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Legal change and children’s shared decision making experiences in mental health: A systematic narrative review

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ABSTRACT

This study systematically reviewed data regarding children and young peoples experience of shared decision making in mental health services before and after the introduction of the English Health and Social Care Act (2012), which encouraged the practice. Studies collecting relevant data between 2008 and 2022 were systematically searched on four databases in April 2022. Studies were excluded based on the age and location of participants and the type of data collected. Data in the field was very limited and under-reported. Despite rigorous screening of 8918 papers, only four studies met the eligibility criteria, creating a strong case for increased reporting of children and young people’s experiences. Detailed analysis of the limited available data suggested that despite services experiencing funding cuts and increased demand, children and young people may have experienced improved shared decision making when the law was introduced. This suggests legal change may have a role in improving patient experience of shared decision making and encourages further research.

1. Introduction

Article 12 of the UN Convention on the Rights of the Child gives children and young people the fundamental right to be heard and taken seriously when decisions are being made about their lives, with article 24 specifying that they have a right to good quality healthcare and information to help them stay healthy (UNICEF UK, 1989). Their right to be involved in their healthcare is reinforced by the UN Convention on the Rights of People with Disabilities (United Nations, 2006) the NHS constitution (Department of Health, 2021) and the European Guidelines on Child-friendly Healthcare (Council of Europe, 2011). In healthcare, this process of information sharing and collaboration between professionals and patients, in which the expertise of both parties is discussed and respected, is known as shared decision making (Barry & Edgman-Levitan, 2012; Coulter et al., 2008; Légaré et al., 2008; Makoul & Clayman, 2006). Within this review, the two key indicators of shared decision making were children and young people feeling that they were involved in discussions about their care including understanding the options available to them, and that they had their views listened to and taken seriously (Martin& Feltham, 2020).

Alongside being the right of children and young people, shared decision making has other important impacts. In mental health care, involving patients in decisions is likely to improve their adherence to medication (Bauer et al., 2014) reducing the chance of relapse (Loh et al., 2007). Some also argue that the practice reduces the trauma of medical treatment (Cornwell, 2021) and patients’ anxiety about their medical treatment (Youngson & Blennerhassett, 2016). Despite these strong arguments for the use of shared decision making, involving children and young people in decisions about their healthcare is not as prominent an element of healthcare practice as experts would hope (Brady, 2017; Maskrey, 2019; Slade, 2017).

This is even more pronounced in children and young people’s mental health care. Healthcare professionals report difficulties in measuring children and young people’s capacity to make decisions due to the individual and changing nature of children and young peoples maturation and understanding of complex information (Ruhe et al., 2015) and a lack of resources to help both clinicians and children and young people learn to share decision making (Macarthur et al., 2021). In mental health services, questions about the capacity of patients are again an issue for practitioners when considering sharing decisions due to concerns that the nature of patients’ illness may reduce their capacity (Lin et al., 2022) or mean that they make decision which are deemed inappropriate by the

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professionals treating them (Farrelly et al., 2016). Children and young people using mental health services may have their capacity questioned both on the grounds of their age and their illness, making it a particularly tricky field for professionals and children and young people to navigate. This can result in children and young people not being included in decisions about their care in a way that children, young people or adults using other services may be (Martin & Feltham, 2020).

In the years since the ratification of the UN Convention on the Rights of the Child (UNICEF, 1989) there have been global policy changes to encourage the practice of shared decision making. The World Health Organization Regional Office for Europe (2015) identified shared decision making as a priority for the years 2015–2020; emphasizing the need to explore patients' views on their care and offer them all options, including doing nothing. In 2016, the World Health Organization identified shared decision making as an important aspect of patient safety, implementing an international policy that made patient engagement an essential part of healthcare. The 2023 submission to the UN Committee on the Rights of the Child on Children's Rights in Great Britain (Equality and Human Rights Commission, 2023) identified independent mental health advocates for children and young people detained under the Mental Health Act (1983) were not always provided, despite access being a legal right to any person detained in this way. The submission identified this as a priority for Great Britain going forwards. In England, the National Health Service Long Term Plan (NHS England, 2019) and Health and Care Act (Department of Health and Social Care, 2022) set out how all parts of the country would be served by an Integrated Care System from April 2021 (Department of Health and Social Care, 2006). Statutory guidance related the outlines how health and care systems should build positive and enduring partnerships with people and communities to improve services and outcomes, including engagement, co-design and co-production (Department of Health and Social Care, 2006). Each of these principles relate strongly to shared decision making in that they place the patient at the center of decision making in health services.

