



# Contact a Family and NHS England's Parent Participation Project:

A briefing for health colleagues



March 2016

# Contents

Summary and purpose of this briefing .....	3
Introduction to South Glos Parents & Carers .....	3
Context and background to Parent Carer Participation .....	3
Local examples of partnership working with strategic partners .....	6
Identified key priorities .....	7
Suggested ways forward .....	8
References .....	8
Appendices .....	9

# Acknowledgements and key partners

We would like to thank the Department for Education who have funded the Health Participation project at Contact a Family, this Participation Briefing and the facilitated workshop that contributed to it have been supported by that project. We would like to take this opportunity to also celebrate our many partnerships across South Gloucestershire some of which are shown below.



## Summary and purpose of this briefing

The aim of this short briefing paper is to promote a shared understanding of the impact and value of Parent Carer Participation at a structured and strategic, rather than personal level.

Building upon the functions and duties of the new structures set up under the Health and Social Care Act 2012, recent legislation in Part 3 of the Children and Families Act 2014<sup>1</sup> has thrown into sharp focus new legal duties on all NHS health commissioners and providers. These include those outlined in Section 26- joint working and joint commissioning arrangements, and the Section 19 duties to achieve ‘best possible

educational and other outcomes’, and having ‘due regard to the views, wishes and feelings of the child or young person, and the child’s parents’<sup>2</sup>; all of which will form the basis of the forthcoming SEND Joint Area Inspections by OFSTED and CQC from May 2016<sup>3</sup>

This briefing paper looks at how working strategically with South Glos Parents and Carers could specifically support and provide evidence in anticipation of these inspections, but much more importantly, can support our joint and mutual goals to improve outcomes for local children, young people and their families.

## Introduction to South Glos Parents and Carers (SGPC)

SGPC is a parent carer led community interest company (not for profit) covering the whole of South Gloucestershire. We offer information, support and a representative voice to local families with a child or young person aged 0 – 25 years who has a disability or additional need. Families can access our organisation whether or not their child has a specific diagnosis.

SGPC helps to improve services for our children and families living in South Gloucestershire. All of our team are parent/carers themselves of children and young people with a variety of different special needs and disabilities. We create a strong community by providing opportunities for families of SEND children to come together, provide support and share experiences.

Parent Carers’ voices are important to us as Parents tell us...

***‘We get frustrated trying to get our voice heard, and the battle to get the right support.’***

***‘Waiting times are too long and it takes a long time to see the right professional.’***

We provide a consultation and participation service which enables parent carers to have a voice about the services and support their children use. We collect parent carer views using many different methods and approaches which include running engagement sessions and focus groups, or by using surveys and social media. We then work closely with our statutory partners in education, health and social care to ensure that both strategy and practice are informed by the families who use the services on a daily basis.

### Reach of SGPC

**597**

Parent Carer Members

**6**

Directors

**42**

Parent Carer Volunteers

**202**

Parent Carers involved in our closed Facebook group

**14**

Parent Reps who are involved in various strategic meetings

**753**

Facebook contacts

**501**

Twitter followers

All our Parent Reps undertake an interview and assessment process and receive training about how to represent families in South Glos. We work in twos and our new volunteers shadow our more experience reps. All our reps sign a confidentially agreement and code of conduct and we offer ongoing support.

We are aware of and monitor the Child Health Profile of South Gloucestershire as evidenced in the CHIMAT data<sup>4</sup> and believe we have a wide, diverse and representative membership to draw on thereby providing the CCG and partner delivery organisations both quantitative and qualitative views and input from parents.

Appendix 1 gives more detail about our membership and reach.

# Context and Background to Parent Carer Participation

The National Network of Parent Carer Forums (NNPCF) was formed in April 2010 and became a formally constituted group in 2013. The Network is made up of 151 local Parent Carer Forums from across England and is a key element of the Strengthening Parent Carer Participation Programme delivered by Contact a Family (CAF) on behalf of the Department for Education.

The NNPCF has built on the participation ground work related to Short Breaks established by parent carers and CAF during the Aiming High Programme. Despite initially having only limited resources, NNPCF has now become an established and credible widely recognised national organization based on an active network of 151 local forums who between them now have over 67,000 members across England.<sup>5</sup>

Further detailed background about parent carer participation, what it means, its impact and how the NNPCF has been developed, can be found in previous Progress Reports and at: [www.nnpcf.org.uk/](http://www.nnpcf.org.uk/)

The NNPCF membership consists of 151 local parent carer forums that are pan disability, parent led and supported by the Department for Education. SGPC is a member Forum.

