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An evaluation of key working for families of children and young people with special educational needs and disabilities

Silvana Mengoni, Janet Bardsley and John Oates

Key working is a way of supporting children and young people with special educational needs and disabilities (SEND) and their families, and is highly regarded by families and practitioners. However, there is a lack of up-to-date research exploring key working in the current context of policy reforms in England. This article reports an evaluation of key working in four sites in England, with a particular focus on the SEND policy reforms. Key working resulted in a number of positive outcomes for children and young people, families and services, including helping services to meet the requirements of the SEND reforms. Challenging aspects included managing transitions and the relationship between key working practitioner and family, but successful strategies were identified. Key working supports the implementation of specific aspects of the English SEND reforms along with more general cultural change in services to align with families’ needs and well-established aspects of good practice.

Key words: key working, key workers, child disability, child development, service evaluation
Introduction
The reforms to the special educational needs and disabilities (SEND) system in England through the Children and Families Act (2014) and SEND Code of Practice in September 2014 (Department for Education & Department for Health, 2014) set out statutory requirements for education, health and social care services to work together and put families at the centre of service delivery, for example when producing Education, Health and Care (EHC) plans. Key working embodies these cultural changes, and adoption of this way of working can help local authorities to meet the requirements of the new legislation. To prepare for the changes, between 2011 and 2014, 20 Pathfinder sites, comprising 31 local areas in England, trialled ways of implementing changes to the SEND system, and findings from the Pathfinder programme suggested that key working had a positive impact on families’ understanding of the new assessment and support planning process and of its implementation (Craston et al., 2013), and that key working had been successfully delivered in a number of different ways to support the 20-week EHC plan process (Hill et al., 2014). The effects and benefits of key working in non-Pathfinder areas and in a broader range of circumstances beyond supporting assessment and planning have not been explored in the current policy context.

Key working and the evidence base
Families of children with SEND often receive support from a number of different professionals and services. This can lead to a range of issues including receiving unco-ordinated information and services, repeating information to multiple professionals and carrying out administrative tasks (Every Disabled Child Matters, 2012; Watson et al., 2002). Key working aims to co-ordinate services, improve support and empower families by facilitating the team around the child (Early Support, 2012; Limbrick, 2012; Sloper et al., 2006). As such it is a way of working that families and services value and which is highlighted in policy recommendations and current legislation (Department for Education & Department for Health, 2014).

Key working can be ‘designated’, ‘non-designated’ or a blend of the two forms. In a designated service, staff are employed solely to carry out key working, whereas for non-designated key working, a practitioner already working with the family in another capacity, for example as a SENCo, physiotherapist or social worker, takes on key working functions. In some local areas, key working is provided by statutory services and in other areas it is provided by the private, voluntary and independent (PVI) sector. People who carry out key working functions can be known by a number of names including ‘key worker’, ‘care co-ordinator’ or ‘Early Support worker’. This article will refer to ‘key working practitioner’.
In a literature review of key working evaluations, Liabo et al. (2001) highlighted that there was no set formula for key working, but that there was a broad consensus on important elements such as placing key working in a multi-agency setting, focusing on the needs of the whole family, empowering families and taking a needs-based, rather than service-based, approach to assessment. Although key working is implemented differently from area to area, it is increasingly being seen as a way of working rather than a discrete role carried out by an individual. Early Support (2012) stressed that key working is most usefully defined as a set of 10 functions enabling an integrated approach to supporting children and their families, rather than an ‘add-on’ service. These functions are shown in Figure 1 and are conceptualised into four primary areas: emotional and practical support; co-ordination; planning and assessment; and information and specialist support.

Liabo et al. (2001) reported that access to a key working practitioner improves the overall quality of life of families with children with disabilities; more specifically it was found to lead to parental empowerment, a more family-centred way of working, better relationships between families and services, improved access to statutory and discretionary benefits, and reduced levels of parental stress. Key working was also found to have positive effects for services with enhanced professional development opportunities for staff. Subsequent research has confirmed these findings (Carter & Thomas, 2011; Greco et al., 2005, 2006, 2007; Rahi et al., 2004). Factors found to be important for a successful and efficient key

Figure 1: Functions of key working outlined by Early Support (2012)
working service include stable multi-agency funding and resources, administrative support, training opportunities, clear job descriptions, provision of a broad range of support, steering groups with parent representatives and regular proactive contact with families (Greco et al., 2005, 2007; Sloper et al., 2006).

