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Title Page

Descriptive title: **Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?**

Short title: **Models of key worker services for disabled children**

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Abstract

Background: Research has shown that families of disabled children who have a key worker benefit from this service and recent policy initiatives emphasise the importance of such services. However, research is lacking on which characteristics of key worker schemes for disabled children are related to better outcomes for families.

Methods: A postal questionnaire was completed by 189 parents with disabled children who were receiving a service in seven key worker schemes in England and Wales. Path analysis was used to investigate associations between characteristics of the services and outcomes for families (satisfaction with the service, impact of key worker on quality of life, parent unmet need, child unmet need).

Results: The four path models showed that key workers carrying out more aspects of the key worker role, appropriate amounts of contact with key workers, regular training, supervision and peer support for key workers, and having a dedicated service manager and a clear job description for key workers were associated with better outcomes for families. Characteristics of services had only a small impact on child unmet need, suggesting that other aspects of services were affecting child unmet need.

Conclusions: Implications for policy and practice are discussed, including the need for regular training, supervision and peer support for key workers and negotiated time and resources for them to carry out the role. These influence the extent to which key workers carry out all aspects of the key worker's role and their amount of contact with families, which in turn impact on outcomes.

Introduction

Families with disabled children are in contact with a number of different agencies, including health, education, social services, housing agencies, the benefits agency and voluntary agencies. In one year, on average families are in contact with ten different professionals and have more than twenty visits to hospitals and clinics (Sloper & Turner, 1992). When these services are not coordinated, families report problems understanding what services are available and how to access them, understanding the roles of the different agencies and professionals, getting professionals to understand their situation, and dealing with delays in receiving what they need (Sloper, 1999).

An answer to these problems, recommended in policy from the Court Report (1976) onwards, is for families to have one person who acts as their main point of contact, collaborates with professionals from their own and other services and ensures that access to and delivery of services from the different agencies and professionals is co-ordinated. Both key workers and families have reported that the role of the key worker encompasses: providing information and advice to the family, identifying and addressing needs, accessing and coordinating services for the family, providing emotional support, and acting as an advocate for the family (Mukherjee *et al.*, 1999; Tait & Dejnega, 2001).

Research investigating effects of key workers has shown positive results, suggesting that families with key workers have better relationships with services, fewer unmet needs, better morale, more information about services, higher parent satisfaction,

and more parental involvement than families not receiving such a service (Glendinning, 1986; Liabo *et al*., 2001).

However, the majority of studies have compared parents who have a key worker with those who do not. Few have explored different service models. Small-scale evaluations of pilot key worker services have begun to identify some of the important components of the service (Appleton *et al*., 1997; Mukherjee *et al*., 1999; Tait & Dejnega, 2001). These include: multi-agency care planning meetings, pro-active regular support from key workers, the ability of key workers to work across agencies, and a family centred approach. However, the differences in the services studied, and the small numbers involved in each study, make it difficult to ascertain what would constitute good standards in key worker services, either at the strategic planning or individual practice levels.

As more areas begin to develop key worker services for families with disabled children, and different models of services proliferate, work is needed to evaluate larger scale implementation, and different models, of key worker services. This research aimed to identify which features of key worker services contribute to improved outcomes for disabled children and their families.

Methods

Procedure

Ethical approval for the study was obtained from a Multi-Centre Research Ethics Committee. Questionnaires were sent to 644 families who were users of seven key worker services for disabled children in England and Wales. Services were chosen

according to the following criteria in order to ensure a spread of services in the case studies: whether they had designated (full-time) or non-designated key workers (who key work for some families in addition to their ordinary role), dedicated funding or not, resided in an urban or rural area, and whether longstanding or more recently set up.

Measures

Demographic variables

Respondents provided age of themselves and the child, ethnicity, child gender, number of children in the family, marital status of the respondent, socio-economic status, length of time they had used the service, and diagnosis of the child.

Contact with key worker

Respondents were asked over the past three months how often they had contact with their key worker, how long these contacts normally last, whether they wanted more or less contact with their key worker, and whether their key worker was proactive in making contact.

Questionnaires

The following questionnaires were used.

1. Disability scale: an eight-item scale measuring the type and level of difficulty experienced by the child in communication, behaviour, learning, mobility, health, vision, hearing, and continence. Respondents rated whether their child had difficulties in each area, either “Not at all”, “Moderately so”, or “Very much so”.

2. *Aspects of key working*: a ten-item scale measuring how much the key worker performed various aspects of the role (Mukherjee *et al*., 1999). Examples of items are: emotional support, information about your child's condition and information about services. Respondents rated items as 'Not at all', 'Some' or 'Very much', according to the support they received from key workers. Alpha reliability was 0.95.