SGPC actively take part in regular Regional Network meetings to share best practice along with our colleagues from the SW Region; we also manage the regional finances on behalf the region.

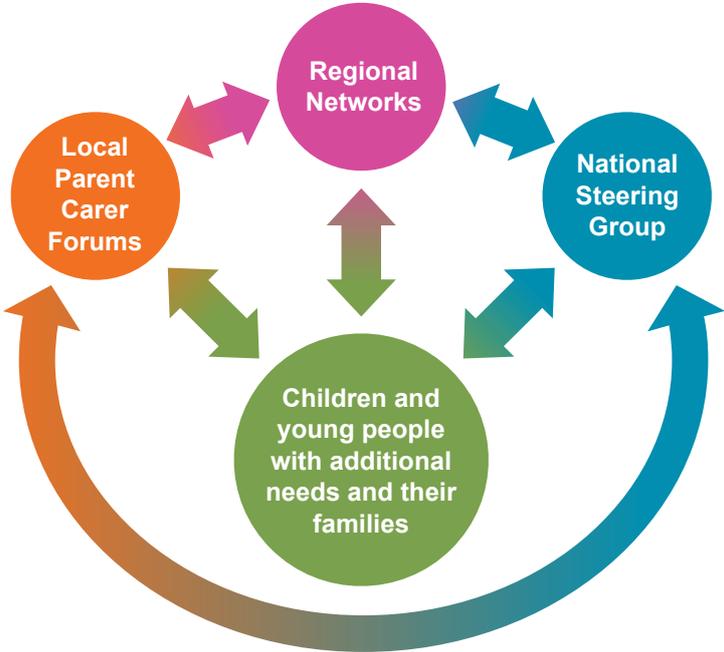
We are linked with, and work pro-actively on national issues with the many other parent carer forums across the country that make up the NNPCFF.<sup>6</sup>

*“It’s very important that we keep moving forward. People’s experiences of the system need to be positive. That’s the purpose of our reforms and we know that when parent carers, children and young people are properly involved in planning right from the start, those experiences continue to improve.”*

**Edward Timpson**  
Minister of State for Children and Families



South Glos Parents and Carers in action



## The aims of the National Network of Parent Carer Forums are to:

- Ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen.
- Develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England.
- Strengthen the pan disability, parent led model of local forums and boost our collective voice.

Working very closely with and supported by Contact a Family, SGPC is one of just nine selected Pilot Sites for a DfE funded Health Participation Project to promote strategic partnership working between CCGs and Parent Carer Forums. The aim of this project is to bring participation with health partners in line with the levels of joint working and co-production that the vast majority of Local Authorities have developed<sup>7</sup> preparing for and implementing the SEND reforms outlined in the Children and Families Act 2014<sup>8</sup>

## Key messages from our national partners

*“I believe in true parity for all children and young people, and am always reminded of what an amazing disabled young man called Corey says - we do not deserve to be in the shadows of society.”*

**Jackie Cornish**

National Clinical Director for Children, Young People and Transition to Adulthood, NHS England

*“Within parent carer forums, we do not choose our members, they choose us”*

**Karen Wooddissee**

NNPCF Steering Group member

*“The NHS England guide to Transforming Participation in Health and Care talks about listening to and acting on parent carer feedback at all stages, including commissioning and arranging; ... commissioners should publish what they have done and their evidence, it is not just about ticking a box.”*

**Flora Goldhill**

Director Children, Families & Maternity and Health Inequalities, Department of Health

*“We are far better working together than trying to do this in our separate little silos.”*

**Michelle Mello**

Deputy Director of Nursing, NHE England

# Local examples of partnership working with different strategic partners

As outlined in the CCG’s own Prospectus<sup>9</sup> “We’re committed to involving patients and the public in our work. Your experiences and views play a vital role in helping us to plan, purchase and monitor health services for local people”. This closely mirrors the strategic role of the National Network of Parent Carer Forums, one that is funded and monitored by government.

