

Engagement and Participation with Parent Carers,  
Children and Young People (Version 6 - March 2015)  
Appendix 8 –SEND Local Offer Feedback and review  
from parent carers, Bedford

# Bedford Borough SEND Local Offer

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Feedback and review from parent carers

March/April 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 the Local Offer**

The information provided in this report was collected in the following ways:

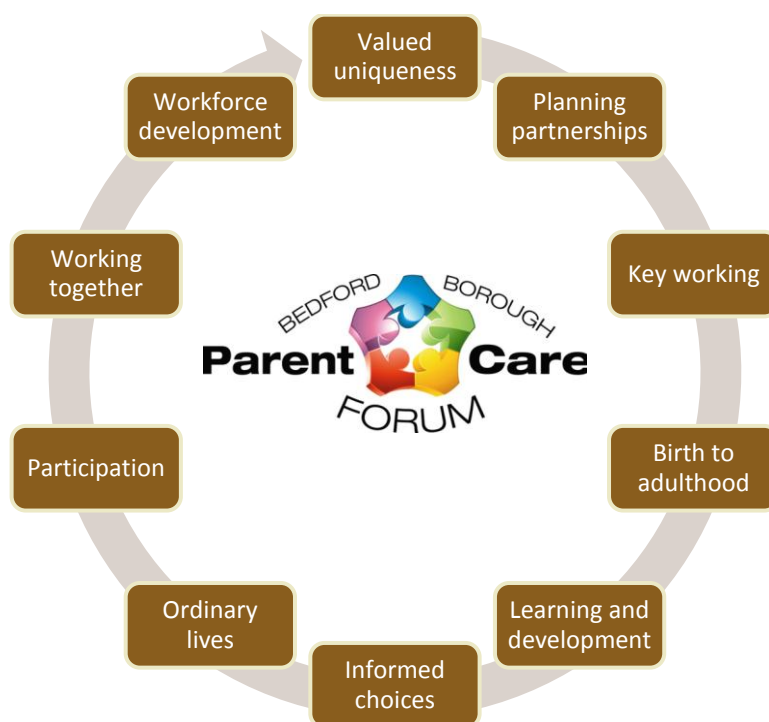
1. A series of 4 meetings held at different locations throughout Bedford Borough and at different times to attract as many parent carers as possible. 2 meetings were also opened to the children and young people of those parent carers and the children and young people participated in their own activities to give their views. The children and young people's feedback and views will be presented separately.  
A total of 35 parent carers attended the meetings.
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 colour rating:

**Dark Blue:** Areas where parent carers felt very strongly and should be non-negotiable

**Mid Blue:** An area that was highlighted several times and parent carers felt was important

**Light Blue:** Areas that were occasionally highlighted by parent carers and would be nice to have.

**Grey:** No particular issues raised or N/A

# Summary Findings

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## *General Principles for the Local Offer:*

All parent carers recognised that individual families will have a differing view of what is good or useful to them but they also felt that other parent carers views were an important aspect of decision making and all agreed that ratings/reviews should be an integral part of the local offer. At all meetings it was agreed that there needs to be some form of quality assurance of those services included in the local offer and that public and private services should be assessed by the same criteria. Parent carers want access to as wide a range of information as possible and this must include specialists and specialist centres, even if they are not currently commissioned or provided by the local area.

## *Website Format:*

The website should be parent and child friendly and information presented in a way that is meaningful to parents and children. A good search is essential with varying filters in order for parents to access the right information. A 'parent forum' and a 'practitioner forum' where members can chat and ask for advice, guidance and support was generally agreed to be a good idea.

## *Access to Services:*

There appeared to be very different experiences for families in how they accessed information, services and support. Transparent, honest, realistic and easily accessible information about available services is important to parent carers but it is also important to ensure equitable access to the help and support that is available.

## *Education:*

Parent carer's decisions about schools are more about the ethos and culture of the school rather than achievement and a key message again was around transparency, honesty and communication. A skilled workforce and partnership between home and schools were emphasised.

## *Service Reviews:*

Again it was noted that different families can have very different experiences of services and even the same practitioner. However, skilled staff and volunteers are essential to parent carers but also that a positive, willing and adaptable 'attitude' was important too. From the feedback we received, there are many good services within Bedford Borough but perhaps the choice available is currently limited.