3. *Impact of key worker on quality of life*: a seven-item scale measuring effects of having a key worker on parental quality of life (Mukherjee *et al*. 1999) comprising items such as 'My physical health or well-being (e.g. sleep, rest, exercise)', 'My emotional/mental health (e.g. stress, anxiety, depression)' and 'Time to myself (e.g. work, studies, interests)'. Participants rated items as 'Positive impact', 'Negative impact' or 'No impact' over the past six months. Alpha reliability was 0.85.

4. *Measure of Processes of Care*: the anglicised version (McConachie & Logan, 2003) of the Measure for Processes of Care (MPOC, King *et al*., 1995) was used. The MPOC assesses family-centred behaviours of professionals in services for disabled children and the extent to which specific behaviours of care professionals occur. Respondents rated items on a four-point scale from 1 (Never) to 4 (Always), or 'not applicable'. Factor analysis did not identify separate factors and the scale was scored as a single variable. Alpha reliability was 0.99. As items of the MPOC can be rated as not applicable and if rated in this way are not scored, the mean of items scored was used in analysis.

5. *Parental unmet need*: the 23-item scale of parental needs (Quine & Pahl, 1989; Sloper & Turner, 1992; Beresford, 1995) comprises items covering needs common to

parents with disabled children, such as 'getting a break from caring for my child', 'help managing my child's behaviour', and 'help getting the information we need'. Items are rated on a three-point scale, of 'Getting enough help', 'Need help' or 'Help not needed'. Alpha reliability was 0.85.

6. *Child unmet need*: the 11-item scale of child needs (Beresford, 1995) comprises items such as help with: communication, moving about independently, social/ relationship skills. The items are rated on a three-point scale, 'Getting enough help', 'Need help' or 'Help not needed'. Alpha reliability was 0.77.

7. *Satisfaction with the service*: one item measured how satisfied the respondent was with the key worker service. Satisfaction was rated on a four-point scale from 'Very satisfied' to 'Not at all satisfied'.

Service context variables

Services were coded according to whether they met eight criteria, which emerged as important in interviews carried out with staff in the services (Greco *et al.*, 2005). These were having:

1) induction and ongoing training for all key workers
2) ongoing, regular supervision specific to key working for all key workers
3) peer support with other key workers
4) some dedicated funding for the scheme
5) a dedicated service manager who runs the scheme, organises training and supervision for key workers, and whom they can approach for support
6) parental involvement in the steering group

7) a clear, written, job description for all key workers
8) designated or non-designated key workers.

Coding of criteria was binary. There was 100% overlap between training, supervision, and peer support and these were combined. Clear job description and service manager also overlapped 100% and were combined.

Length of time services had been in operation was also coded. Two services had been in operation for over ten years, one for five years, one for three years, and three for two years.

Analysis

Path analysis was used to investigate relationships between child, family and service characteristics and four outcome variables: impact of key workers on parent quality of life, unmet needs of parent and child, and satisfaction with the service. Separate path analyses were carried out for each of these outcomes. Path analysis requires a series of multiple regressions based on assumptions of potential causal order reflected in the grouping of variables into blocks (Davis, 1985). Table 1 shows variables included in each block.

TABLE 1 HERE

Block 1 variables are exogenous, having no predicting variables and comprise key demographic variables and the service context variables. Block 1 variables are potential predictors of Block 2. Block 2 represents the mechanisms by which the service may impact on families: the extent to which key workers carry out aspects of

the role; frequency, duration, appropriateness of contact with key workers; and whether contacts are proactive or reactive. Block 3 – MPOC scores – is a measure of process outcome, that is whether parents perceive services as providing information, coordinated, respectful and supportive care, and working in partnership with them.

The path analysis followed the same procedure for each outcome variable. All independent variables having a significant bivariate relationship with the outcome variable were identified, using ANOVA and correlations, and entered into a multiple regression, identifying variables with a direct relationship to the outcome that was independent of the effects of other variables in the regression. Following this, if the Block 3 variable (MPOC) was significant in the regression it was then treated as a dependent variable in its own right and the procedure was repeated. The stages of the analysis then continued with any Block 2 variables identified as predicting the outcome measure or MPOC treated as dependent variables in further multiple regressions.

Results

Participants

Two hundred and five (31.83%) questionnaires were returned, of which 16 families did not have a key worker at the time, or had only very recently received the service, and were unable to answer many questions. 189 questionnaires were analysed. The response rates varied considerably between services, ranging from 19.4% to 65.4%. In services with the lowest response rates it appeared that both 'active' and 'passive' cases had been sent questionnaires. In order to establish whether there were any differences in respondents between services with high (>50%) and low (<50%)

response rates, differences on demographic variables were compared. There were no significant differences on any variables.

Table 2 provides details on the characteristics of families.

TABLE 2 HERE

The average amount of time families had used the service for was three years and four months (SD 3.11, range 6 months-16 years).

