West Sussex Local Area
Feedback Report VOICES Event

16th March 2018

by Genuine Partnerships in partnership with Contact
on behalf of
Voices: National Alliance for Local Area Partnership Working
Contents

Pages

3  Context: Voices National Alliance, Genuine Partnerships, Contact

6  West Sussex VOICES Day: people involved

8  The process: An Appreciative Inquiry

9  West Sussex Co-Production Narratives

10  Working wall: Hopes and Dreams

12  Hopes and Dreams in summary

14  West Sussex Narratives

15  Welcome and Care

18  Value and Include

21  Communicate

24  Work in Partnership

27  West Sussex co-produced action planning

28  Summary of Strengths and Next Steps
1. VOICES: National Alliance for Local Area Partnership Working
This report has been produced for West Sussex Local Area by Genuine Partnerships, in partnership with Contact (formerly Contact a Family), on behalf of VOICES: National Alliance for Local Area Partnership Working.

Co-production involves children, young people, families, practitioners and partners working jointly together in an equal and reciprocal relationship. It enables genuine participation in decision-making. Although there are many models of co-production across the country, there are no real measures of participation, or formal measures of the good practice underpinning the principles of the Children and Families Act and the SEND* code of practice.

The VOICES Alliance recognises the need for a shared approach to partnership working, together with examples of good practice and resources, to help Local Areas establish and embed recognisably good co-production. The development of the Alliance and its aims are supported by the Department for Education (DfE) and the Department of Health (DH). Within Health, co-production at an individual and collective level is a cornerstone of the Health and Social Care Act (2012) and the NHS Constitution (2015).

The VOICES Alliance has agreed terms of reference signed up to by the following organisations:

- The National Development Team for Inclusion (NDTi)
- The National Network of Parent Carer Forums (NNPCF)
- Leicester City Local Authority
The purpose of the Alliance

The purpose of the Alliance is to ensure there is a nationally agreed framework, process and principles for whole area co-production and participation that can be used in partnership by all stakeholders in each Local Area in England.

These should capture the shared values that all Alliance members have in relation to participation and co-production and reflect the intent of the Children and Families Act (2014), Health and Social Care Act (2012) and the NHS Constitution (2015) in ensuring families, parent carers and children and young people are fully involved in individual and strategic decisions that affect them.

VOICES intends to achieve its purpose by promoting the use and understanding of the cornerstones of co-production which have been developed, quality assured, and are adopted from, the Rotherham Charter and wider Genuine Partnerships model.

The Four Cornerstones of Co-production are:

- Welcome and Care
- Value and Include
- Communicate
- Work in Partnership

Developing and nurturing each of these to build

Trust
The Alliance sees these cornerstones as a common language of co-production that will support Local Areas to develop their own locally agreed and understood approach to partnership working.

The Alliance hopes that a common framework for Local Area partnership working that is recognised and supported by a wide range of reform partners will help develop a shared level of expectation to which all Local Area partners can aspire.

Developing locally agreed approaches to partnership working which are based on nationally recognised models of good practice will mean that local reform partners can offer consistency of values, approach, language and communication, and engagement and co-production across all services informed by evidence from their Local Area.

From March to July 2017, the Alliance worked with 3 Local Areas to pilot the VOICES model. These pilots have been evaluated and a report of the outcomes presented to the DfE, DH, Ofsted and the Care Quality Commission (CQC). VOICES projects have since been rolled out in other Local Areas around the country.

2. **Genuine Partnerships** is a friendly, Rotherham-based team made up of skilled practitioners, parent carers and young people with a diverse range of experiences, which models and inspires co-production. Using the Rotherham Charter as a foundation, the team’s unique packages of support, training and tools are incorporated into an appreciative inquiry approach. This means the team builds upon and celebrates good practice, and promotes the meaningful involvement of parent carers and young people in decisions that affect them at individual, organisational and strategic levels.