2. England's health and social care act

The focus of this study lies in England, considering the introduction of the Health and Social Care Act in 2012 (Department of Health and Social Care) as an interesting timepoint; as it provided new rights to patients, including children and young people, to share decisions in their care, without any increase in funding. Ostensibly, the Health and Social Care Act (2012) centrally valued both patient choice and cost reduction. A pause in the introduction of the Act was taken between 2010 and 2012; reportedly due to a professional attitude that it was not possible to meet both aims (Glover-Thomas, 2013). Critics said the Health and Social Care Act (2012) undermined the professional competence of National Health Service workers over "Any Qualified Provider" (Speed & Gabe, 2013; p.563) and favored lower-cost services over the standard of care (Sanderson et al., 2017). The change in law thus had the potential to mean healthcare commissioners would prioritize reducing costs over good shared decision making practice. Reducing costs was generally part of the agenda in the UKs National Health Service (NHS) around the time of the Health and Social Care Acts introduction in 2012. NHS Funding had been steadily rising as a percentage of GDP from 4.9% in 2000 to 7.6% in 2010 (Appleby, 2018). After 2010, a stagnation in funding coincided with the Health and Social Care Act's first iteration being brought to parliament, meaning the development of the Health and Social Care Act (2012) took place in the context of financial change for the NHS. An additional criticism was the general rhetoric change around children and young people's mental health employed by the government who introduced the Health and Social Care Act (2012). Callaghan and colleagues (2017) argued that the use of language around patient choice was used to mean patient responsibility, particularly in making good choices that supported their own mental health and reducing reliance on services; rather than a shared practice in which the views of both parties are considered and discussed.

However, alongside criticism, the introduction of the Health and Social Care Act (2012) held promise for shared decision making in child and young people's mental health services in England. The Health and Social Care Act (2012) included long fought for "parity of esteem" between mental and physical health, meaning that children and young people should be involved in decisions about their mental health in a similar way to all other aspects of their health. Additionally, with the introduction of the Health and Social Care Act (2012), being involved in healthcare at every level, including in their individual care, reinforced shared decision making as a patient's legal right, rather than good practice on the part of the clinician. The Health and Social Care Act (2012) thus creates a rare situation in which patient rights have increased in an environment in which there is no financial support or additional training on offer for the medical professionals responsible for implementing these changes.

This makes 2012, when the act was introduced, a particularly interesting timepoint to centre this review around. While the review does not directly explore children's experiences of the introduction of the Health and Social Care Act (2012), it presents data surrounding a period in which health services were being overhauled in a way that should have improved their experiences of shared decision making. This review is centred around the introduction of the Health and Social Care Act (2012) on the basis that changes in children and young peoples experiences were intended to be significantly changed at this time. It intends to explore whether a change in children and young peoples experiences coincided with the introduction of the Health and Social Care Act (2012) as a proxy for the impact the law may have made, given that data directly exploring the link is not available in existing literature.

3. Data quality

Wolpert & Rutter (2018) provide a case for analyzing data that is "Faulty, Uncertain, Proximate and Sparse" (p.2) in a narrative way to begin an academic and professional dialogue about an issue which might not otherwise be considered. In context, the data used in this review is likely to be "Faulty" in nature due to biased or unclear measures and "Uncertain" due to difficulty in definitively measuring experience and attitude in children's mental health without other factors influencing results. The term "Proximate" refers to the perspective that the data approximates reality with no one truth when dealing with experiences, perspectives, and opinions. Finally, the data is 'Sparse'. Shared decision making in children's mental health is not widely reported, as will become clear through this systematic review. Within this review, "Faulty, Uncertain, Proximate and Sparse" data is likely to be the best available. However, this does not mean that it is not useful. Wolpert and Rutter's (2019) paper, which they described as "part case study and part vision for the future" (p.2), argued that where gold standard evidence is not available, using "Faulty, Uncertain, Proximate and Sparse" (p.2) data is highly useful. They argue strongly that ignoring data based on its characteristics endangers important academic conversations led by related findings and hypotheses and thus the possibility of moving academic discourse and research forwards. In the case study element of their paper, they described their use and dissemination of findings from "faulty, uncertain, approximated and sparce" data in children and young people's mental health. In discussions within the case study, well-respected academics recommended against sharing their findings on the basis that they may mislead readers. Wolpert and Rutter report considering this carefully, but ultimately deciding that if the issues with the data are openly discussed throughout writing and dissemination, the results can be a useful starting point for curiosity and conversation. The 'vision for the future' element of the paper does appear to be coming to life, with the 24 citations within four years of its publication (as reported by Web of Science in June 2022) representing its impact. This review will add to the building community of researchers reporting this different kind of data.