The most common diagnoses of the children were: autistic spectrum (N=46), cerebral palsy (35), developmental or global delay (N=32), epilepsy (N=31), visual impairment (N=20), Down's syndrome (N=15), hearing impairment (N=11), dyspraxia (N=10), and muscular dystrophy (N=5). The sample also included children with a range of rare conditions which each occurred in only one case. One hundred and forty six children (91.8%) had multiple difficulties (three or more difficulties rated on the Disability Scale).

Descriptive statistics

Means, ranges and standard deviations for continuous independent and outcome variables are shown in Table 3.

TABLE 3 HERE

29.2% (N=49) of families wanted to see their key worker more often, 68.5% (N=115) wanted to see them the same, and 2.4% (N=4) wanted to see them less often. 28.3%

(N=47) of families wanted to talk to their key workers more often, 69.9% (N=116) wanted to talk to them the same, and 1.8% (N=3) wanted to talk to their key workers less often. 61.2% (N=104) reported that the key worker generally contacted them. 38.8% (N=66) reported that they generally contacted the key worker.

47.4% (N=90) of families had a key worker with regular training, supervision and peer support. 85.3% (N=162) of families had a key worker who worked in a service with dedicated funding. 56.8% (N=108) of families had a key worker with a service coordinator and a job description. 54.2% (N=103) had a key worker who worked in a service with parent representation on the steering group. 38.6% had a designated key worker (N=73) and 59.8% had a non-designated key worker (N=113); this information was not available for three families.

Path analysis

Quality of Life (QoL)

The first stage of the analysis was to identify variables with a significant bivariate association with QoL scores. Table 4 summarises these results, identifying the variables selected for inclusion in multiple regression analysis on QoL scores, as the first stage in path analysis.

TABLE 4 HERE

Figure 1 shows the results of path analysis for impact of key worker on parental QoL.

FIGURE 1 HERE

The regression explained 47% of the variance (Adj R^2=0.47, F=34.22, p<0.0001), with two variables acting directly on the outcome measure. These were aspects of key working and having a service manager and clear job description for key workers. Another two service variables acted as prior variables predicting aspects of key working – having regular key worker training, supervision and peer support, and the service having been in operation for a shorter length of time. This latter variable was not directly related to QoL, but was related to aspects of key working.

Satisfaction with key worker service

Table 5 shows variables with a significant bivariate relationship with satisfaction scores.

TABLE 5 HERE

Figure 2 shows the results of the path analysis for satisfaction with the key worker service.

FIGURE 2 HERE

The regression explained 70% of the variance (Adj R^2=0.70, F=37.57, p<0.0001). Four variables acted directly on the outcome measure: aspects of key working scores, greater duration of telephone contacts with key worker, appropriate amount of contact with key worker and the service providing regular training, supervision and peer support for key workers. The service having been in operation a shorter period

of time was related to higher aspects of key working scores and having dedicated funding was associated with longer telephone contacts. Higher levels of disability were related to duration of telephone contact, however this was not significantly associated to the outcome variable in the bivariate analysis, indicating that the level of the child's disability is only relevant to satisfaction when associated with more contact. Finally, training, supervision, and peer support was also associated with appropriate levels of contact and high aspects of key working scores.

Parental unmet need

Table 6 shows variables with a significant bivariate relationship with parent unmet need scores.

TABLE 6 HERE

Figure 3 shows the results of path analysis.

FIGURE 3 HERE

The regression explained 28% of the variance (Adj R^2=0.279, F=7.78, p=<0.0001). Two variables, MPOC scores and age of child (older child – higher unmet need) acted directly on the outcome measure. MPOC was itself predicted by aspects of key working and appropriate levels of contact with the key worker, which in turn were predicted by key worker training, supervision and support. Length of time the service had operated predicted aspects of key working and higher child disability predicted appropriate contact with the key worker.

Child unmet need

Table 7 shows variables with a significant bivariate relationship with child unmet need scores.

TABLE 7 HERE

Figure 4 shows the results of the path analysis

FIGURE 4 ABOUT HERE

The regression only explained 6% of the variance (Adj R^2=0.062, F=3.97, p=0.009). Only MPOC scores acted directly on the outcome measure. MPOC was predicted by aspects of key working, which in turn was predicted by training, supervision and support and length of time a service had been in operation. The latter three variables had no significant bivariate association with the outcome variable, indicating that these factors were only relevant to child unmet need when they were associated with general processes of care.

Discussion

The topic of key workers for families with disabled children has received considerable emphasis in recent policy, including the Children's National Service Framework (Department of Health/Department for Education and Skills, 2004), the Early Support Programme (Department for Education and Skills/Department of Health, 2004) and *Improving the Life Chances of Disabled People* (Cabinet Office, 2005), and there has

been an upsurge in the development of key worker services. However, existing key worker services vary in how they are implemented and how the role of the key worker is defined and interpreted (Townsley *et al.,* 2004) and this research can contribute to understanding of what factors within these services relate to better outcomes for families.