Genuine Partnerships works with schools, settings, Education, Health and Care services. In June 2016 the team began working nationally and was invited to contribute to VOICES: National Alliance for Local Area Partnership Working.

3. **Contact (formerly Contact a Family)** is a family-focused charity covering all four nations that supports families with disabled children whatever their disability or health condition. Support is offered via national and regional teams and includes: publications; a Freephone helpline (including specialist benefits and education advice); website and SENDirect; information on rare conditions and medical information; linking families with other families, and with support groups; parent and practitioner workshops and information sessions; hospital and hospices, and early years work.

Contact is the Department for Education’s contracted partner and has been supporting the development of parent carer forums and co-production since 2008. Contact coordinates the VOICES Alliance, which is a tangible opportunity to develop national standards for co-production based on the principles of Rotherham’s Genuine Partnership model.
West Sussex VOICES Day 16th March 2017

West Sussex facilitators:
Debbie Buckwell SEND Strategic Commissioning Manager, Care, Adults, Families, Health & Education Directorate
Michael Rhodes-Kubiak SEND Commissioning Manager (Short Breaks)
Lara Roberts Management Team West Sussex Parent Carer Forum
Grainne Saunders Management Team & Trustee West Sussex Parent Carer Forum
Rachel Sadler SEND Youth Participation Worker

Representing VOICES National Alliance:
Aisia Howard Kids

Representing Genuine Partnerships:
Claire Whiting Genuine Partnerships Co-Strategic Lead, Educational Psychologist (Area Specialist) Rotherham Metropolitan Borough Council (RMBC), VOICES: National Alliance
Jayne Fitzgerald Genuine Partnerships Co-Strategic Lead, Strategic Lead Rotherham Parent Carer’s Forum, VOICES: National Alliance
Eleanor Smith Year 2 Psychology student at Sheffield Hallam University on work placement with Genuine Partnerships
Eva Ogden Genuine Partnerships Strategic Management Group, Business Support Manager RMBC
Jemma Wilkinson Genuine Partnerships Strategic Management Group, Educational Psychologist RMBC
Kayleigh Harrison Genuine Partnerships Implementation Team, Rotherham Parent Carer Forum Administrator and member
Louise Mulligan Genuine Partnerships Implementation Team, Young Person’s Information Officer 0-16, Rotherham SENDIASS* RMBC
Scott Johnson Genuine Partnerships Implementation Team, Trainee Educational Psychologist RMBC
*Special Educational Needs and Disabilities Information, Advice and Support Service

Representatives from the West Sussex Local Area from each of six key partner areas attending Focus Groups:

Young People: 2 young people with 1 adult supporting; young people attending M8s Youth Group also contributed via a written activity facilitated by an adult.

Parent Carers: 7 parent carers including representatives from West Sussex Parent and Carer Forum.
Schools and Settings: 6 practitioners including: Principal School Transport Officer; Playgroup Manager; Nursery SENDCO* and Deputy Manager; Pre-school Manager and SENDCO; LA SEND Commissioner, Engagement and Intensive Planning Team Officer; Officer for Young People’s Voice and Duke of Edinburgh Award (DofE).
*Special Educational Needs and Disabilities Coordinator.

Local Authority (LA) Education: 6 practitioners including: Principal Manager for SEND; Head of Inclusion; a Secondary school SENDCO; Senior Educational Psychologist; Team Manager at SENAT (Special Educational Needs Assessment Team); Team Manager for SENDIASS.

Care services: 7 practitioners including: Group Manager, Children’s Social Care Disability Services; Student Social Worker, Choice Team; Learning Disability Commissioning Team (Adults); Leaving Care Team Manager; SEND Children’s Commissioning (Early Help secondment); Advocacy Service; Advanced Practitioner (Permanence & Resilience) Children’s Team; Independent Visitor Scheme Coordinator.