The importance of key working for schools
The SEND Code of Practice (Department for Education & Department for Health, 2014) sets out a graduated approach of special educational needs support in schools. Assessments of special educational needs should include parental concerns and the views of professionals from education, health and social care who are working with the child. Where a graduated approach is not sufficient, EHC plans, which replace Statements of special educational needs, outline the special educational provision necessary to help children and young people meet their goals, and importantly, the plans specify how education, health and social care will help them do this. Children and young people value being asked about the type of support that they would like (Lewis et al., 2007) and this principle should be reflected in the assessment process, along with co-ordination of the different practitioners involved, person-centred planning and a single point of contact for the parent and/or young person. A key working approach can assist schools and other services in meeting the SEND requirements of children and young people as it embodies a person-centred, co-ordinated approach to working which aims to fully involve and empower families. It also encapsulates a dynamic approach, which continually assesses needs and whether they are being met.

Barnes (2008) noted that families and SENCos value multi-agency working and have particularly highlighted the key working approach as useful and effective. Indeed Webb et al. (2008) found that school staff felt positively about key working and the subsequent improvements in liaising with other local services and communication in the team around the family. Most of the key working practitioners in this study were not based in schools. However, where this was the case, for example where a SENCo was a key working practitioner, it was felt that while detailed knowledge of a child was an advantage, insufficient time for the role and the risk of conflict of interest if parents had concerns about the school were potential issues within the process.

The current study
In the light of the new SEND policy context, this study intended to review and validate the evidence for key working in England, important factors contributing to its success and potential benefits in helping services meet the new statutory requirements. Through evaluating key working services at four sites by conducting
focus groups with families, key working practitioners and managers, it was also intended that overarching themes and examples of best practice would be identified for the production of national key working guidance.

**Methods**

**Participants**

Data were gathered from four key working sites across England, including rural and city locations, designated and non-designated provision, and delivery through statutory services and the PVI sector. The sites were identified through Early Support and the manager of each site distributed study information to potential participants. The focus groups and interviews were carried out in January–February 2014.

Site A has a non-designated key working approach based in the health and local authority services for SEND. Here, three focus groups were conducted with six parents, five key working practitioners and four managers. Site B operates a designated key working service based in the PVI sector and staff from two local areas contributed to the research. Here, a focus group with nine parents from one local area and a single focus group with seven key working practitioners and four managers from the two local areas were conducted. A young person who had previously received key working from Site B also took part in a semi-structured interview. Site C has designated and non-designated key working provision based in local authority services. Four focus groups were conducted with seven parents, five designated key working practitioners and six managers. Site D offers non-designated key working provision through statutory services. Here, a telephone interview was conducted with a manager.

In total, information was gathered from one young person, 22 parents, 17 key working practitioners and 15 managers. The managers included those who directly managed key working services, those who managed related services at a strategic level and local authority commissioners. Some of the managers also performed non-designated key working functions in Sites A and C. Non-designated key working practitioners came from a range of different services, and the children of the parents in the focus group had a range of physical disabilities and special educational needs, and were aged two to 15 years.

**Data collection and analysis**

Key themes from previous research were used as a basis for the interview schedule, which guided the focus groups. The focus groups with parents and key working practitioners were structured into discussion about positive and negative
aspects of key working with a list of prompts available to the interviewers. In focus groups with managers, a list of topics and prompts was prepared to ensure that information about the structure of key working was gathered, for example regarding the involvement of different services and whether there was a dedicated funding stream. For the interview with the young person, open-ended questions were asked, guided by prompts where needed. Focus groups and interviews were audio-recorded and transcribed verbatim. Following a review of the ethics protocol, a favourable opinion was given by the Open University Human Research Ethics Committee.

In the first stage of analysis, each member of the team developed independently a set of key themes and sub-topics based on the recordings and the experiences of meeting with the various participants. The next stage was a comparison of the emergent themes; this showed a very high level of concordance among the three analysts, and minor differences were resolved by conferencing.