Taking the results of the path analyses of all four outcomes as a whole, there was considerable consistency between analyses of the different outcomes. First, the extent to which key workers carried out the various aspects of key working was a strong predictor of family outcomes. These aspects comprise provision of emotional support, information about services and the child's condition, advice, identifying and addressing needs of all family members, speaking on behalf of the family when dealing with services, coordinating care, improving access to services and provision of support in a crisis. Key workers carrying out the role to its full extent was the strongest predictor of parental satisfaction with the service and positive impact on QoL, outcomes that measure direct key worker impact. However, for the two unmet need outcomes, the MPOC scores, which measure processes of care provided by services in general, were the strongest predictors. This finding was not unexpected, as parent and child needs are met by a range of services, not just the key worker. However, the key worker's role in identifying needs, coordinating care and improving access to services, is clearly an important influence. Where key workers carried out this role, parents were more likely to rate services in general as providing coordinated, respectful and supportive care.

Secondly, when key workers had appropriate amounts of contact with families, levels of unmet need were likely to be lower and satisfaction higher, indicating the importance of key workers having enough time to carry out the role. Thirdly, the provision of regular key worker training, supervision focused on the key worker role and peer support strongly influenced the extent to which key workers carried out the aspects of the role and engaged in an appropriate amount of contact with families, which in turn had an impact on outcomes. Having a service manager who was accessible to and provided support for key workers and having a clear job description for key workers was directly related to impact on quality of life, and these were important components of the service.

The fourth variable to appear in all the path analyses was length of time the service had been in operation. 'Younger' services were associated with key workers carrying out more aspects of the role. Why this should be is unclear, but perhaps the fact that research identifying the elements central to key working is recent resulted in more emphasis being placed on these when the 'younger' services were set up.

Having a designated key worker and parental involvement in the steering group were associated with better outcomes in bivariate analyses but not in path analyses. It appears that the potential disadvantages of non-designated key workers can be overcome if the service is clear about what the role encompasses, and provides induction and regular ongoing training for the key worker role, together with supervision specific to the role and opportunities for key workers to learn and gain support from each other. Results also suggest that parent involvement is valuable,

but it cannot overcome disadvantages of key workers not carrying out all the aspects of the role.

Finally, the low amount of variance explained in child unmet need scores indicates that other factors outside the key worker services are affecting whether children's needs are met. Factors such as the general amount of resources for children, children's access to play and leisure facilities and their relationships with friends and peers, may be stronger influences on disabled children's unmet needs. There is also a possibility that key worker services may be mainly focusing on supporting parents.

The findings support the Care Coordination Network UK Key Worker Standards (www.ccnuk.org.uk) and highlight the importance when planning and implementing key worker services of ensuring that the role of the key worker is clearly defined and understood, that training and supervision is provided for key workers, key workers have enough time to carry out all the aspects of the role and there is a service manager to support them. They also suggest the need for key worker services to focus on children as well as parents. Key workers themselves suggested that they needed more training in communicating and working with disabled children (Greco *et al.*, 2005).

However, the limitations of the study must be acknowledged. The low response rates in some of the services are of concern. Although analysis of differences on demographic variables between these services and the high response rate services showed no significant differences, it is difficult to predict what effect the response rate may have on the findings. A further limitation of the study is that we were only able to

obtain the views of a minority of children through questionnaires and interviews (see Greco *et al.,* 2005). The great majority of these children had positive views of their key worker, but we cannot generalise from this finding. Children with very complex needs and communication impairments were less likely to take part in the research. The difficulties of obtaining the views of these children, and the resources needed to do this, should not be underestimated and this is an area where both services and research require further development.

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Tables and figures

Table 1: Blocks of path analysis variables

Block 1: family and service context	Block 2: service mechanisms	Block 3: process outcome	Family outcomes
Family and child context: -age of child -level of disability -social class Service context: -dedicated funding -length of time in operation -regular training, supervision and peer support -dedicated service manager -clear key worker job description -type of key worker -parent representation on steering group	Aspects of key worker role Key worker contacts with family: -frequency -duration -appropriate -proactive	MPOC scores	Impact on QoL Satisfaction with key worker service Unmet parent needs Unmet child needs