Health: 4 practitioners including: Matron of Children and Young People’s Community Nursing; Speech and Language Therapy Locality Manager, also representing Physiotherapy and Occupational Therapy Services; Team Lead for Healthy Futures, also representing other Healthy Child Teams; Carer (also a grandparent member of West Sussex Parent Carer Forum).
The Process

An Appreciative Inquiry
VOICES projects are purposefully grounded in appreciative inquiry. An appreciative inquiry is an optimistic, strength-based model that supports organisational change and involves people talking and working together towards common hopes.

Key features of the process in West Sussex
- Focus Group research interviews drawing upon narrative approaches
- with each representative SEND group
- Presentation and group activities (building relationships): modelling co-production
- West Sussex co-productive activity: Hopes and Dreams, Going Well? Could be better?
- Feedback report to support co-productive action-planning

Use of a systemic, critical narrative approach
Within narrative practice there is an understanding that as they try to understand their own lives, and the lives of others, people tell stories (narratives) to express meaning. These stories change over time, and they are collaborative. They are co-constructed with other people.

This approach is systemic because it focuses on relationships within whole systems like families and organisations. It is also critical, because power imbalances are acknowledged and adjusted so that all voices can be heard equally. Different versions of the same event are validated, blame is removed and relationships can be strengthened.

By applying a systemic, critical narrative approach the Genuine Partnerships team deliberately prioritises the voices of children and young people, and their parents and carers.

The use of Focus Groups enables individuals likely to have common agendas to share their stories. Ground-rules are established at the beginning to ensure participants feel they are in a safe, supportive space in which they might voice the 'not yet said'. Questions are purposefully open and, to avoid assumptions being made, the agenda of the participant leads the way: In terms of the Four Cornerstones of Co-production, What is going well for you in West Sussex? What could be better? The voice of the researcher is acknowledged in informing the new narratives co-created.
West Sussex Co-production Narratives

Introduction

A VOICES day project aims to start a lengthy process of transformation to improve the experiences of, and outcomes for, children, young people and their families in West Sussex. By inviting young people and parent carers as well as key practitioners from Education, Health and Care services it is possible to start a dialogue that can form the foundations from which greater co-production emerges. Further work of this nature will be needed in order to carry the momentum forward, as well as continued firm commitment and investment from West Sussex strategic leaders to genuinely promote this way of working.
West Sussex Hopes and Dreams (Working Wall)
Co-Production is everyone’s business not just a few

Everyone being involved right from the start and their voices valued

We have a Co-production Framework, let’s use it!!

All Children, Young People & their families are enabled to participate in all aspects of school life
ALL services involved & taking ownership

Local services will all work together to maximise the voice of young people & the impact they have on developing & improving services they access

Make sure that people are not left behind, has to be for all

Everybody being on the same level and treated as an equal at all times

For parent carers to have been told/given the opportunity to know what Co-production is. To work together as one

Some really great stuff happening. Let's share that, practice “infect West Sussex” & spread the contagion

All schools, settings, colleges are committed to including ALL young people & their families in all aspects of education
West Sussex Narratives

The narratives presented here are organised under the Four Cornerstones of Co-production headings. As indicated above, priority has been given to the voices of the young people and parent carers involved in the day. Their words and the key narratives co-constructed shape the structure of the feedback.

It is important to recognise that the Focus Group feedback provides only a few of the many narratives that potentially exist in West Sussex. It is inevitable that perspectives will differ, and likely that not everybody will be aware of all the developments and activities taking place. Honest, open communication is a key feature of co-production; it proves that people are listening, and that every voice matters. These narratives should provide a starting point for further discussion and the strengthening of relationships. Continuing to work together will create a positive climate for resolving any differences.

Please see the Appendix for the narratives in detail, including transcribed quotes.

Chair of West Sussex Parent Carer Forum, Carrie Phillips, with Jon Philpot, Head of SEN and Inclusion
Young people: “...[the staff] listen to us and allow us to be ourselves...”

Parent carers: “...it was a totally non-judgemental environment where I felt accepted and I felt that my daughter was accepted...”

Schools and settings: “...we make sure we are readily available at all times ...”