In order to ensure data quality within this context, studies were screened using a clear, predetermined set of criteria. These were that studies reported views on shared decision making from children, young people or their parents obtained in the four years before and after the introduction of the Health and Social Care Act (2012). Exploring any changes to children and young peoples experiences of shared decision making before and after the Act was introduced allows a comparison to be made between these two time points, and inferences to me made as to whether the Act met its purpose in improving patients experiences of shared decision making. To ensure the best data quality possible the review only considered quantitative data. While this further limited the number of studies used, making them more sparce, using studies with the binary outcome only found in quantitative studies reduced the amount of biased, uncertain and approximated measurement of child experience.

3.1. *Methods*

The systematic review was registered on the PROSPERO database on 06/01/2022 (CRD42022301446). It originally planned to analyze clinician reported attitudes, but changes were made due to a lack of suitable data. The review focused on CYP reported experience instead, with the intention of using the results for a novel study on the relationship between clinical attitudes and CYP experience. The review protocol was updated twice, with the second update resulting in a systematic narrative review instead of a *meta*-analysis, and a reduction in the number of subgroups to only two: studies reporting shared decision making related CYP reported experience measures collected before and after the introduction of the Health and Social Care Act (2012). Only studies from England were included, as the Act only covers this region. These changes allowed for a more accurate representation of the limited available evidence and avoided potential inaccuracies and bias in the results.

3.2. *Search strategy*

Following scoping searches to establish keywords PubMed, PychInfo, OAlster and Science Direct were systematically searched for

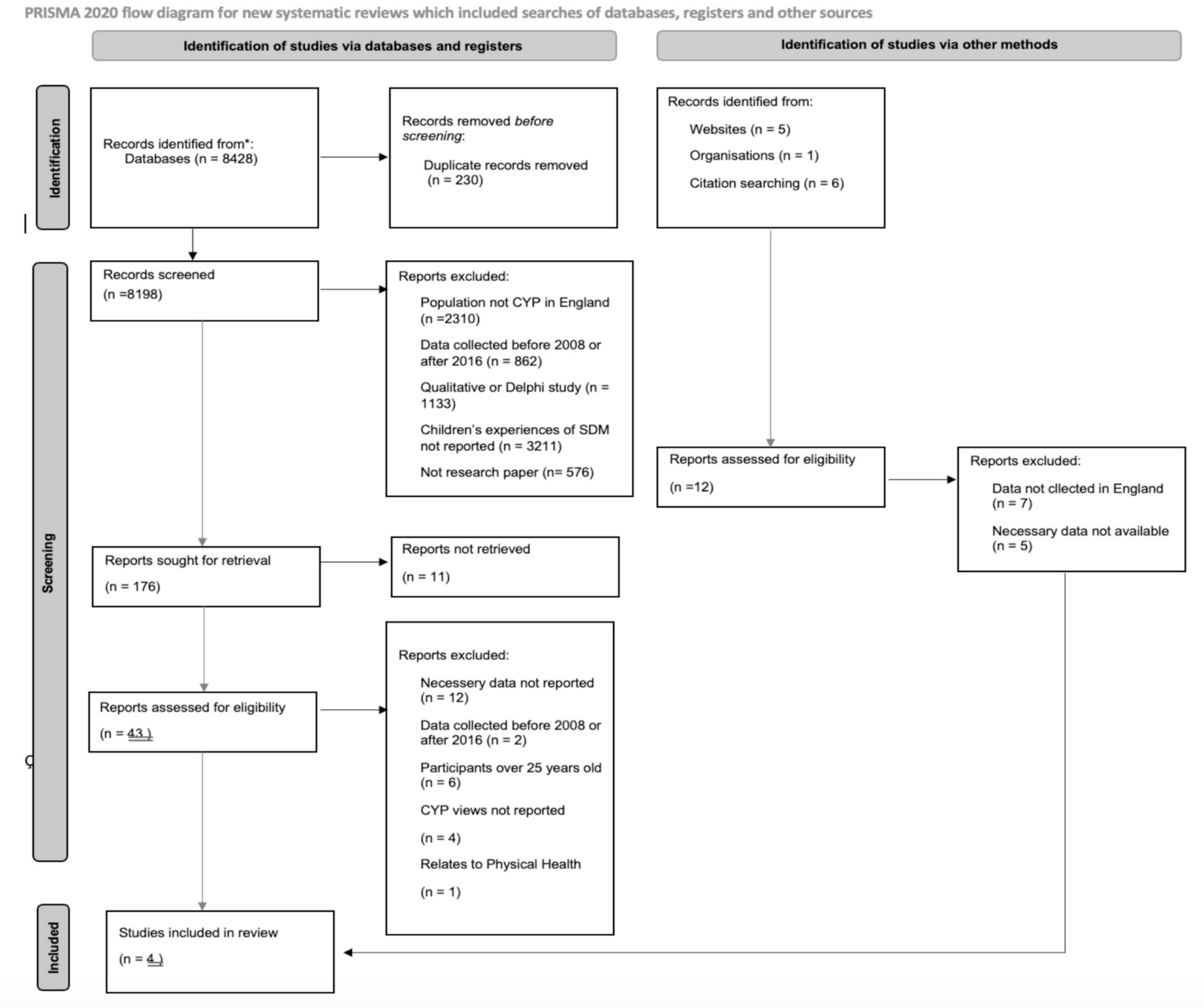

Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. *From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. https://doi.org/10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/.