Table 2: Characteristics of sample

Respondents	
Relationship to child	
Natural mother	166 (87.8%)
Natural father	17 (9.0%)
Foster carer	3 (1.6%)
Grandparent	2 (1.1%)
Guardian	1 (0.5%)
Age	Mean = 38.15 SD = 7.46 Range = 19-64yrs
Marital status	Married or living as married 135 (71.4%) Single 23 (12.2%) Separated/divorced 21 (11.1%) Missing data 10 (5.3%)
Ethnic background	White 179 (94.7%) South Asian 7 (3.7%) Mixed race 2 (1.1%) Missing data 1 (0.5%)
No. of children in family	Mean 2.57 SD 1.38 Range 1-9
Employment status	Not employed 108 (57.1%) Employed 69 (36.5%): full-time 22; part-time 47 Missing data 12 (6.3%)
Socio-economic classification[1]	1 58 (30.7%) 2 5 (2.6%)

	3 15 (7.9%) 4 19 (10.1%) 5 15 (7.9%) Missing data 77 (40.7%)
Disabled children	
Age of child	Mean = 8.06 SD = 4.72 Range = 6mths-20yrs
Gender of child	Male 126 (66.7%) Female 63 (33.3%)

[1] National Statistics Socio-Economic Classification (NS-SEC) 2001: 1 = managerial and professional occupations; 2 = intermediate occupations; 3 = small employers and own account workers; 4 = lower supervisory and technical occupations; 5 = semi-routine and routine occupations

Table 3. Descriptive statistics of continuous outcome and predictor variables

	Mean (SD)	Median	Range	N
Predictor variables				
Disability scores	15.98 (3.17)	16	10-24	159
No. of key worker calls in 3 months	4.42 (7.18)	2	0-60	161
No. of key worker visits in 3 months	2.84 (3.69)	2	0-24	168
Duration of calls	10.36 mins (8.27)	10mins	0-60	141
Duration of visits	1.04 hours (.71)	1hour	0-5	151
MPOC	2.99 (0.74)	3.05	1-4	173
Aspects of key working	22.43 (6.30)	23	10-30	163
Outcome variables				
Parent unmet need	6.47 (4.85)	6	0-20	129
Child unmet need	4 (3.12)	4	0-10	139
Satisfaction	3.23 (.88)	3	1-4	187
Impact of key worker on parent quality of life	16.61 (2.64)	16	7-21	173

Table 4: Predictors of QoL scores: bivariate analyses

Block 1	*Block 2*	*Block 3*
Service context Dedicated funding**** Regular training, supervision, peer support*** Service manager and clear job description**** Parental involvement in steering group** Type of key worker*	Aspects of key working**** Number of key worker visits** Duration of visits*** Duration of telephone calls**** Appropriate number of contacts**** Proactive contact****	Measure of Processes of Care****

****p<0.0001; ***p<0.001; **p<0.01; *p<0.05

Table 5: Predictors of satisfaction scores: bivariate analyses

Block 1	*Block 2*	*Block 3*
Family context	Aspects of key working****	Measure of Processes of Care****
Age of child*	Number of key worker visits***	
Service context	Duration of visits****	
Length of time service in operation*	Number of key worker telephone calls****	
Dedicated funding***	Duration of telephone calls****	
Regular training, supervision, peer support***	Appropriate number of contacts****	
Service manager and clear job description****	Proactive contact****	
Parental involvement in steering group*		
Type of key worker***		

****p<0.0001; ***p<0.001; **p<0.01; *p<0.05

Table 6: Predictors of parent unmet need scores: bivariate analyses

Block 1	*Block 2*	*Block 3*
Family context Level of child disability** Age of child*	Aspects of key working* Appropriate number of contacts****	Measure of Processes of Care****
Service context Dedicated funding* Regular training, supervision, peer support* Service manager and clear job description* Type of key worker*		

****p<0.0001; ***p<0.001; **p<0.01; *p<0.05

Table 7: Predictors of child unmet need scores: bivariate analyses

Block 1	*Block 2*	*Block 3*
Family context Age of child*	Appropriate number of contacts**	Measure of Processes of Care**

**p<0.01; *p<0.05

Figure 1 Path Analysis of Impact on Parental Quality of Life (QOL)

