



**THE VIEWS OF PARENT CARERS ON SUPPORT AND SERVICES
IN SURREY**

Executive Summary

**Produced by
Geraldine Bolam
Independent Consultant
For Surrey County Council**

**On behalf of Action for Carers (Surrey)
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In partnership



“....Enabling carers to have a voice and realise a life outside

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An Executive Summary

Background Information

This report has been produced for Action for Carers (Surrey) to provide specific evidence from the views gleaned by parent carers about how well the Council is currently supporting them. The focus of the engagement has been to consider what outcomes have been achieved for them. The report has also examined the support given to young carers where this has been highlighted by young carers and revisits some of the salient messages in an earlier report on young carers produced for Surrey County Council and on behalf of Action for Carers (Surrey). The report author used a mix of telephone interviews and focus groups with parent carers in November and December 2010 to inform the report and an online questionnaire will shortly be produced to provide further information. Contact was achieved with 7 carers via the format of 1-1 interviews and a further 17 carers via focus groups making a total of 24 carers canvassed.

The report and its recommendations should therefore be read with some caution as it is only a small scale qualitative study and cannot be said to be representative of all parent carers in Surrey. It does however provide some interesting insights about those parent carers interviewed in Surrey and there are some key messages to give consideration to. The report also looks at additional research material available from a more in depth literature review on parent carers. The report also considers the views of professionals supporting parent carers in Surrey.

Research Findings.

Having access to short term breaks was prioritised by parent carers as being the most important outcome to them. In common with a study undertaken by The University of York (Social Policy Research Unit)¹ parent carers did attach importance to spending quality time with the disabled child and achieving a better balance and time spent with the family. Access to short term breaks helped to assist parent carers in achieving these objectives. The parent carers did comment on the need to have more control over their lives and this was expressed with a particular focus on their health and employment needs. The carers also spoke about the intolerable stresses on their lives and in some cases the consequences for their employment as a result of the caring role. Case studies are provided in the report and provide examples of this.

The point that is repeatedly stressed by the parent carers in the research is that their inability to access short breaks and or in sufficient quantity for their needs is that their child does not meet eligibility criteria and because of funding constraints. This in turn they feel denies them access to a carer's assessment. The report author does make clear in the report and subsequent recommendations that it is very important that refreshed eligibility criteria for access to Children's services by disabled children provide clarity about how they will take into account carers' legislation and the right of parent carers to request an assessment. The report makes clear how important it is that parent carers can access breaks as they are at increased risk of stress compared to other parents.

The feedback from the parent carers contained in the report is rich in detail about a wide range of issues including the difficulties experienced by them at the time of Transition. The report notes the failure of professionals in some cases to provide useful information to parent carers

¹ The University of York (Social Policy Research Unit) "Outcomes for parents with disabled children and carers of disabled adults: Similarities, differences and the implications for assessment practice" 2007

to inform their decision making. The majority of parent carers also commented on the stressful nature of the assessment process and in particular the questioning by social workers of their parenting skills. The report author adds that this may be in part because of the Child in Need assessment framework. The reader is reminded by contrast of the importance that guidance to carers legislation gives to the recognition of parent carers' expertise. It is also in recently produced documents such as "Recognised, valued and supported – Next Steps for the Carers Strategy" and inherent in the personalisation philosophy of social care.

By and large parent carers in the report discuss experiences of being "embattled", having to fight for their rights. The report acknowledges that a common theme in research is the need for parents and children to have an ordinary and reasonable quality of life. The research in Surrey suggests that there is some way to go before the achievement of their desired outcomes is realised. Limited access to short term breaks in particular is also constraining the lives of parent carers and their families. The feed back in general is also suggestive that carers needs assessments do not sufficiently address the holistic aspects of carers lives. Parent carers spoke eloquently about the failure of assessors to address employment aspirations and cases are quoted where a parent carer was made redundant in part, he said, because of the caring role. In another case a carer's relationship with her employer was under strain. Carers also expressed disappointment in some cases that that their health needs were insufficiently addressed and that they were not referred on to useful support and/ or services.

Parent carers also commented that assessments did not deal with contingency planning which was another source of disappointment as this would promote peace of mind and is a highly desired outcome. The report makes a series of recommendations about the important areas that carers have prioritised and are considered worthy of further analysis. The report author envisages that with anticipated future clarity about parent carers' rights especially with regard to refreshed eligibility criteria (Children's services) some progress will be made possible for parent carers. A recent Ofsted Report ² found in its Review that that there was a high level of demand from parent carers for additional services for their children but that it is not something that legislative or regulatory change in itself can address easily. The report adds that such changes could make the system better focused on the outcomes that parent carers want for their children and more effective in use of necessarily limited resources. In addition, the introduction of the Short Term Breaks Regulations will, it is hoped, make a significant difference to parent carers' aspirations for short term breaks. With the accent on the wider family approach in assessment and recent Ombudsman decision making with respect to the importance of assessing parent carers' needs within the wider family context, parent carers' rights are further enhanced.