relevant articles published from 2008 onwards to explore data collected before and after the introduction of the Health and Social Care Act (2012). The searches were completed in March and April of 2022. No filters concerning specific diagnoses or interventions were included to broaden the search in a field with limited data.

Additionally, routine reports of outcomes in mental health services were manually sought through google and google scholar, using the keywords in the original sources, considering relevant reports from the first 10 pages. Finally, the citations of papers reviewed in full text for any studies were hand searched. Hand searching and manual imports from google and google scholar ultimately did not provide any usable reports.

3.3. *Study selection*

Online systematic review software Rayyan (Ouzzani et al., 2016) was used to remove duplicates and screen titles and abstracts. Searching gray literature helped to reduce the level of publication bias in the study, as null results are more likely to be found in this data source (Paez, 2017), and is identified as an important step in gold standard literature reviews where published literature is low in volume or quality (Benzies et al., 2006).

Full text papers of any studies meeting the inclusion criteria were sought. Where gray literature was identified the permission of the original author was requested. Ultimately, no gray literature was used as permission was not granted. The reasons for exclusion or acceptance are in a Prisma Diagram (Fig. 1).

The current article is accompanied by a record of all papers assessed and reasons for rejection. This file is available in the Figshare repository and accessible as Supplementary Material via the SAGE Journals platform. Relevant approvals were granted for this data sharing.

3.4. *Data extraction*

For the purposes of data extraction, shared decision making was defined as the extend to which children and young people felt listened to, had their views taken seriously, and had input into decisions and an understanding or how they were made. This is in line with the framework set out by Martin and Feltham (2020).

As data was extracted from existing reports and not ambiguous, one researcher extracted all data, From each paper, the researcher extracted the author, year of publication, date of data collection, measurement scale used, age of participants, country of data collection and percentage of positive responses to the shared decision making elements of the experience of service questionnaire. ‘Percentage of positive responses’ refers to the percentage of children, young people and parents who replied ‘certainly true’ or ‘partically true’ to elements of a questionnaire asking if they had received good quality shared decision making. The precise methods for calculating the percentage of positive resposnse for each paper are listed below.

Duncan et al. (2020) and Hunter et al. (2020) provided the most specific data, reporting the percentage of positive responses to the individual Experience of Service Questionnaire items. As such, a mean average four items relating to SDM as identified in previous research (Edbrooke-Childs et al., 2016) was extracted.

Kyriakopoulos and colleagues (2013) reported average scores on the experience of service questionnaire regarding sharing of information with parents and carers for two types of intervention. The average number of positive responses was reported as a percentage.

Liverpool and colleagues (2021) reported the least specific data, stating that over 90% of responses to the shared decision making element of the experience of service questionnaire reported CYP had a positive experience of SDM. This figure was used as the best available.

Two independent reviewers (KL and AF) extracted data using a standardized form, with discrepancies resolved through discussion and consultation with a third independent reviewer (PB). Data is presented in Table 1with the data extraction table is accessible via the SAGE Journals platform available as supplementary material.

3.5. *Quality assessment*

Quality of the studies was assessed using the 20-item IHE Quality appraisal Checklist for Case Series Studies (Edmonton (AB) and Institute of Health Economics, 2014). The tool explores whether the study objective, study design, study population, intervention (and co-intervention), outcome measures, statistical analysis, results, and conclusions are appropriate and clearly reported. This was selected as the best available quality assessment tool, despite it being designed for case series studies. This was partly because each study varied in its design, making it difficult to find one appraisal tool to meet all studies. Two questions which were not relevant to this review were removed. One dealt with whether patients were at a similar point in their illness, which is difficult to assess. The other referred to the effect of any intervention, which is not of relevance to this review.

3.6. *Risk of bias*

The most used tools to assess the risk of bias in systematic reviews are the Newcastle-Ottawa Scale and the ROBINS-I (Farrah et al., 2019). The Newcastle-Ottawa Scale (Wells et al., 2014) is designed to assess studies which compare two groups, such as case-control or cohort studies. In

Table 1
Description of studies included in this review.