The newly published NHS England Patient and Public Participation Policy<sup>10</sup> contains the Engagement Cycle as in Appendix 2 which is something we would really welcome a dialogue about with CCG colleagues, and which we are delighted to see in the CCG’s own strategy. This policy also includes the Ladder of Engagement and Participation that outlines a variety of forms of engagement and participation. The policy states it is to be used as a best practice tool by NHS England staff in a flexible way to ensure appropriate and proportional participation. Using the different stages shown on the ladder, here are a few examples from the work that SGPC have been engaged in:

## Collaborating

An example of co-production is our role on the 0-25 Project Board; South Gloucestershire Council invited the forum to sit on this strategic meeting right at the start before anything was planned. Another example of our work is reflected here:

*“The Parent Carer Forum have been an essential and inspirational element of a major service redesign; as a result the voice of parents have been reflected in the decisions about the design and development of the service. Without their voice we would not have been able to achieve genuine engagement and co-design of a major service and cultural change”*

**Denise Porter**

Head of Adult Services, 0-25 SEND team and Housing South Gloucestershire

## Participation

We were invited to take part in looking at the Children’s Community Health partnership specifications and has recently met the interim provider to seek ways of working together to improve outcomes for children across the local area.

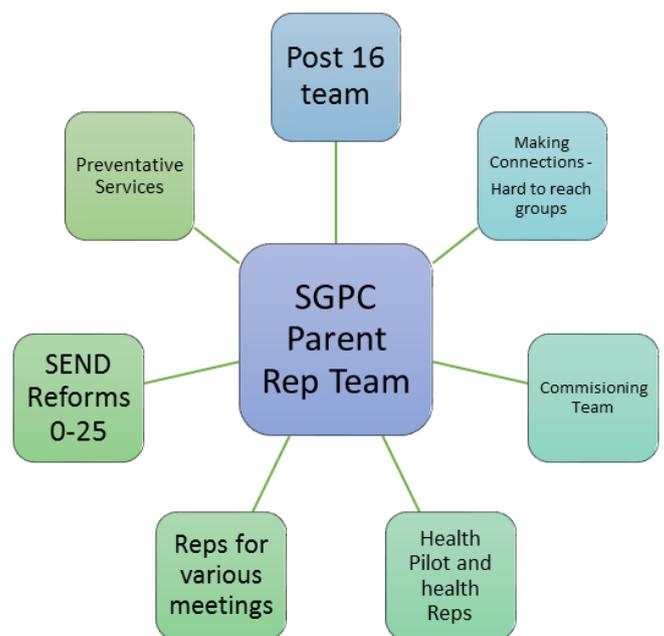
## Consultation

SGPC were asked for our views at a consultation for preventative services when they were looking at the potential closing of the children’s Sure Start Centres and youth clubs.

We were asked to look at the relevant proposals and make comments on which proposal we felt was the most appropriate.

## Information

A working group consisting of LA, Health and schools was looking at materials regarding anxiety issues; they asked the parent forum to read and make comments regarding the work they had completed and to input any information we felt was missing.



**SGPC Parent Reps Team**

## Identified key priorities

As part of this Pilot work, Forum members attended a workshop facilitated by a Contact a Family Associate to look at national and local health structures and commissioning priorities. The table below illustrates where key priorities for both the Forum and the CCG overlap and where the Forum members can support the CCG to meet its stated strategic aims.<sup>11</sup>

SGPC CURRENT PRIORITIES FOR HEALTH		South Gloucestershire CCG priorities
<p>SGPC is acutely aware of its new role in the forthcoming OFSTED and CQC SEND inspection framework and would like to build on the CCG’s proactive approach to engagement by working with the CCG to support the local area to be ‘inspection ready’ and to meet the new ‘best possible outcomes’ duties.</p> <p>Coordination of care is a massive issue to our families including integrated assessments and planning of care across all the health, education and care aspects of children’s lives- this will be a fundamental aspect of the inspections.</p>	 Linked by statutory duties/roles	<p><b>Making the best start in life</b> – enabling every child and young person to thrive and develop skills to lead a healthy life and achieve their full potential.</p> <p><b>Fulfilling lives for all</b> – enabling people with long-term conditions, physical disabilities and mental health problems to lead independent, fulfilling and dignified lives.</p>
<p>The Forum has been involved with consultations around the interim provision and re-commissioning of this key service that is of vital support to its members, and would like to increase involvement at a more strategic level. We have the governance, structure and training in place to work at a co-production level with all strategic partners both at commissioning and provider level.</p>	 Mutual goals and clear links	<p><b>Better community health services for children and young people, including mental health services</b> – improve the capacity and performance of mental health services for children and young people.</p>
<p>The Forum is very pleased to see a focus on Autism, but have concerns that although much needed, as this is an adult service we need to flag up the fact that children’s early identification, diagnosis, provision of interventions/support is currently falling behind. Having a clear pathway for children with ASD is inevitably, due to sheer demographics, a very high profile issue for the members of SGPC.</p>	 Mutual goals and clear links	<p><b>Commission a local Autism diagnostic service</b> to include specialist assessment and, in conjunction with the local authority, to provide on-going therapy, support and practical assistance, in compliance with the joint CCG and South Gloucestershire Council ‘South Gloucestershire Autism Strategy’.</p>