# General Principles

**Key Findings:** All parent carers recognised that individual families will have a differing view of what is good or useful to them but they also felt that other parent carers views were an important aspect of decision making and all agreed that ratings/reviews should be an integral part of the local offer. At all meetings it was agreed that there needs to be some form of quality assurance of those services included in the local offer and that public and private services should be assessed by the same criteria. Parent carers want access to as wide a range of information as possible and this must include specialists and specialist centres, even if they are not currently commissioned or provided by the local area.

Principle	Definition	Findings	Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Universal, specialist and targeted services should be included together and include information about accessibility for children and young people with SEND <b>It was highlighted at each meeting that different families will have different perceptions of what is good/useful</b> More accessible services are required including fully accessible leisure services (e.g.: swimming pools with full disabled changing not just for mobile disabled – ‘changing places’)	Mid Blue
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	Complex needs children particularly need to be assessed and treated based on <u>their</u> baseline of ‘wellness’ and not judged by a practitioners expectation of a ‘normal’ child. Care should be individualised.	Mid Blue
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Information about support, advice, further information for parent carers and families is essential including how to access all services (both for the parent carers and the children and young people), where to go for help, information about conditions (with links to <u>good</u> sources of further information), glossary of common language and specific terms	Dark Blue
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child’s life and through		Grey

	preparation for adulthood		
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Grey
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	Specialist centres of excellence should be included as some can be a cost effective use of resources preventing future deterioration, parent carers need access to information about specialism in order to make informed choices – they may wish to access these services privately if they are able.	Dark Blue
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.	Do not want to be categorised by disability/need e.g.: autism, cerebral palsy or outcome e.g.: mobility, communication etc. Do not want to be categorised by service provider e.g.: health education etc. – not child focused.	Light Blue
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	All services should be assessed by the same criteria as to what goes in the Local Offer. Just because a service is commissioned by BBC or its partners should not automatically assume inclusion. Private providers should be included in order to 'inform' parents but need a mechanism to ensure quality of service provided.	Dark Blue
<b>Working Together</b>	Multi-agency working practices and systems are integrated	Border links are essential for those families that access services across borders (both those outside BB and those within BB). Better co-ordination of care is needed with ALL practitioners involved, including paediatricians with more joined up working. Specifically better communication is needed between community-hospital-specialist hospitals.	Mid Blue
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	Review/rating system is essential – parent carers need to know how good a service is, not just what is available. Perhaps a 'kite mark', use of the BBPCF Charter or even a 'parent's panel' to assess quality of services included within the Local Offer.	Mid Blue

# Website format

**Key Findings:** The website should be parent and child friendly and information presented in a way that is meaningful to parents and children. A good search is essential with varying filters in order for parents to access the right information. A 'parent forum' and also a 'practitioner forum' where members can chat and ask for advice, guidance and support was generally agreed to be a good idea.

Principle	Definition	Findings	Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Must work for families with English as 2 <sup>nd</sup> language and those with poor IT skills. What must be included on service template (one click from search or browse) – Opening times, eligibility criteria, telephone number, disabled access including changing & toilets (not just a baby change), maps, ratings/reviews, location, disability awareness (staff training etc.)	Mid Blue
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families		Grey
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.		Grey
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child's life and through preparation for adulthood	It needs to be child and parent friendly; symbols may put off young people and adults. A combination of pictures and writing was agreed by most.	Light Blue
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted		Grey
<b>Informed Choices</b>	Children, young people and families are able to make	Search function is essential but needs to work! Filters by age, SEN/disability inclusion (particularly schools and universal	Mid Blue



	informed choices	services). Parent carers did not want too many clicks to get to basic information – do not want 3-4 clicks to find the service is not appropriate.	
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.	News and events specific to SEND would be useful.	Light Blue
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	Parent led part of the website, forum, portal. Where parents can put own information on, ask advice, chat, constructive criticism etc.	Mid Blue
<b>Working Together</b>	Multi-agency working practices and systems are integrated	'top tips' – particularly from health providers – would be useful - what activities, interventions can be done by family whilst waiting to access a service or while on waiting list	Light Blue
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	A practitioners portal to allow for sharing best practice, ask advice, outreach services etc.  What date service was added – i.e.: how new/established is the service	Light Blue

# Access to services

**Key Findings:** There appeared to be very different experiences for families in how they accessed information, services and support. Transparent, honest, realistic and easily accessible information about available services is important to parent carers but it is also important to ensure equitable access to the help and support that is available.