Author	Data collection timeframe	Aim	Sample size	Client age range	Participant type
Liverpool et al, 2021	2011–2016	To examine the relationship between child / parent experience of shared decision making with clinical outcomes	3,175	0–18	Child and parent proxy
Kyriakopoulous et al., 2015	2009–2012	To explore whether emergency admissions to mental health wards are as acceptable as planned admissions	82	0–13	Child and parent proxy
Hunter et al., 2022	2012–2017	To evaluate the effectiveness of a new service aiming to provide early intervention mental health support for infants	77	0–2 and family	Parent proxy
Duncan et al., 2018	2015–2017	To assess the demographic of young people accessing mental health services	2,144	11–25	Child

this review, not all studies were of an intervention style, making this tool inappropriate. The ROBINS-I (Sterne et al., 2016) held the advantage of being recommended as a measure by the esteemed Cochrane Collaboration for Systematic Reviews (Higgins and Green, 2011), but as with the Newcastle-Ottawa Scale, was designed to assess controlled or cohort studies.

The Cochrane Collaboration were however developing a new tool, which would subsequently be known as the ROBINS-E. The ROBINS-E assessed exposure, rather than intervention studies, removing assessment of bias regarding comparison of more than one group within the study. This tool was identified as the best available, with an acknowledgment that it was still in the development phase. As the tool was still in the piloting phase when used by this review, the questions in the early drafts were applied. These questions addressed the following possible elements of bias: confounding, participant selection, classification of exposures, departure from intended exposure, missing data, measurement outcomes and selection of results. It also suggests the researcher list an overall risk of bias judgment based on these points. The results of the risk of bias and quality assessments are shown in Tables 2 and 3 respectively.

The IHE Quality appraisal Checklist and ROBINS-E assessed the challenges of the data, and these were reflected in the results. However, as established in the introduction, the analysis necessitated the use of “faulty, uncertain, approximated and sparce” data, and as such studies were accepted regardless of risk of bias and quality assessment.

4. Results

Overall, 8428 reports were identified through database searching, including 230 duplicates. Through hand searching, including looking for government and service evaluations and reference searching twelve further records were identified, however on closer inspection none of these provided relevant data and as such were not included. As can be seen in figure 1, after abstract and full paper screening only four records were found to be suitable for inclusion.

The studies differ considerably in sample size, level of bias, study quality and age of participants surveyed. Despite this, there are some useful points of similarity. All studies have reported scores from the Experience of Service Questionnaire (Child Outcome Research Consortium, n.d.), a measure commonly used in child and adolescent mental health services. Despite being widely collected in child mental health services, particularly as a measure the esteemed Child Outcome Research Consortium recommend their members use, some aspects of the measure are concerning. The measure consists of a 12-item, three-point Likert scale questionnaire. The options are ‘Certainly True’, ‘Partly True’ and ‘Not True’; with an additional ‘Don’t know’ option (p.16; Attride-Stirling, 2003). None of the items are reverse coded, and both ‘Certainly True’ and ‘Partly True’ are considered as a positive experience, creating a strong bias towards positive responses being recorded. There are also three free text questions, however there is no suggestion in existing literature about how to code and report this. The measure has not been assessed for reliability (Brown et al., 2014). Not all studies reported raw data, making the comparison less direct.

Table 2
Risk of Bias as assessed by the ROBINS-E.

Possible Bias	Liverpool et al., 2021	Kyriakopoulous et al., 2013	Hunter et al., 2022	Duncan et al, 2018
Confounding Variables	Serious	Serious	Critical	Low
Selection Bias	Low	Moderate	Moderate	Moderate
Bias in Classification	Low	Moderate	Low	Low
Unintended Co-variate	Low	Moderate	Low	Low
Missing Data	Low	Low	Low	Low
Measurement of Outcomes	Moderate	Low	Low	Low
Reporting Bias	Low	Critical	Low	Low
Overall Bias	Moderate	Moderate	Low	Low

A strength of the studies included is that they cover data collected in England between 2009 and 2017, meaning that a suitable period around the introduction of the Health and Social Care Act (2012) has been considered. Notably, publication lag does mean that much of the data reported in the ten-year period from 2012 to 2022 may currently be unpublished, and the included studies is vary extensively based on sample size, study quality, and risk of bias.

Of the four papers, one reported CYP reported experience measures collected data before the introduction of the Health and Social Care Act (2012), one considered the period during the introduction of the Act, between 2011 and 2015, and two collected data after the introduction of the Health and Social Care Act in 2012.