## Suggested ways forward

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In addition to working with CCG colleagues on the current procurement processes, we would suggest an initial informal small, targeted meeting with CCG lead officers to scope out the following issues:

- To identify the key successes/issues/challenges regarding the new duties on health partners in the SEND Reforms
- How the Forum, Local Authority and CCG could work together to meet their obligations around parent engagement of children and young people with SEN and disabilities and therefore be OFSTED/CQC 'ready'
- To agree priority areas for strategic engagement with the CCG as outlined in above table
- To agree structures, named leads and timelines to take this work forward

## References

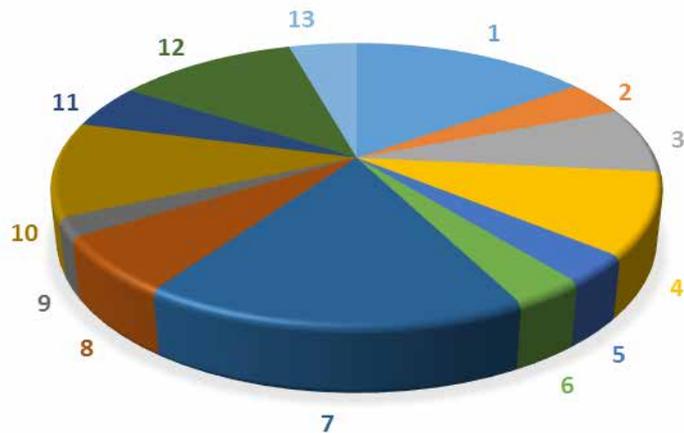
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1. Children and Families Act 2014 [http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga\\_20140006\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf)
2. SEND Code of Practice [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND\\_Code\\_of\\_Practice\\_January\\_2015.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)
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5. NNPCF Annual Report 2015 <http://www.nnpcf.org.uk/nnpcf-annual-report-2015/>
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# Appendices

