via telephone calls with a lead person in even a sample of LAs? I fear the information gathered and reported here does not constitute robust evidence for 'treatments as usual' let alone 'support as usual' as it under values the other forms of support being provided by LAs and their independent providers.

Response: No formal cross-checking took place but co-authors were asked to provide input based on their expertise. Again, our focus was information contained in Local Offer sources and via a survey with professionals – perspectives missing from existing research (which has included a parent perspective as cited) and thus adding to the picture of parenting and family based supports.

9. The highly structured questions focused on named programmes and thus provided little scope for reporting other forms of support.

Response: We have provided further information throughout the manuscript clarifying the focus of this study.

10. The self-selected sample (with a bias to responses from more affluent areas of England as per Table 1) adds little robust evidence and could perhaps could charitably be classed as a pilot study.

Response: We shared the anonymous survey through different networks. As the survey was anonymous, we do not have information about why people chose to respond or not respond to our survey, and we were unable to follow up with participants.

11. I fear the authors in their discussion rather over sell the usefulness of their information in relation to RCTs and the setting of national standards. They need to be more upfront about the limitations of their information gathering and more forthright about what should be done. For example, if you want to define 'support as usual' as part of a trial for economic assessments, you need to get the information directly from parents, and find out not just which supports they currently access (and maybe have accessed) but those they found of help to them and why.

Response: We have edited the discussion to focus more on the utility of the data for its intended purpose and deleted the reference to national standards which on reflection we

agree is not appropriate.

Competing Interests: No competing interests were disclosed.