Results
Thematic analysis generated eight themes, which are shown in Table 1 along with their core elements, and which are discussed in detail below. Similar patterns were found across all four sites.

Maximising benefits to families, children and young people
Parents described how key working saved them time and energy through sign-posting, explaining terminology and processes, performing administrative tasks, providing emotional support and problem-solving. Importantly, key working practitioners were seen as being proactive in offering this support, thus helping parents to access information and services that they may not otherwise have been aware of. Many parents stated that they would have struggled to cope without key working and would not have known how to access the appropriate services to meet their child’s needs, nor have known which services were inappropriate.

‘You just don’t have the knowledge that they do and I think that they set you on the right path, I think without them you’d just be, I mean we couldn’t have done it without them. I wouldn’t have known where to start.’

(parent, Site A)

Having a single and consistent point of contact for families was recognised as an important role, which was distinct to key working. One of the key working practitioners described themselves as providing the ‘glue’ between all the other
Table 1: Eight themes and their core elements from thematic analysis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Establishing a shared philosophy of putting families at the centre of decision-making and planning</th>
<th>Empowering parents</th>
<th>Providing continuity to families through transitions and changes</th>
<th>Providing support early to avoid problems escalating</th>
<th>Enhancing efficiency and cost-effectiveness through co-ordinated service delivery</th>
<th>Building from existing working practices, local context and range of provision</th>
<th>Providing appropriate training, supervision and administrative support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key working is essential</td>
<td>Whole family approach</td>
<td>Advocacy</td>
<td>Supporting transitions</td>
<td>Identifying needs</td>
<td>Multi-agency communication and information sharing</td>
<td>Multi-agency way of working</td>
<td>Clear roles and responsibilities</td>
</tr>
<tr>
<td>Flexible approach</td>
<td>Positive relationship between services and families</td>
<td>Promoting</td>
<td>Changing key working practitioner</td>
<td>Addressing problems early</td>
<td>Co-ordinated services</td>
<td>Local context</td>
<td>Personal qualities of key working practitioners</td>
</tr>
<tr>
<td>Co-ordinated support</td>
<td>Working in partnership</td>
<td>Reducing support</td>
<td>Continuum of provision</td>
<td>Workforce development</td>
<td></td>
<td></td>
<td>Administrative support</td>
</tr>
<tr>
<td>Practical support</td>
<td>Building practitioner networks and shared outcomes</td>
<td></td>
<td></td>
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<tr>
<td>Emotional support</td>
<td>Encouraging participation and shared understanding from all practitioners</td>
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<td>Time and energy saving</td>
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<tr>
<td>Availability of information about key working</td>
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services a family may be in contact with (Site C). Key working practitioners also felt that this stability allowed time for a positive relationship to build between themselves and the family.

**Establishing a shared philosophy of putting families at the centre of decision-making and planning**

Managers and key working practitioners felt strongly about the importance of working in partnership with families and putting them at the centre of their service delivery. This was translated into practice; for example, in Site A, families were always given a major say in the choice of key working practitioner rather than having a specific person allocated to them. Parents felt that key working practitioners recognised them as experts about their child and valued this approach.

‘I think they really count, parent’s views, you know, especially with the approach of the key worker; in fact your view actually comes before everybody else’.

(parent, Site A)

At Site C, parents discussed the importance of them being involved in delivering staff training and recruitment, and helping practitioners understand what it is like to be a parent of a child with SEND. Key working practitioners also talked about the importance of their role in ensuring the child or young person had the opportunity to make an input to meetings and assessments. Parents valued the support provided for themselves, their child with SEND and their other children through the flexible, personalised and adaptable nature of key working, and some families noted that this was in contrast to their experience of other services.

**Empowering parents**

The presence and support of the key working practitioner helped families to formalise, record and monitor the decisions made in relation to their child and family. Parents reported that they sometimes needed someone to advocate on their behalf as they did not feel confident or were not sure about their rights. However, they were aware of possible conflicts of interest if a non-designated key working practitioner undertook an advocacy role for them; for example, one parent who had recently had a change of key working practitioner felt that she could not discuss the same issues due to the position and role of her new key working practitioner (Site A).
As part of the provision of emotional and practical support, key working aims to enable and empower families. At Site A, two parents who had become their own key worker spoke about how their key working practitioners encouraged them to contribute to meetings and explained what their rights were and what support they were entitled to. As a result of this, the parents now felt empowered and confident to take on the key working role independently.