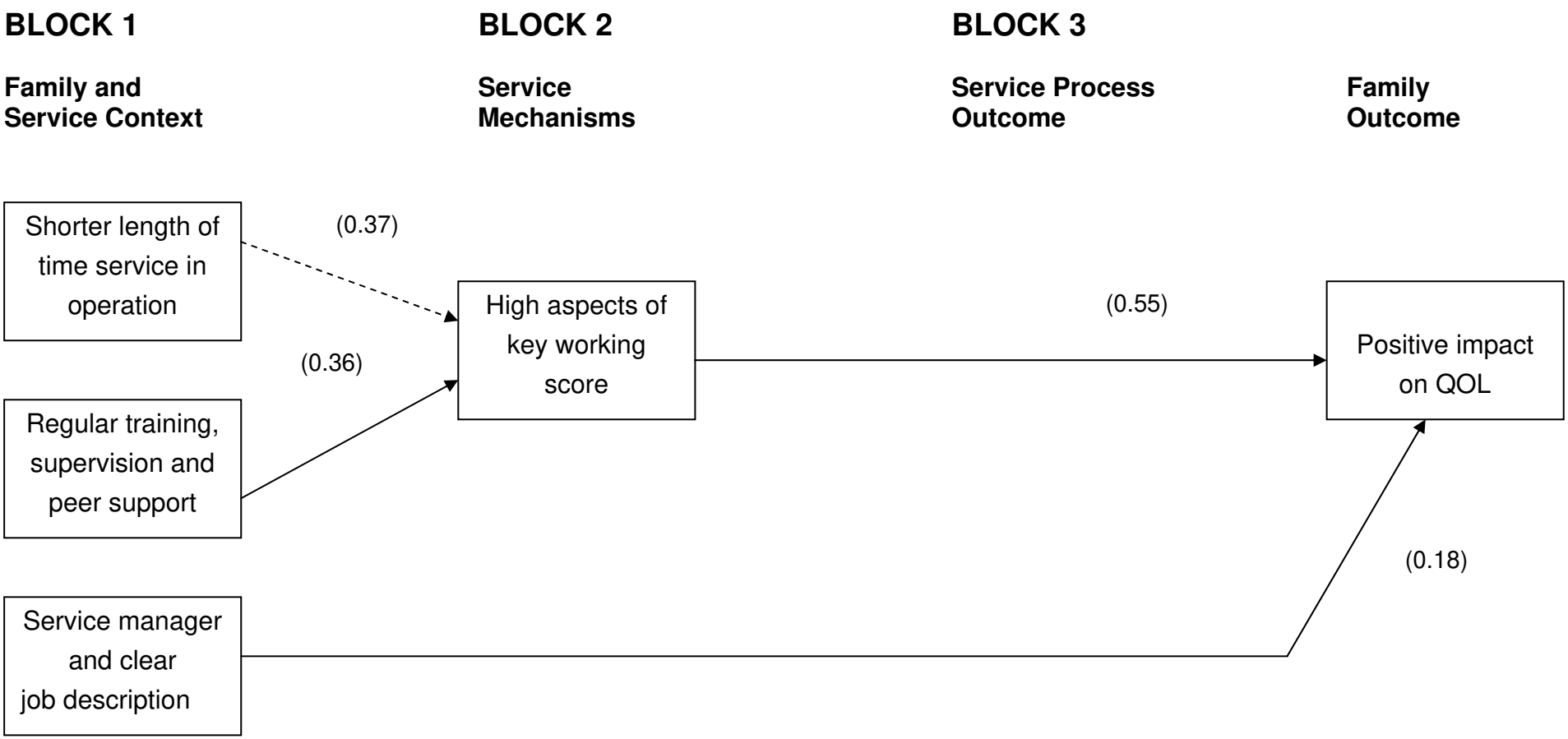

Figure 2 Path Analysis of Satisfaction with Key Worker Service