Principle	Definition	Findings	Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Inclusion must work both ways – specialist services should be encouraging mainstream children and young people as well as mainstream including SEND. Some service providers already really know how to support our children – they should be championed and developed.	Dark Blue
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	How needs are identified, how to access social workers, where/who to go to get help. Information about social workers and eligibility to social care, short breaks, direct payments/personal budgets.	Mid Blue
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Health – parent carers need information about the ‘system’ – not just how to access a service but also what they can expect to happen next. If ‘pathways’ are used, information about them should be included. Need to understand and know about waiting lists and expectations of when they will be seen. ‘Top Tips’ of what parent carers can do whilst waiting to be seen.	Light Blue
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child’s life and through preparation for adulthood	The Children with Disabilities Register was discussed as an idea to gain more information about the needs of the families in the area – needs to be voluntary but discussion centred around incentivising being a member – the previously used card was valued by parent carers as it ‘proved’ your child’s disability. Suggestions included schools promoting the register, highlighting the benefits of registering, working with local providers to have ‘special offers’ The name was slightly controversial and suggested a change to SEND register	Light Blue
			Mid Blue

<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted	After schools clubs/breakfast clubs that accommodate children with SEND, including special schools. Clear information about what services are available after school. Information about social activities outside (and without) the family to promote independence.	Mid Blue
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	Cross border information and links - for education, health and social care are essential as many families may fall through the gaps particularly at the outer edges of Bedford Borough – not being able to get GP within county may affect eligibility to services that could impact on how integrated care is. Transparent information about on eligibility criteria and why a family may not be able to access a particular service.	
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.	Information about how to access funding for play schemes/clubs etc., particularly for low income families. Information about charities that may fund specific equipment or therapies. Support for parent carers that identify and meet a need for the child but also give the parent carer a break too. A better understanding of the impact on the health needs of the extended family.	Light Blue
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	Some services that are not offered (as far as we know) but would be useful were: <ol style="list-style-type: none"> <li>1. counselling – post diagnosis and also whole family support</li> <li>2. services for teenagers – perhaps a mentoring service to allow teenagers to access age appropriate activities <u>without</u> their parent carers</li> <li>3. Support and activities for high functioning disabilities</li> <li>4. Breakfast/after-school clubs for SEND particularly at special schools</li> </ol>	Mid Blue
<b>Working Together</b>	Multi-agency working practices and systems are integrated	Explanations of cross border access to services as especially those on the borders will have to access services from two different areas (e.g.: Rushden address, BBC school) – need both sets of information. Improved co-ordination of care and collaborative working is needed with easier & simpler routes into specialist services, particularly, but also for signposting to relevant services.	Mid Blue
<b>Workforce Development</b>	Children, young people and families can be confident the	It was felt to be difficult to assess how well a new service (or new to the family) would meet the needs of the children & families. Again suggestions of BBPCF	Light Blue

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people working with them have appropriate training, skills, knowledge and experience

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endorsement would help but also 'try before you buy' sessions would be a good way to introduce new services to children and YP.



# Education

**Key Findings:** Parent carers decisions about schools are more about the ethos and culture of the school rather than achievement and a key message again was around transparency, honesty and communication. A skilled workforce and partnership between home and schools were highlighted.

Principle	Definition	Findings	Rating
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Need to be able to filter those schools that offer specialist provision – don't want to search through whole list of schools to find those who offer appropriate support.	Mid Blue
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	Parent carers would like to know school funding and what they can expect from that funding – transparency Ofsted ratings do not mean very much to parent carers of SEND children & young people The SEN Governor should be contactable – information about how parent carers raise concerns (particularly if they are about the school)	Light Blue
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Parent partnership can be very helpful and supportive.	Light Blue
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child's life and through preparation for adulthood	Would like information split into Key Stages + Early Years + Preparing for Adulthood. Better home/school communication including training and support. Better collaboration between schools and adult services. Better collaboration between different local authorities.	Light Blue
<b>Learning &amp; Development</b>	Children and young people's learning and development is monitored and promoted	Information about the statutory assessment system is essential. Along with realistic expectations about what should happen and when. For example a child currently at School Action/Plus – if they are not making significant progress when should their support be evaluated? IEP's were discussed and were felt to	Mid Blue