Health: “...sometimes clinics are a less welcoming environment but it is still the person that provides the welcome ...”

Going well

😊 When adults consider how young people like to be acknowledged they appear more open and welcoming

😊 Individuals who show understanding and are approachable make young people feel relaxed and at ease

😊 Young people feel it is important they are respected

😊 Parent carers say that being involved in planning individual futures that are realistic for their children and young people enables them to feel cared for

😊 An initial contact that is inviting helps parent carers feel welcomed and accepted from the start

😊 Being able to interact with reception staff and other practitioners who are non-judgemental can be life-changing

😊 Parent carers can find it difficult to manage the needs of the whole family when they have a child who requires additional support; some individual provisions are recognised as welcoming and caring because they take into account the rest of the family too

😊 Specific individuals play central roles for parent carers in helping them feel welcomed and cared for, projecting that the environment they represent is also welcoming

😊 Early Years teams feel they work hard to ensure that families are given a warm welcome and that they have access to advice whenever they need it

😊 Co-production is considered to be a central aspect of work in Early Years, and that involving parents from the start and throughout their journey gives families and children the best opportunities

😊 Local Authority (LA) Education services recognise that friendly introductions are important to everybody, reducing anxieties and strengthening relationships that develop; being a human face is encouraged

😊 Attention is given to practice that helps young people feel comfortable

😊 Personalisation has been strong and there has been good use of person centred planning (PCP) tools

😊 Schools have a key role to play in ensuring that everyone is made to feel welcome
The e-PEP* system enables a more holistic approach to supporting children who are Looked After.

The NHS services in West Sussex try to ensure that everyone introduces themselves before treatment or care starts: ‘Hello my name is...’

Practitioners work hard to make sure that families and young people feel comfortable when they are visiting.

*e-PEP - Electronic Personal Education Plan
Could be better

- Young people feel that approachable attitudes needed to be displayed by all practitioners, and not just those who choose to be approachable.
- They want to feel they can be themselves without being judged.
- Parent carers are often uncertain of how practitioners will respond, which generates anxiety for them when engaging with a new person or service.
- Small comments have a big impact on parent carers as to whether or not they experience a sense of battling.
- They feel that positive experiences are left to chance and relate to individuals, or 'pockets' of good practice rather than something purposefully built into services and provisions; the positive examples might be used to demonstrate to others how to help parent carers feel welcomed and cared for.
- The impression of being thrown 'back out' by services gives parent carers a sense of having to start again in their journey to finding support for their child or young person, leading them to feel that they are not cared for despite often already difficult circumstances.
- The size of the Local Area is perceived by some parent carers to be an excuse for some of the difficulties experienced by practitioners, and therefore also parent carers, children and young people; it seems to have become a potential limiting factor in practitioner confidence in making improvements.
- Early Years services sometimes find that schools children move on to do not assist with transition as much as they could; welcoming, inclusive practice is inconsistent.
- Examples of good practice in schools need to be shared.
- Capacity issues mean 1-1 support cannot be guaranteed and this has created tensions with some parent carers.
- There could be better educational provision for the 19-25 age group.
- There is also concern for the wellbeing of care leavers at the age of eighteen 'cliff-edge': should services be extended to 25?
- There is a tendency to concentrate time and resources on higher needs children and young people.
- When trust is lost it must be recognised and addressed supportively.
- It is not all about outcomes; dialogue to review practice should be ongoing.
YOUNG PEOPLE: "...you say what you need to say and they’ll feedback on it."

PARENT CARERS: "...where you are valued, you are included, the other children are taught to maybe understand... it’s not just the child’s needs it’s the family unit..."

SCHOOLS AND SETTINGS: "Where ...the placement is breaking down, rather than ‘farming them out’ we are looking at more creative solutions ...it’s about looking at the family in a completely holistic way..."

LA EDUCATION: “Hopefully it feels more like a dialogue than a process that’s done to them...”

