

# Social care provision for children with disabilities

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Feedback and review from parents and carers

January / February 2014



# Introduction

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## **The Bedford Borough Parent Carer Forum**

A parent carer forum is a group of parents and carers of disabled children who work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families

The Bedford Borough Parent Carer Forum was formally launched in February 2014 but has functioned with a steering committee since May 2013. We have approximately 100 members covering all areas of SEND.

Our objectives are:

- to be the strategic, consultative and collaborative body within Bedford Borough representing families of children with special educational needs and disabilities, providing a liaison point for Statutory and Voluntary Agencies within Bedford Borough;
- to work co-operatively with local service providers and commissioners to enhance and develop the range and quality of services provided for all children in Bedford Borough with special educational needs and disabilities;
- to consult with, inform and train our membership in order to be an independent, parent carer-led body that determines and acts upon the priorities of its members.

## **Our review of social care**

The information presented in this report was gathered at two meetings:

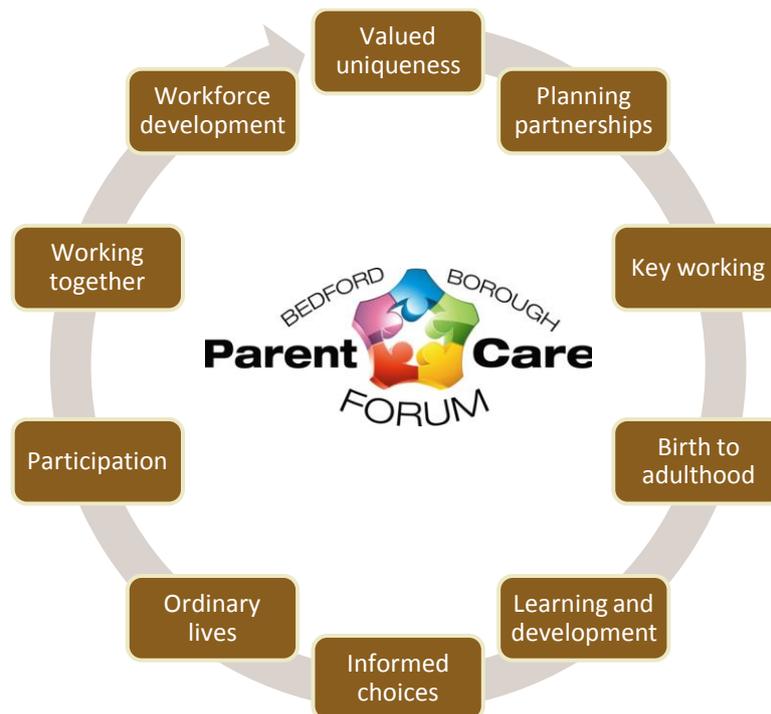
1. On the 17 January 2014, we held an open forum meeting devoted to the theme “social care”. Open forum meetings are open to all members of the forum and 16 members participated in a facilitated workshop to gather their views on the provision of social care in Bedford Borough.
2. At our launch on 27 February, we sought the views of parent carers who attended our event through asking them to write thoughts onto a comments board. Approximately 40 parents attended this event.

The evidence collected is anonymous and anecdotal. However, we filter out points and opinions that are not supported by the group as a whole and where families are willing to come forward, we can supply case studies.

## Our methodology

Our vision is that all services provided for children with SEN and disabilities are child, young person and family centred. We believe that service providers should aspire for excellence and that all services provided are underpinned by the Early Support 10 principles.

We have adopted the Early Support principles as our charter and all services are assessed against the criteria outlined herein.



For more information see <http://www.ncb.org.uk/early-support/about-early-support/10-principles>

We have given each area highlighted by our members a red amber green rating:

**Red:** This is a critical failing that prevents the service in question meeting the requirements of families and young people. We recommend it is addressed urgently.

**Amber:** An area that causes concern or issue for parent-carers. Whilst this does not prevent the service delivering value to parents, these problems render a service inefficient or ineffective in some ways.

**Green:** No significant issues raised or positive feedback received from parent carers.

# Summary Findings

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By the very nature of the exercise conducted much of the feedback presented here is negative. However, overall there was an impression that whilst there were many areas for improvement, social care provision in Bedford Borough was not failing or in crisis. Parents were appreciative of the work that the social care team performed and in particular many parent carers pointed to excellent relationships with their social workers.

The following areas came under the spotlight in our discussions:

*Introductions and transitions:* Families often have the greatest need at the point of diagnosis and when things change, usually for the worse. These introductions and transitions are critical points in providing a benchmark of how effective social services are at supporting families. Families had very inconsistent introductions to social services and there was confusion and a lack of information around the support available when things changed. In general, families felt that at the point of greatest need, services were not responsive enough

*Direct payments:* Direct payments for short breaks care is only a partially effective means of supporting families. Carers raised concerns about the bureaucracy associated with the process and the support offered by council staff. In addition, there was a sense that direct payments was simply a way of cutting costs and pushing yet more administrative burden onto already stretched families. Finding, training and retaining competent short breaks staff is a major concern for families.