## Appendix 1

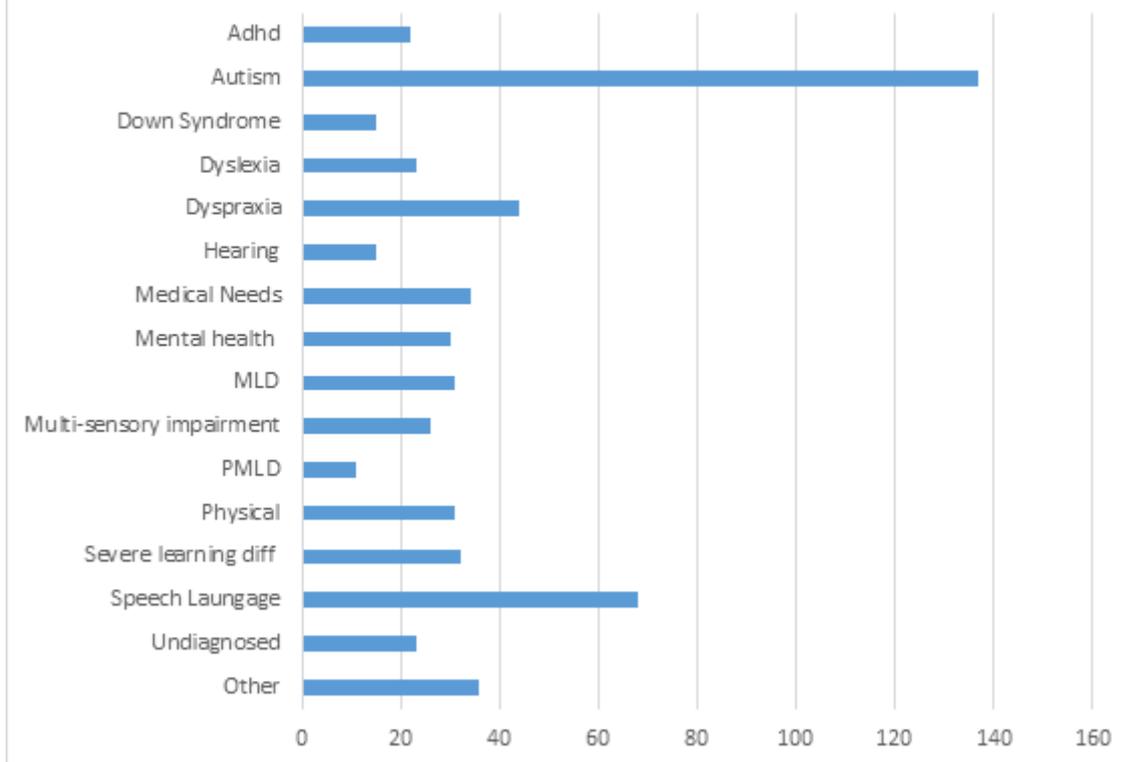
**LOCATION OF OUR MEMBERS**

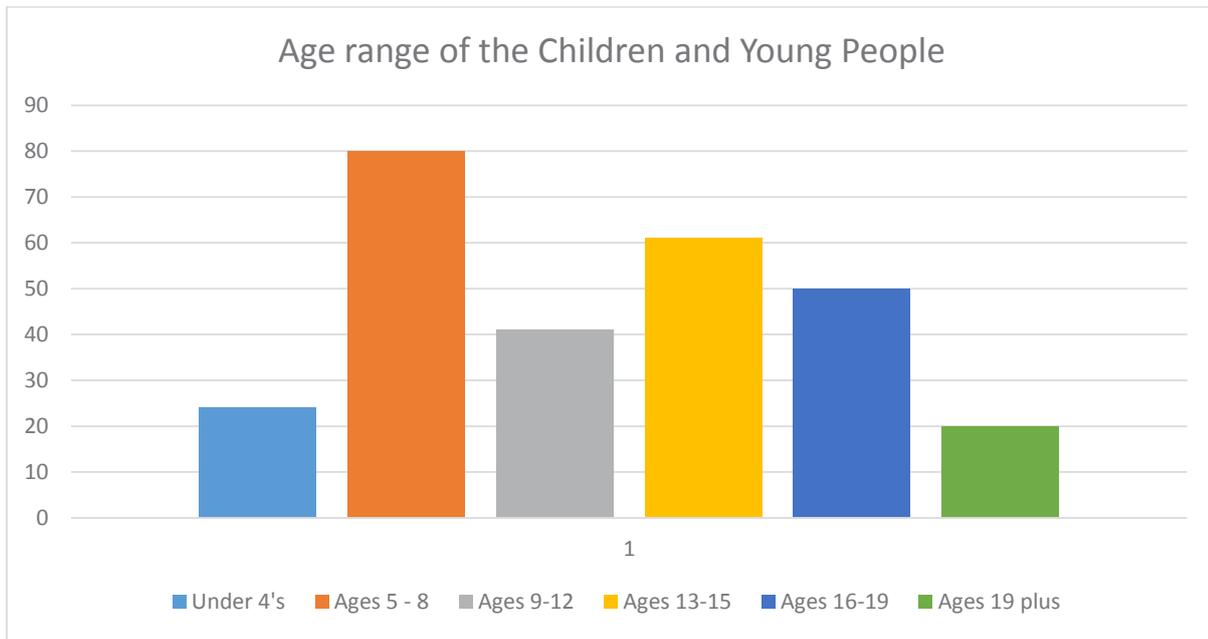


1. Downend, Bromley Heath and Emersons Green, Lyde Green
2. Staple Hill, Rodway and Mangotsfield
3. Kingswood
4. Hanham and Longwell Green
5. Oldland Common, North Common, Bitton, Cadbury Heath and Willsbridge Wick
6. Siston, Warmley, Boyd Valley, Bitton Village,
7. Yate, Chipping Sodbury Pucklechurch and Dodington
8. Winterbourne, Frampton Cotterell, Westerleigh, Coalpit Heath, Iron Acton, Hambrook and Frenchay
9. Charfield, Cromhall, Tortworth, Falfield, Rangeworthy, Wickwar,
10. Thornbury, Alveston, Severn and Aust
11. Filton and Patchway-Sevenside
12. Bradley Stoke, Stoke Lodge and The Common
13. Stoke Gifford, Cheswick, Little Stoke Harry Stoke and Stoke Park

(We have a further 247 members for whom we do not hold this information)

**Range of Needs we have data for.**





## Appendix 2



# Contact details

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South Glos Parents and Carers

Phone: 01454 501009 (answerphone)

Email: [parents@sglospc.org.uk](mailto:parents@sglospc.org.uk)

Website: [www.sglospc.org.uk](http://www.sglospc.org.uk)



*'If you want to know how well a pair of shoes fit you ask the person wearing them not the person who made them, or paid for them.'*

Anon