		<p>be a useful way of following their child's progress but opinion differed – perhaps some template IEP's for schools and parents to use.</p> <p>Better training for school staff in observing children and better access to specialist services that can aid schools, e.g.: EP's.</p>	
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	<p>Information that parent carers find useful in decision making around schools: How many SEN children – both those with EHCP and those on register, how many children per class, how much does the school invest in training staff, home-school communication and how well a school includes parent carers. Schools should be 'judged' on their successes with SEN children.</p>	Mid Blue
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.		Grey
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	<p>Transparency and honesty is essential but works both ways – this includes parent carers too.</p> <p>Ratings for schools would also be useful – parent carers value the opinions of other parent carers.</p>	Light Blue
<b>Working Together</b>	Multi-agency working practices and systems are integrated	What do schools do to support transitions, not just leaving school but between phases. What/when and how? What help to schools provide to young people when choosing 'options'?	Mid Blue
<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>Parent carers want to know whether staff have additional training, not just disability awareness but also how many staff have specialist training. Particularly in upper schools – TA's experience and knowledge</p> <p>Need to know as a minimum – SENCo's name, contact number, email, qualifications &amp; experience.</p> <p>Training for school staff on how to observe children effectively as well as more condition specific training in order for school staff to meet the individual children's needs better.</p>	Dark Blue

# Service Reviews

**Key Findings:** Again it was noted that different families can have very different experiences of services and even the same practitioner. Skilled staff and volunteers are essential to parent carers but also that a positive, willing and adaptable ‘attitude’ was important too. From the feedback we received, there are many good services within Bedford Borough but perhaps the choice available is currently limited.

Principle	Definition	Findings
<b>Valued Uniqueness</b>	The uniqueness of children, young people and families is valued and provided for	Again it was noted that different families can have very different experiences of services and even the same practitioner. However, services that were family centred’ and who worked ‘holistically’ were valued.
<b>Planning Partnerships</b>	An integrated assessment, planning and review process is provided in partnership with children, young people and families	Some services/practitioners can tend to be ‘gatekeepers’ to their own or further services and in some instances support can only be accessed in specific ways (e.g. attending groups or if parent carers remain on the premises) which can make them less valuable. Some services were described as ‘idealistic’ at times.
<b>Key Working</b>	Service delivery is holistic, co-ordinated, seamless and supported by key working.	Voluntary organisations appear to be more willing to ‘go over and above’ than public services although specific practitioners within a public service can be seen to “go above and beyond role”.
<b>Birth to Adulthood</b>	Continuity of care is maintained through different stages of a child’s life and through preparation for adulthood	Many services have age restrictions which limits choice for families.
<b>Learning &amp; Development</b>	Children and young people’s learning and development is monitored and promoted	Collaboration with schools is essential, particularly for therapy services and good services will provide ‘troubleshooting’ and/or advice where needed.
<b>Informed Choices</b>	Children, young people and families are able to make informed choices	Although many services were mentioned, there was often little choice about which service a family accessed as eligibility was based around age or disability leaving only one appropriate service. Many parent carers were unaware of the services other parent carers were

		mentioning.
<b>Ordinary Lives</b>	Children, young people and families are able to live 'ordinary lives'.	There were differences of opinion about whether specialist services should include siblings – on the one hand it allows children to access activities together but on the other hand, perhaps the sibling would prefer to have a break from their brother/sister. However, services that did include siblings were felt to be more 'inclusive'.
<b>Participation</b>	Children, young people and families are involved in shaping, developing and evaluating the services they use	Although participation in service development was not specifically mentioned, most parent carers could provide at least one example where a service could be improved or expanded but do not necessarily feed this back to the service.
<b>Working Together</b>	Multi-agency working practices and systems are integrated	A good service is one that listens to parents, includes them in decision making and provides support, training or advice to both the family and the wider community the child accesses, e.g. support for schools, liaison with other practitioners/services, working with other providers.
<b>Workforce Development</b>	Children, young people and families can be confident the people working with them have appropriate training, skills, knowledge and experience	A recurrent theme about all services was about the staff. Good services tend to have "flexible, adaptable" and "skilled" staff and a "good attitude" towards children with SEND. Those services that are "willing" and "listen to parents" are viewed more positively.