Kyriakopoulos et al. (2013) collected data from a small sample of 82 children and young people under 13 and their parent proxies between 2009 and 2012. The study reported children and young people had a positive experience of SDM 83.33% of the time. This was on the basis that at least one positive response to the shared decision making questions indicated an overall positive experience. The study noted that the experiences of children, young people and their parents may have been improved by the provision of family accommodation, allowing a parent to stay close to the hospital for the first few days of the child’s admission, The concern regarding separation from parents is not captured by the ESQ but is a highly relevant consideration when considering children as the main population. It is possible to speculate that children, young people and their parents may find it easier to partake in SDM when they are physically close and the child or young person is not suffering separation anxiety. Thus, the study may have reported more positive experiences of SDM due to the provision of family accommodation for the population studied.

Liverpool, Hayes and Edbrooke-Childs (2021) combined data collected both before and after the introduction of the Health and Social Care Act (2012). The study analyzed data routinely collected between 2011 and 2015 by 58 CAMHS sites in England resulting in a convenience sample size of 3175 children and young people; by far the largest sample size in this review The data extracted from the paper states that CYP reported experience measures regarding shared decision making were positive 90% of the time, in that on average children and young people had ticked one of the positive options related to shared decision making on the experience measures. They noted that the necessity of parental involvement in children’s care can be an additional factor making SDM more difficult for this demographic. This may be due to moving decision making from the dyad of CYP and practitioner to a triad by including parents makes the process more complex. This suggests that using parents as a proxy for children’s experience may not be accurate, as the child’s experience may be different in decisions that don’t require parental involvement.

The comparison of two studies on CYP experience before and after the introduction of the Health and Social Care Act (2012) is flawed due to limited data and potential selection bias. However, analyzing the percentage of positive responses suggests a slight improvement in children and young people’s experience of shared decision making. This is based on two studies, with the first study possibly having a selection bias favoring positive responses. Despite limitations, the comparison is presented as a starting point for academic discussion following the guidance of Wolpert and Rutter (2018).

As a point of comparison, two studies reporting shared decision making CYP reported experience measures collected after the introduction of the Health and Social Care Act (HSCA; 2012) were identified.

Duncan et al. (2020) opportunistically collected the relevant elements of the experience of service The researchers reported that 91% of the 169 participants gave positive responses to the shared decision making elements of the experience of service questionnaire. Data was collected in community and voluntary services, and the authors noted

Table 3
Study quality as assessed by the IHE Quality Appraisal Checklist for Case Series Studies.

Overall Measure	Individual Measures	Liverpool et al., 2021	Kyriakopoulous et al., 2013	Hunter et al., 2022	Duncan et al, 2018
Study Objective	Was hypothesis stated?	Y	Y	Y	Y
Study Design	Was study prospective?	Y	Y	Y	Y
	Were there multiple sources of data collection?	Y	N	N	Y
	Were participants recruited consecutively?	Y	Y	Y	Y
Study Population	Was population effectively described?	Y	P	P	Y
	Were the eligibility criteria stated?	Y	Y	Y	Y
Intervention and Co-intervention	Was description of intervention clear?	Y	Y	N	Y
	Were co-interventions described?	N	N	N	N
Outcome Measure	Were measures established apriori?	Y	Y	Y	Y
	Were assessors blinded?	N	N	N	N
	Are methods appropriate?	Y	N	N	Y
Statistical Analysis	Were tests appropriate?	Y	Y	Y	Y
Results and Conclusions		U	Y	Y	Y
	Was follow up length appropriate?				
	Were participant withdrawals reported?	NA	Y	Y	Y
	Was random variability reported?	N	N	N	N
	Were adverse events reported?	N	Y	N	N
	Were work inclusions appropriate?	Y	Y	Y	Y
	Were competing interests reported?	N	N	N	N

[i] Key: Y = yes, N = no, NA = not applicable, P = partial, U = unclear.

that more children and young people reported ‘feeling listened to’ than in statutory CAMHS services. The types of service which data was collected in were often provided under the ‘Improving Access to Psychological Therapies’ scheme, which was introduced in 2011 to provide help for CYP who would not meet the criteria for support from CAMHS. It is possible that CYP in this category may be more likely to experience being listened to due to the nature of their difficulties compared to their counterparts accessing CAMHS.

The final study, by Hunter and colleagues (2020) a service for 0–2 year-olds and their families, creating some difficulties in comparability with the other studies due to the age discrepancy. The measure used was once again the experience of service questionnaire, and as with Kyriakopoulos and colleagues (2013) study from before 2012, parent experience was used as a proxy for CYP experience. In this age group, while the child is the listed patient it is arguably the parent receiving intervention and support from the service. This reduces the decision making tryad seen in children and young people’s mental health to a dyad, possibly making it the SDM approach simpler to follow. While CYP age and reporting type limit the generalizability of this study within the review, it has been included as approximated data. Of the 169 parents sampled, 96.25% responded positively to shared decision making elements of the experience of service questionnaire.

4.1. Quality and risk of bias

It is important to note that the studies varied considerably in terms of quality and risk of bias.