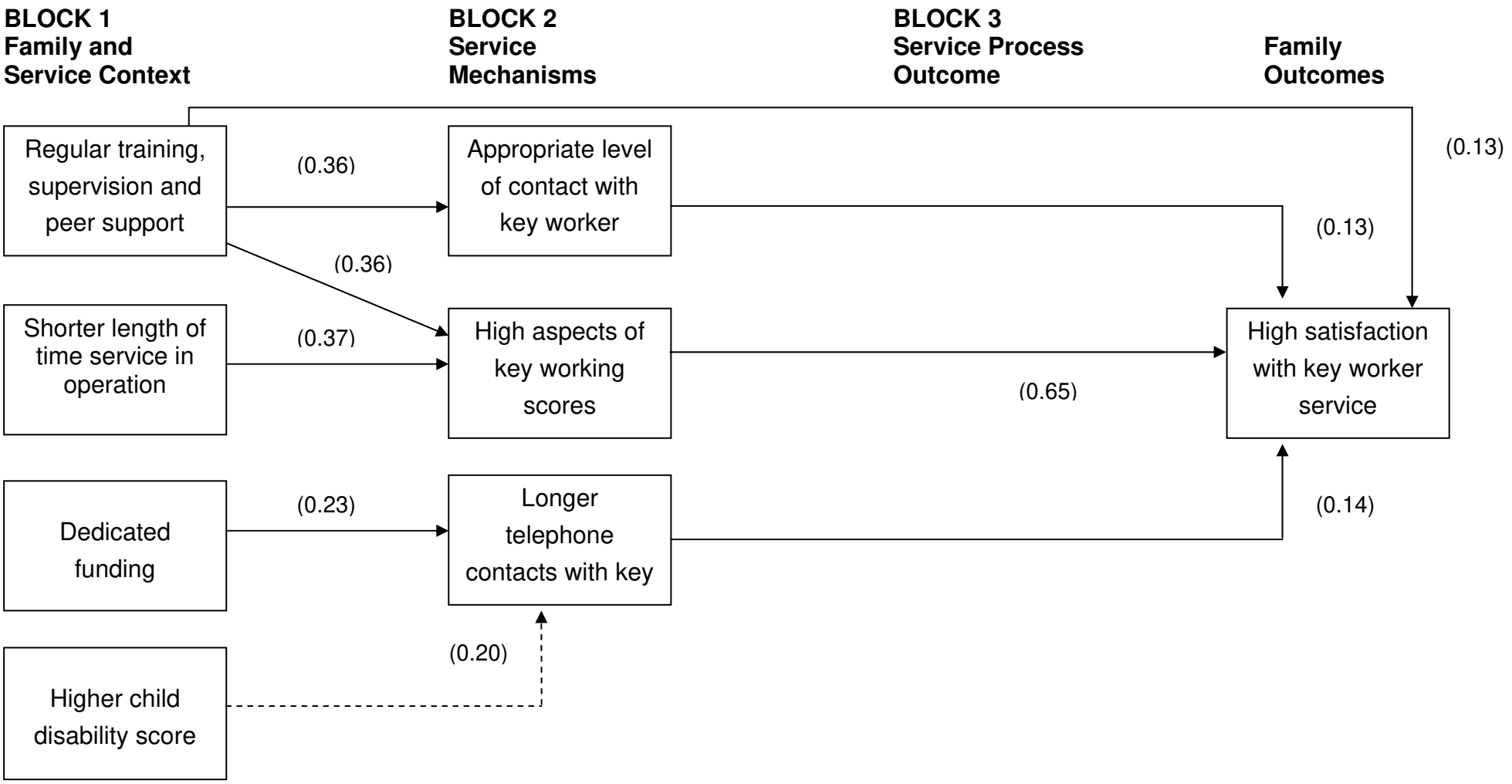

Figure 3 Path Analysis of Parent Unmet Need Scores

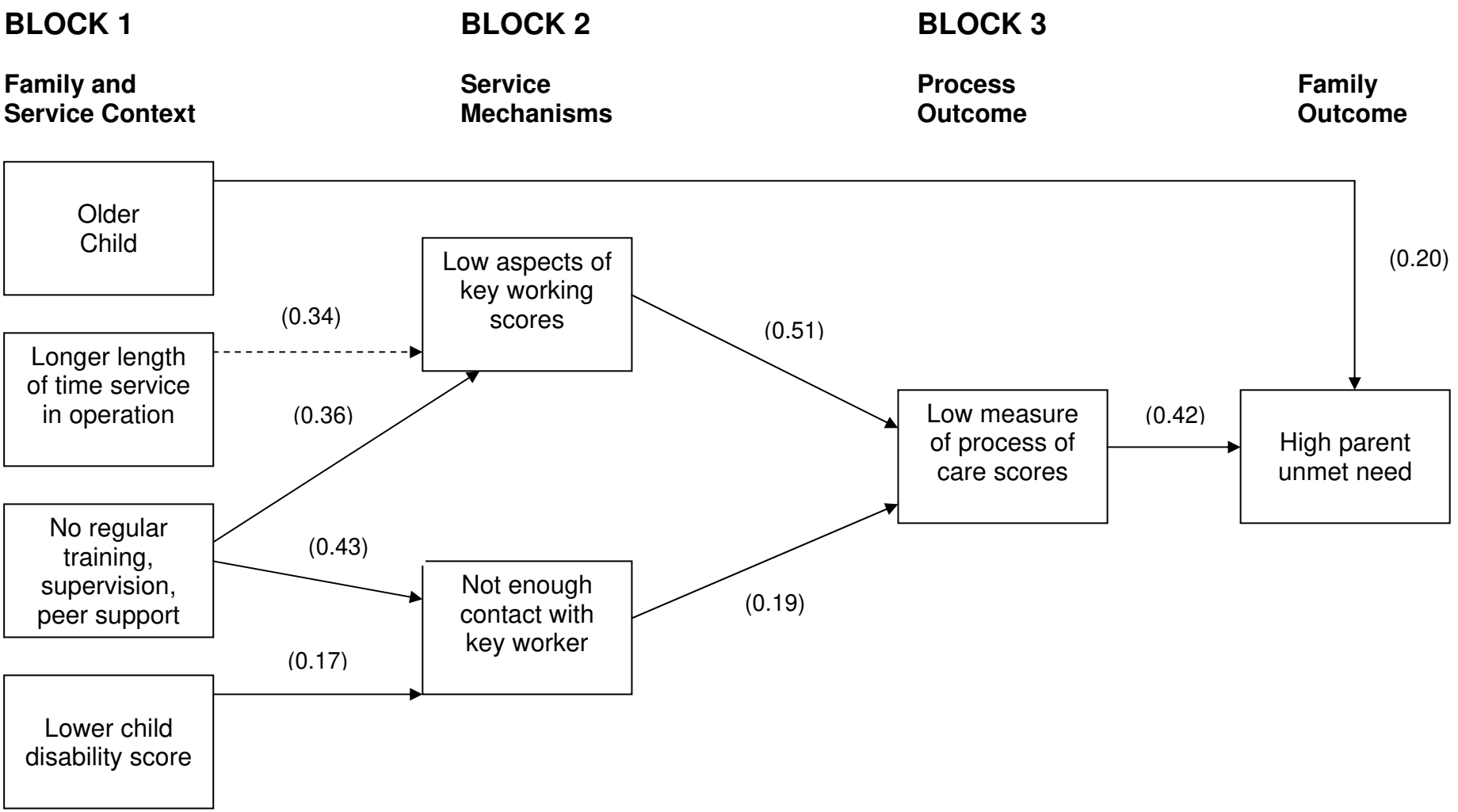