‘I personally feel a lot stronger as a parent and as a person as well, they give you that confidence to be able to cope and deal with that situation, so I believe you do become that better and stronger person with the situation and with other people around you really don’t you?’

(parent who had become their own key worker, Site A)

A close bond can develop through key working, with parents describing their key working practitioner as friends or ‘as another member of the family’ (Site B). This has the potential to undermine the ultimate goal of empowerment. In contrast, managers and key working practitioners saw the relationship between key working practitioner and parents as solely professional. They spoke about the importance of managing this asymmetrical perception of the relationship with the key working practitioner, for example by carefully distinguishing between the key working role and the family’s personal or social life, setting boundaries and managing ‘withdrawal’ as families became more independent.

Providing continuity to families through transitions and changes
Changing key working practitioners was noted as a potential difficulty by parents, particularly as this tended to happen at times of other transitions, for example moving from early years services to school. In Site A, although key working was not restricted to early years, it appeared to be better established in these services than in schools, and following the move into statutory schooling, some parents reported that they did not receive as much key working support. There is great potential in key working supporting periods of transition; for example, the young person at Site B spoke about how their key working practitioner helped with the transition to independent living, such as finding housing, navigating public transport and setting up benefits.

Managers recognised the potential challenges associated with transitions. At Site A, they spoke about how new and old key working practitioners would work alongside each other for a period of time. They acknowledged that key working
can be difficult to implement in schools and also had concerns about young people when they entered adult services. At Site B, a designated service, if and when families exited key working support, it is made clear to them that they can return for advice and support.

Key working was seen by managers as part of their continuum of provision for families. Managers felt that key working helped them to respond flexibly to the varying needs of families; for example, managers stressed that key working was appropriate for children and young people with SEND who did not have EHC plans, but they expressed concern about the potential impact of funding cuts on provision for these families.

‘It’s kind of those levels isn’t it, of key working so there might be times when they’re doing lots, when they’re having lots of input and doing a lot of practical things and getting things in place but there’ll be other times when they’re just kind of meeting and having those conversations that parents want to have . . . it’s as and when they need it’.

(manager and non-designated key working practitioner, Site C)

Providing support early to avoid problems escalating
Parents felt that key working enabled them to receive support as early as possible. They noted that such close and continuing involvement of a practitioner with their family meant that potential problems were more likely to be identified earlier and appropriate support packages put in place. Referral to key working was highlighted as a possible issue by families and this is particularly important as it affects how early support can be provided.

‘I think the role of the key worker is to get to know that family isn’t it, rather than just being on the periphery, try to get into that family and get to know more about them. So you can pick those things up if they do arise.’

(key working practitioner, Site A)

All groups of individuals highlighted long-term benefits related to an early intervention approach including better outcomes for children, greater independence for families, reduced demand on higher cost intervention services at a later date, enhanced safeguarding and a more positive relationship between services and families.
Enhancing efficiency and cost-effectiveness through co-ordinated service delivery

Some families in the focus groups had very complex support packages with the involvement of up to 14 practitioners. When families are in receipt of multiple services, key working practitioners can help to co-ordinate, streamline and support this process. Parents talked about how they valued this support as it made them feel more confident, in control and informed. Staff also reported an increase of service efficiency by reducing duplication of work, streamlining bureaucracy and paperwork, navigating through threshold requirements, reducing the number of meetings and targeting local area resources more effectively. Key working practitioners in Site C talked about their role in explaining the rationale of service decisions, and helping parents to understand and evaluate the levels of support their family was offered.

‘We can use the key working meeting as a CIN [child in need] meeting as well and cover everything, not trying to put parents under stress going to two meetings plus other things, and if you do it all in one, that’s been helpful’.

(key working practitioner, Site A)

Key working was discussed positively by managers as being in the spirit of the SEND reforms and as a tool to help services meet the requirements of the SEND Code of Practice (2014) and prepare for EHC plans. However, staff also highlighted that key working was helpful to a wide range of families, not just those going through the EHC plan process.