*Panels:* “We don’t trust panels,” was the clear message that came from virtually all parents and families. The damning assessment was that they are “inefficient and ineffective” with people who do not know their children “sitting in judgement” on their families. There was cynicism about whether panels really responded to assessed need or were there to ration resources.

*Care agencies:* Generally, there is a perception that care agencies do not deliver a good service and value for money to the council or to families. Too often families are simply not helped by the work that care agencies do. There is criticism of the quality, experience and turnover of staff. There is a perception that care agencies work for the council, not for families

*Social workers:* There is a lot of very positive feedback around social workers with many examples of good practise highlighted. The main issue was one of inconsistency with some parent-carers giving examples of insensitive treatment. Families regard social workers as a key relationship – the good ones know when to engage with families and when to monitor from the background.

# Introductions and transitions

## Key Findings:

Families often have the greatest need at the point of diagnosis and when things change, usually for the worse. These introductions and transitions are critical points in providing a benchmark of how effective social services are at supporting families. Families had very inconsistent introductions to social services and there was confusion and a lack of information around the support available when things changed. In general, families felt that at the point of greatest need, services were not responsive enough.

Principle	Definition	Findings	RAG Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	The individual differences and circumstances in family situations are not recognised quickly enough. Families in desperate need are not treated with enough urgency and focus. Parents reported that emergency care and crisis responses were too slow and not good enough.	Red
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families		Green
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.		Green
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child's life and through preparation for adulthood	<p>Communication of changes between children and adult care was reported to be poor. Parents did not understand the differences in the way that children's and adult's teams worked.</p> <p>There was confusion about how the 17-19 age group will be managed under the provisions of the new SEND reforms in the Children and Families Act.</p>	Amber

<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Green
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	Families felt that they were not well informed with regards the choices they had when things changed. They relied upon advice and information from other parents and social workers often did not seem to have the right information readily available. For example, families do not understand the entry criteria for different levels of social care or what the criteria are for accessing the continuing care team.	Amber
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.		Green
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use		Green
<b>Working Together</b>	Multi-agency working practices and systems are integrated	Introduction to social services was very inconsistent. Some parents reported a seamless referral and uptake whilst others reported a complete lack of information and understanding when they most needed help. The common theme seemed to be that introductions were very dependent on the competence of the health visitor or the person with whom families had "first contact". Some knew how to use the system to support families others did not. Where failures happened, it was almost exclusively because services were not joined up and as a result families fell through the gaps. What can the social care team do to ensure more agencies are better informed of their work and when to refer?	Amber
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience		Green

# Direct Payments

## Key Findings:

Direct payments for short breaks care is only a partially effective means of supporting families. Carers raised concerns about the bureaucracy associated with the process and the support offered by council staff. In addition, there was a sense that direct payments was simply a way of cutting costs and pushing yet more administrative burden onto already stretched families. Finding, training and retaining competent short breaks staff is a major concern for families.

Principle	Definition	Findings	RAG Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Payment rates are not tiered dependent upon needs so the most complex and needy child is awarded the same hourly rate as a child who needs a little more than normal babysitting. This meant that parents were unable to find and retain appropriately trained staff. There was a sense that this was inequitable and unfair on those with the most complex and greatest needs.	Amber
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families		Green
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.		Green
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child's life and through preparation for adulthood		Green
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Green
<b>Informed Choices</b>	Children, young people and	There is a perception that direct payments are pushed onto parents because the	Amber

	families are able to make informed choices	local authority sees it as a means of cutting costs and pushing the administrative burden onto families who have little enough time already. The difference in pay rates for direct payments hours and what is paid to care agencies is stark, further fuelling this perception.	
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.		Green
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	The direct payments system is considered too bureaucratic with the focus on process rather than effectiveness and maintaining financial control. Parents are adamant that personal budgets under the SEND reforms must not work like this.	Red
<b>Working Together</b>	Multi-agency working practices and systems are integrated		Green
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	<p>There is a common perception that staff are too focussed on the process and do not empathise with what a particular family is experiencing. The phrase, "Staff need to care" was used repeatedly, the implication being that they currently do not.</p> <p>Families reported a consistent difficulty in finding suitably qualified and able carers who could do the job for a period of time. Retaining carers when they found a good one was also an issue for parents (the good ones move on quickly). Training for direct payment carers was also an issue, with the burden again, falling on parent carers.</p>	Red

# Panels

## Key Findings:

“We don’t trust panels,” was the clear message that came from virtually all parents and families. The damning assessment was that they are “inefficient and ineffective” with people who do not know their children “sitting in judgement” on their families. There was cynicism about whether panels really responded to assessed need or were there to ration resources.