Recommendations

Eligibility. Carers Assessments and Outcomes.

- The refreshed Eligibility Criteria for Children's services will demonstrably take into account carers' legislation and provide improved clarity about the right of parent carers to a carer's assessment
- The eligibility policy should be fully explained to parent carers with reference to the decision making process in individual cases and rationale for outcomes
- When eligibility decision making is formulated, it takes into account that neither the 1995 nor the 2000 Carers Acts includes a stipulation (found in social security law) that

² Ofsted – The Special educational needs and disability review (A statement is no enough) Sept 2010

the care provided to the disabled child must (for instance) be “substantially in excess of the normal requirements of persons of his age”

- Explanation is given to parent carers about the meaning, purpose and value of a carer’s needs assessment. The explanation should provide a full account of the range of outcomes of carer’s needs assessments and the anticipated time frames for the receipt of paper work, the delivery of any services, an explanation of the arrangement for future reviews and a conclusion to the process.
- Parent carers are pro-actively informed of their rights and entitlements to carers needs assessments
- Parent carers should have clear expectations in relation to time frames and performance targets for responses to correspondence and telephone calls in general
- Parent carers are routinely told when social workers leave and they are informed and or involved as appropriate in the hand over process.
- Anticipated time frames for the repair and delivery of equipment should be made clear

Information and advice

- There needs to be an increased understanding that access to relevant and timely information and advice is vital throughout the caring role but particularly at times of significant change for example at times of Transition from Children’s services to Adult health and social care services. Information and advice/referral from Children’s Services about Parent Partnership services needs to be reviewed and better targeted.

Training, knowledge and skills set required:

- The training, knowledge and skills set required can be demonstrably shown to be up to date and conversant with the carers’ and other relevant legislation and guidance, and is appropriate to the needs of parent carers whom social workers are supporting.
- Specifically assessment practice and procedures support parent carers wish to pursue education, training or work, or leisure activities if that is their desire. That their aspirations should be taken into account when assessing a carer’s need for support is a requirement of the Equal Opportunities Act 2004
- The clear relationship between poor health and caring that increases with the duration and intensity of caring is better understood by social workers. Training, support and supervision of social workers needs to take into account that young working adults, for example caring for a child with either physical or mental health problems, are more likely to suffer ill health than non carers of the same age.
- Social work practitioners can sufficiently encourage carers during the carer’s needs assessment process to fully explore the impact of caring, recognise their expertise in caring and examine their feelings about caring. This process should support the parent carer’s self esteem, satisfaction in caring and identify what support is available to sustain both the caring role and a life outside of caring.
- Assessment practice, procedure and review addresses the need to take into account contingency planning and recognises the importance parent carers attach to this as a desired outcome of assessments.
- Social workers are enabled to assist parent carers in looking at their situations, to identify solutions and to link up with other support networks

- Social workers are able to demonstrably show skills of empathy, understanding and listening and can understand the context of a parent carer's life within wider family circumstances
- Social workers are further encouraged to think about the wider family approach and understand that care and support can be tailored to support the family as a whole rather than parent carers being expected to provide care and then being offered carers' services which do not tackle the underlying needs of the family
- Parent carers should be regarded as "rights holders" and not just co-producers of care

Short Term Breaks

- Published information about short term breaks in line with the Short Term Breaks Regulations provides clarity about the range of short breaks services in Surrey and the local authority's criteria for accessing them
- Commissioning strategies have been informed by the need to develop comprehensive and coordinated short breaks services that provide positive and inclusive experiences to disabled children and offer flexibility and choice to families
- There is a more enhanced understanding of the importance and desirability of short term breaks for parent carers and the high priority that is attached to them by parent carers in sustaining their caring role and providing access to a life outside of caring. Training programmes, support and supervision programmes for social workers should address this.

BME Carers

- Provide evidence that the recommendations in the report "Review of the views of Black and Minority Ethnic Carers in Woking on Surrey County Council services, in relation to the Care Quality Commission – Outcomes and performance characteristics for carers services" have been fully considered and their appropriateness for parent carers fully taken into account. Information needs to be produced about what recommendations can be taken forward and applied in the care and support of BME parent carers
- Commissioning strategies, support and services recognise that:
 - National research has indicated that BME carers want more information about their child's disability and in particular, services for their child and themselves. However, poor interpreting support and limited availability of translated materials could make access to appropriate information difficult, particularly for Bangladeshi families
 - Indian and Black African/Caribbean families reported least support from their extended family, with levels of support lower than that found among the survey of white families. Mothers from all ethnic groups represented reported lower levels of support from their partners than white mothers had reported.
 - Overall families from minority ethnic groups caring for a severely disabled child were more disadvantaged than white families in similar situations. Families' experiences, needs and circumstances varied across ethnic groups.