Kyriakopoulos et al. (2013) has a moderate risk of bias and the study quality is notably lower than other studies considered in this review. While the study was observational rather than controlled, CYP were separated into two groups for data collection and analysis, and there may be a risk of researcher bias as data was collected by clinical staff treating the CYP, rather than independent researchers. The study aimed to address whether emergency, as opposed to planned, admissions to mental health wards were a viable option; and there was a strong emphasis in the paper on the way this may address the known shortage of hospital beds. If proving that emergency admissions are acceptable was on the researchers’ agenda when collecting data, unconscious bias may have affected the way the questionnaires were administered. The risk of bias and flawed study design may both favor more positive results.

Liverpool, Hayes and Edbrooke-Childs (2021 analyzed a convenience sample with a moderate risk of confounding variables including unrelated interventions being introduced alongside data collection. CYP experience was collected by proxy from parents; as is the case in other included studies. While this is not a direct measure of CYP experience, it is used consistently in the literature and is accepted here as part of the use of uncertain and approximated data.

Duncan et al. (2020) was non-experimental, and the data collected was not to assess a shared decision making intervention group, suggesting it may be reasonably generalizable within children and young people's shared decision making in England. The risk of bias was low in most areas, only showing a moderate level of possible bias in the selection of children and young people into the study. The level of bias identified was based on the use of self-selection, rather than routine measurement of all CYP. The study quality was high. Given the design, size, and implementation of the study, the results hold considerable weight.

The final study, by Hunter and colleagues (2020) had a notably low risk of bias and high-quality, suggesting an excellent design. However, it concerned a service for 0–2 year-olds and their families, creating some difficulties in comparability with the other studies due to the age discrepancy. As with Kyriakopoulos and colleagues (2013) study from before 2012, parent experience was used as a proxy for CYP experience. While CYP age and reporting type limit the generalizability of this study within the review, it has been included as approximated data.

The full detailed assessments of risk of bias and study quality are provided in tables two and three respectively. In line with the attitude to data in this study, no studies were excluded due to a high risk of bias or low quality. The very small number of studies included represents the scarcity of available data, with any study identified through searches with data collected from children and young people in the specified time period were included. The only exceptions to this were studies which did not report any data related to SDM separately from the results of larger questionnaires. This was because it was impossible to assess experiences of SDM distinctly from a wider experience of their treatment and outcomes.

It is worth noting that two studies reporting data collected after the introduction of the Health and Social Care Act (2012) tended to be of a higher quality and lower risk of bias than those with data collected before 2012. It is difficult to predict whether this represents more capacity or willingness to collect and report shared decision making CYP reported experience measures since the introduction of the HSCA (2012), or whether this difference in data collection is coincidence.

If crudely taking the average of these two studies, there was a mean of 932% positive responses to shared decision making CYP reported experience measures. This is far from an accurate synthesis of the results; not taking into consideration risk of bias, study quality, or sample size.

Comparing the data from before, during and after the introduction of the HSCA (2012) provides a potentially helpful insight. The only study available from before the introduction of the HSCA (2012) had an 83.33% average positive response rate. The study which straddled the introduction of the Act reported this figure as 90%, and the average of the two studies from after 2012 was 93.2%. This slow increase is an interesting primary insight into how shared decision making experiences may have improved over time. Comparing the similar studies below supports this suggestion.

Kyriakopoulos and colleagues (2013) and Duncan et al. (2020) are studies which are somewhat comparable. As well as using the same CYP reported experience measure, they had similar sample sizes, participant ages and both take a non-experimental design. When the two studies are directly compared, there is an increased positive response rate in the study which collected data after the introduction of the HSCA (2012). They have significant limitations in that in both cases their data collection was local to one service, reducing generalizability, and had small sample sizes of 82 and 169 respectively.

This review tentatively suggests that CYP experience of shared decision making in children and young people’s mental health in England could have improved since the introduction of the HSCA (2012). This is based on four accepted studies which present faulty, uncertain, approximated and sparce, but usable data. A comparison of crude average scores and two similar but small studies shows a possible improvement in experience after the introduction of the HSCA. The major lack of data and the low quality and high risk of bias in the data which is available would mean that in normal academic circumstances this review would report inconclusive results. An additional limitation is that none of the studies directly discussed the impact of law and policy on the outcomes they measured. Instead, this review uses data collected for other purposes to speculate on a possible impact of law and policy in the absence of any such studies. The results of the current study are published as a starting point for academic discussion which could lead to clearer, more reliable research than that is currently available.

5. Discussion

The review reports crude, unweighted, figures alongside a narrative synthesis reflecting on the strengths and limitations of each study and of the comparisons between them. It is important that neither the figures, nor the narrative review should be considered fact. As identified in the introduction, this systematic narrative review is intended to create only a starting point for academic discussion.