‘Not all of those families were children that might be in the Education, Health and Social Care plan and there’s a huge assumption, a huge assumption that it’s only that group of children; actually it can be an episodic piece of work that right now, that family is having a bit of a rough time and they need this’.

(manager, Site C)

Although managers and key working practitioners acknowledged that funding and budget cuts were issues, all talked about how key working was helping them to deliver a more cost-effective service for families, use their resources in a more targeted way, reduce costs in the long term and provide higher quality support.
Building from existing working practices, local context and range of provision
All four sites had a multi-agency and person-centred way of working that was often reported to be built on the Early Support principles, which include involving families in decision-making, maintaining continuity of care through the different stages of a child’s life and into adulthood, and integrated assessment and planning processes. This ethos was seen as an essential platform for key working.

The history of ways of working in a local area was vital to the key working approach and how it was implemented. For example, the key working delivered in Site B built on a history of successful collaboration between the PVI organisation and the local authority. For key working delivered within statutory services, the relationship between health, education and social care services is important, as multi-agency communication, information-sharing and resource provision are all important factors. Staff who worked in sites which hosted a number of different health and local authority services on the same premises, for example physiotherapy, early years services and community paediatrics, felt that this made multi-agency working easier, although it was not deemed to be essential.

When key working was first introduced into an area, key working practitioners in Sites B and C spoke about how they built their reputation in their local area through successful service delivery, joined-up working with existing provision and positive outcomes for services and families.

Providing appropriate training, supervision and administrative support
Managers discussed how they were developing key working training for their local area by adapting existing Early Support training, involving parents and offering opportunities for new key working practitioners to shadow experienced staff members. It was also highlighted that the wider workforce needed training to promote awareness and understanding of key working. Parents valued the opportunity to input into staff development and felt that this resulted in a culture of partnership working, which they had not always encountered in the past.

‘It’s parents that have interviewed them and train with them as well, which has got to have some sort of impact on why they act very differently to other professionals.’

(parent in Site C referring to the recruitment of designated key working practitioners)
Key working practitioners acknowledged the need for role supervision; staff in designated and non-designated services felt well supported. Key working practitioners need to have a wide knowledge base and be able to access information easily. Ongoing training was suggested to address this, including external workshops or speakers at internal events. Non-designated key working practitioners valued how their role promoted their knowledge and skills outside the remit of their primary role and contributed to their professional development (Site A).

Some aspects of key working take up additional time and a strong message from staff was that they needed dedicated administrative support.

‘So for every half an hour that a senior physio spends ringing round trying to get people to come to appointments and then they’re ringing them saying “No I can’t” or the family cancelled, that is time wasted.’

(manager and key working practitioner, Site A)

At Site A, a non-designated service, both managers and key working practitioners felt caseload to be an issue as there was no formal limit to the number of families that a practitioner would support through key working. Although time demands have more potential to be a difficulty for non-designated services, it is worth highlighting that several of the designated key working practitioners reported that they regularly worked over their paid hours.

**Guide production**

As part of the overall project, the evaluation of key working was intended to feed into the production of a national guidance document to disseminate and promote evidence-based best practice in key working. With iterative cycles of consultation with Early Support representatives, the evaluation sites and a SEND lead in a local authority that had not been involved in the data gathering, a guide was produced using the content of the thematic analysis restructured into a more practice-based format, using headings of ‘What is key working?’, ‘Outcomes’, ‘Impact’ and ‘Structure – what needs to be in place for effective key working?’ (Mengoni et al., 2014).

**Discussion**

This study confirmed the findings of previous studies of the wide-ranging benefits of key working reported by families and staff, including high levels of service satisfaction from families, more effective use of resources and improved quality of service provision. Managers and commissioners spoke about how key working
reduces the demand on higher-cost ‘crisis’ services through identifying and addressing potential issues early. It has been noted that it is difficult to estimate costs and savings for key working services (Beecham et al., 2007). This is an important issue for services and one possible route forward would be to model costs and savings using example pathways for case study families.