Principle	Definition	Findings	RAG Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Parents were concerned that panels do not appreciate the differences between the cases presented to them. There was a sense that sometimes the urgency and the complexity of the most pressing cases was not appreciated.	Amber
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	Panels do not feel integrated or like a partnership to parent-carers. Parents do not sit on panels and have little insight into an opaque process. The process takes too long and is overly bureaucratic for what are often simple decisions. There was scepticism about the main purpose of panels – do they exist to assess and meet needs or are they there to ration resources.	Red
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Families were very concerned that too many people sit on panels. Parents cannot understand why such sensitive information is shared so widely and people who do not know their children feel able to opine on the right course of action for their families.  There was a call to empower key workers more to cut out the large numbers of people and the bureaucracy surrounding panels. Make key workers more accountable, give them more authority and enable them to make all but the most complex, disputed or expensive of decisions.	Red
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a		Green

	child's life and through preparation for adulthood		
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Green
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	The decision making of panels is not transparent. Parents do not understand the different criteria used and decisions were often unfathomable. For example, there was a feeling that families with moderate needs were given the same packages of care as those with the most extreme needs.	Amber
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.	There is strong sense that because our children are disabled, our families are treated differently. There is perception that panels sit in judgement over families and their lives in an insensitive and impersonal way that mainstream families are not subject to. For example, if a SEND child wants to change school this is subject to panel review.	Amber
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	No parents or carers sit on panels and yet care agencies do.	Red
<b>Working Together</b>	Multi-agency working practices and systems are integrated	Whilst panels are multi-agency, parents do not have the impression that they work together effectively. There were numerous examples from families when decisions were delayed because there were disputes about which panel or agency should be paying in a particular circumstance.	Amber
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience		Green

# Care agencies

## Key Findings:

Generally, there is a perception that care agencies do not deliver a good service and value for money to the council or to families. There is criticism of the quality, experience and turnover of staff. Too often families are simply not helped by the work that care agencies do. There is a perception that care agencies work for the council, not for families.

Principle	Definition	Findings	RAG Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Care agencies do not seem able to provide appropriately trained and tiered staff to meet the spectrum of needs of our young people.	Amber
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	There was a clear feeling that care agencies do not regard families as their client but the commissioners. There were many examples presented of care agencies fulfilling the terms of a contract rather than actually providing support and help for families in a way that was useful to them. There is no accountability to families. Too often needs are not met and there seems to be no follow up. There needs to be a contract with the family, not just the council. For example, there were numerous examples of late cancellations or an inability to find appropriate staff.	Red
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.		Green
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child's life and through preparation for adulthood		Green
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Green

<b>Informed Choices</b>	Children, young people and families are able to make informed choices		Green
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.		Green
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	Families are not involved in evaluating the performance of care agencies or the granting of contracts. When a family's needs are not met the lack of accountability to families is a big issue.	Amber
<b>Working Together</b>	Multi-agency working practices and systems are integrated		Green
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	Parent-carers had major reservations about the quality, motivation and expertise of care agency staff. There was a strong perception that many care agency staff did not care from the managers to the workers on the ground. Staff turnover is very high when continuity is a premium for families given the complexities of SEND children and the time it takes to train an individual and for children to become familiar with them. The good staff are often the ones that leave	Red

# Social workers

## Key Findings:

There is a lot of very positive feedback around social workers with many examples of good practise highlighted. The main issue was one of inconsistency with some parent- carers giving examples of insensitive treatment. Families regard social workers as a key relationship – the good ones know when to engage with families and when to monitor from the background.

Principle	Definition	Findings	RAG Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	There was a perception that families were always directed to the cheapest alternatives first by social workers (e.g. Home start), rather than the ones that best met a family’s needs. More honesty was called for with social workers sometimes arguing that decisions were policy led, rather than budget led.	Amber
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	A major concern was that too often interventions came too late. Parent carers felt that they would need to be at breaking point before urgent and appropriate action was taken	Amber
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Families recognise the importance of social workers. They regard them as a key relationship. Whilst there was mistrust of the profession there was a great deal of trust for individual social workers with whom families had built up a relationship. Interestingly, when parent-carers were asked who they would like to have as their key workers under the new SEND reforms, social workers did not appear on the list.	Amber
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child’s life and through preparation for adulthood		Green
<b>Learning &amp; Development</b>	Children and young people’s learning and development is monitored and promoted		Green

<b>Informed Choices</b>	Children, young people and families are able to make informed choices		Green
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.		Green
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use		Green
<b>Working Together</b>	Multi-agency working practices and systems are integrated	There was consistent frustration at the split between Bedford Borough and Central Bedfordshire councils. Given that care agencies, health services and schools work cross-border the split causes frustration. There was an understanding that this was not the fault of social workers but could something be done to narrow the gap?	Green
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	Families were concerned about the perceived high turnover in social workers and the re-organisation of teams. The lack of continuity the caused was a concern.	Amber