A limitation of this study is a reported ‘halo effect’ of the main measure used: the experience of service questionnaire (Brown et al., 2014). The measure uses a 4 point Likert scale, in which only one option is processed as a negative response, with two options being coded a positive response and the additional 'don't know' option disregarded. This creates a strong bias towards positive responses.

An unexpected finding of the review is that the HSCA (2012) could have increased CYP experience of shared decision making within children and young peoples’ mental health services. This is an early and cautious suggestion, with further research needed to investigate whether the result is coincidental or a direct result of legal change. If this is the case, it would be incredible given that the Act sat within the context of hugely increased pressure on such services. Data from government bodies suggests demand for children and young people's mental health support is increasing. The chief medical officer’s report (Department of Health and Social Care, 2013) claimed a ‘dramatic increase’ in the prevalence of mental health problems based on the only relevant figures they had available which were collected in 1999 and 2004. NHS Digital (2017) provided a more specific idea of the demand for services, with their figures showing diagnosable children's mental health problems rising from 9.7% in 1999 to 10.1% in 2004, and then 11.2% in 2017. In a staggering report from the local government ‘Bright Future’ report (Local Government Organisation, 2022) referrals to child and adolescent mental health services increased by 96% between 2019 and 2021. While the reported numbers are not clear or consistent, and with the last figure needing to be taken in the context of increased pressure due to the COVID-19 pandemic, all reports agree that the need for services is steadily increasing. Despite this there was a 50-million-pound real terms cut to funding for National Health Services for child and adolescent mental health between 2010 and 2015 (Office of the Children’s Commissioner for England, 2018). The combination of the number of referrals and decrease in funding would suggest that children’s mental health services were under increasing pressure during the introduction of the Health and Social Care Act (2012). Given this context, it may have been expected that the practice of shared decision making could suffer. The finding that CYP experience of shared decision making did not fall suggests the possibility that the legal change in support of shared decision making could have been a protective factor against negative changes in practice. There is very limited research on why this may be the case, but Grot and Wensing (2020) suggest that widescale legal change may unite healthcare services to improve the same thing at the same time, concentrating efforts to make an improvement in care more likely. Johnson and May (2015) further suggest that the changing norms and expectations clinicians have of each other within healthcare services may go some way to changing practice in healthcare Further research is needed to understand how the HSCA may have worked to keep children’s experience of service stable in a time of increased pressure on services. In particular, the way in which children’s mental health professionals experienced this change in law, and whether this was a factor in changing practice and thus CYP experience may be of interest.

A more expected element of the review is the sparse available data around children and young people’s experience of shared decision making. As highlighted in the introduction, a similar review on the use of electronic health records faced the challenges of faulty and sparce data. The review noted that while electronic health records were being used, this use was not always reported. There were also limited studies relevant to their review, with thousands of initial hits from systematic searches leading to just 6 studies to include. The present review had a similar issue in finding suitable studies for inclusion; suggesting shared decision making is taking place, but it is not being reported. The lack of published data is speculatively interesting. The Child Outcome Research Consortium collects and collates data including CYP experience of shared decision making from around half of child and adolescent mental health services, which services are free to publish or share (Fleming et al., 2016). Despite so many child and adolescent mental health services being signed up to the Child Outcome Research Consortium and able to publish their reports, none published data to the level of detail needed for this review. This may represent a ‘halo effect’ with results more likely to be published by CAMHS with favorable experience of service questionnaire scores. This would be unfortunate, as unwillingness to share unfavorable experience of service results means that child and adolescent mental health services are less able to collaborate and learn from each other about how best to improve children and young people’s experiences of the service they receive.

The present review has reliable comparisons between studies, supported by the consistent reporting of the experience of service questionnaire. Disease-specific measures such as this are known to be more valid than generalized patient reported experience measures (Bele et al., 2021). As a result, the data becomes less flawed and uncertain while remaining approximated and sparce.

6. Conclusion

This review examines the relationship between the introduction of the Health and Social Care Act (2012) and children and young peoples experiences of shared decision making in England. Despite limited data, the review suggests that children and young people's experiences of shared decision making improved coinciding with the introduction of the Act, which is surprising given the pressures faced by the healthcare system. Given that the Health and Social Care Act (2012) had a strong focus on shared decision making, it may be implied that this change in law was a factor in the apparent improvement in children and young peoples experiences. Direct exploration of children and young people's experiences of legal change is an area for future research.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Studies identified across databases and excluded during the systematic review screening process. Supplementary data to this article can be found online at https://doi.org/10.1016/j.childyouth.2026.109100.

Data availability

Data will be made available on request.

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