Key working reflects the cultural change embodied in the SEND reforms. The flexible and highly personalised support offered by key working can directly support and enhance the EHC plan process, as reported by Craston et al. (2013) and Hill et al. (2014), but it also has a wider role to play in helping local areas, services and schools to fully embed the ethos underlying the reforms.

Important factors for implementing successful key working include the careful management of transitions, managing the relationship between key working practitioner and family members, provision of regular training, supervision and administrative support for key working practitioners, and considering the local context. Importantly, where key working is a designated service, there is a risk that ‘hard-to-reach’ families are less likely to find out about, and access, key working, and this needs to be recognised and addressed.

Two areas that have not been previously widely reported to be of importance by families and staff are transitions and the relationship between the family and the key working practitioner. Families experience transitions into different services or settings, for example into schools from early years settings, referral to new practitioners and moving into adult services, and they can also experience transitions of the key working practitioner. Recent research has highlighted that support is needed to co-ordinate the transition from child to adult services (Rydzewska, 2012) and from school to college (Mitchell & Beresford, 2014) for young people with autism spectrum disorder, along with emotional and practical support for the young person. Even in local areas where key working is well embedded, it may be that when a child or young person enters a new setting or service, this way of working may not be as established; for example, key working has been historically concentrated in early years services (KIDS, 2012). Key working needs to be consistently implemented in all services that work with children and young people with SEND, and one way of achieving this would be through service-wide workforce development.

The principles of a key working approach also underlie other initiatives and service models for vulnerable populations, for example the Family Nurse Partnership programme for first-time young mothers (Barnes et al., 2009), the
Helping Families Programme for families of children with severe conduct disorders (Day et al., 2012), the Troubled Families programme (Department for Communities and Local Government, 2012), services for children with cancer (CLIC Sargent, 2009) and services for young people with mental health problems (Lemma, 2010). This suggests that the key working approach is applicable beyond disability services, and may be helpful for a range of children, young people and families. Universal principles from these different programmes and services could be extracted and included in initial and ongoing training for all professionals working with children and young people. Such workforce development would need to be implemented as part of a long-term plan, with continuing evaluation of service efficiency and outcomes for children, young people and families, in order to fully understand the outcomes of a key working approach.

In the present study, there was a notable disjunction between key working practitioners and families in their perceptions of the relationship between them. Families valued highly the emotional support and readily available contact provided by key working and some spoke of their key working practitioner as their friend and part of the family. They also often spoke of the close bond that formed between the child or young person and the key working practitioner. Although key working practitioners were very clear about the key component of emotional support in their approach, ‘friendship’ was not used to describe their perception of their relationships with families.

This highlights an underlying issue of power inequalities between practitioners and service users. Due to their generally greater knowledge of services, gatekeepers and pathways of referral, initial key working contacts will commonly expose a power imbalance, with the practitioner potentially being seen as having greater influence in securing appropriate services and resources for the family. Practitioners in this study were clear about their agenda to shift this imbalance and to encourage families to become more confident in seeking support. As an ultimate goal of key working is to empower families to be as independent as possible, key working practitioners need to manage the relationship carefully without inadvertently encouraging parents, children and young people to become overly dependent or attached because of the emotional bonds that can form. Withdrawing key working support was often described by both practitioners and families as having been handled well, despite anxieties on the family side about loss of support.

A common approach to managing the perceptual disjunction between ‘friend’ and ‘caring professional’, which can come to the fore again at the termination of key
working, was for the practitioner to say that they, or their colleagues, would still be available for informal contact if issues arose that the family felt unable to cope with. Including recognition of this core element in key working, and strategies for empowering families, could usefully be an explicit component in initial training, as well as a focus for supervision of practice.

In conclusion, key working is a way of working that improves outcomes for families and children with SEND, improves service efficiency and helps services to meet their statutory demands in England. This also has implications for services in different countries as many aspects of the SEND reforms are universal features of ‘best practice’ and reflect a way of working desired by families (Arnadottir & Egilson, 2012; Every Disabled Child Matters, 2007; Kirk & Glendinning, 2004).

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References


Every Disabled Child Matters (2007) ‘“If I could change one thing” summary’ [online at www.edcm.org.uk/resources/resources-for-supporters/if-i-could-change-one-thing].


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