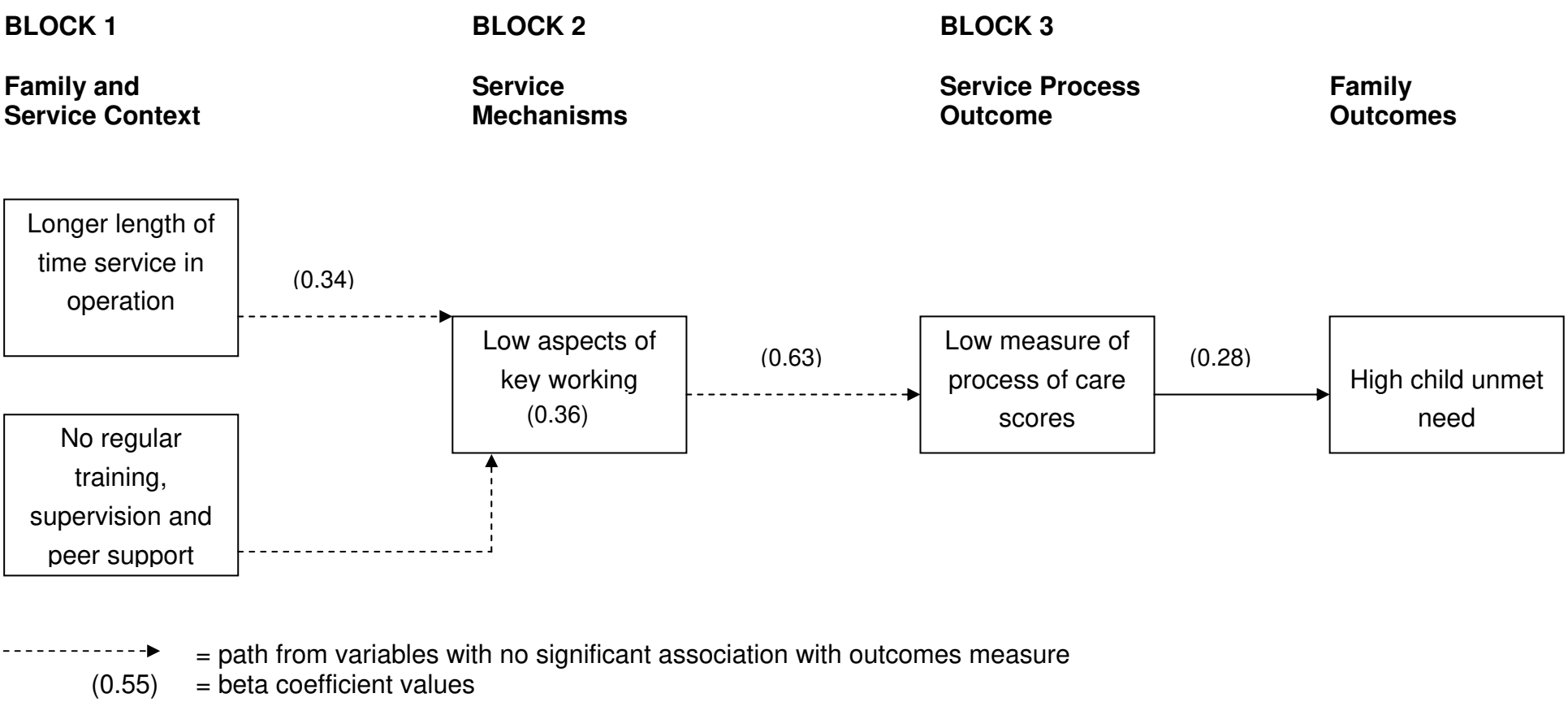
Figure 4 Path Analysis of Child Unmet Need Scores