Going well

😊 Across West Sussex value is given to working in co-production

😊 Practitioners speak of valuing parent carer involvement and being sensitive to their needs; there is also commitment to ensuring young people have a voice at all levels, and that they are included and supported

😊 Ensuring all voices are listened to is viewed as important, and some good examples of this happening are provided

😊 Having young person representatives offers a platform for their opinions and views to be shared with practitioners

😊 It is important that young people are aware of the actions that have then been taken following their contributions

😊 Their child or young person being included without needing a label, and support for every member of the family, makes parent carers feel their opinion is valued

😊 When practitioners involve parent carers in the creation of interventions and plans it also supports their sense of being valued

😊 It is perceived that higher staffing ratios in Early Years are beneficial to the outcomes of the children

😊 A school inclusion framework is starting to develop

😊 The Intensive Planning Team looks for solutions that keep young people in West Sussex, even when placements are becoming problematic

😊 Some Education, Care and Health services have developed innovative ways of gathering feedback from, and listening to, children and young people with SEND and their families (examples include Survey Monkey version of NHS patient questionnaire, use of Words and Pictures by Early Help and My Plan by the Choice Team and the Lifelong Service working on the Signs of Safety mapping tool with families); differentiated tools that are easier to access, more child-focused and more positive for children and young people with SEND are being created

😊 In Health, strategies have been put in place by the Family Nurse Partnership to help some of the different groups of people with additional needs, for example young parent carers with learning difficulties
Learning more about co-production: working together to build Racton Monument with straws and an orange
Could be better

- There is not always enough value placed on the time parent carers and young people give to co-production
- Young people believe they should have the opportunity to talk to people who are able to make decisions, and not always rely on the middle man
- Meetings therefore need to be adapted to make them accessible for young people
- Young people want all the staff in a setting to respond to new initiatives and changes
- The Chat Health help line, which allows young people to text if they are embarrassed to ask questions, is not yet inclusive for all users
- How young people contribute to their EHCP* could also be more developed
- Parent carers talk about not having a sense their voice is valued; some have been led to feel that someone else knows better or they have felt questioned; this has led to them seeking support from organisations beyond LA services
- It is perceived that some schools are more successful at being inclusive than others; this puts pressure on schools that are inclusive, and LA transport
- A personalised approach is required to ensure every child’s voice is heard within a classroom
- LA Education services agree that practice needs to be more consistent so that children and young people with all levels of need, and their parent carers, are supported
- There is considerable pressure on special school places leading to resources being spent on out of County places
- There are also occasions when practitioners feel their contribution is not valued
- It is suggested that service boundaries might be a barrier to them working towards other Council priorities like co-production

*Education, Health and Care Plan
**COMMUNICATE**

**YOUNG PEOPLE:** "...one of the good things that they did was to write some notes down so I know what is what..."

**PARENT CARERS:** "When we did get a social worker who went through personal budgets and everything else that was very empowering...I was able to sit down and write a plan for him thinking about his needs for the future..."

**LA (EDUCATION):** "...it's about making sure people's voices are heard..."

**CARE:** "...SEND Commissioning...they did a lovely piece of work, they did a video with young people...all about what an assessment is..."

**HEALTH:** "...if I ring a parent I always ask them if it's a good time to talk...I try to time my phone call to avoid the school pick up."

---

**Going well**

😊 Some adults communicate with young people in a way that makes them feel comfortable

😊 Adapting communication styles to suit individual preferences is important and helps young people to feel supported

😊 They find the internet to be a positive and accessible source of information

😊 Parent carers value being encouraged to voice their opinions; through being heard they feel valued

😊 They appreciate it when practitioners take the time to 'sit down' with them

😊 The most effective communication is to reflect an honest position

😊 When Short Breaks contracts with the Local Authority are up for renewal parent carers are asked for feedback; this information is used to make sure provision is fit for purpose

😊 LA Education services emphasise the need for good communication with parent carers from the start of processes, and that communication should be personalised

😊 The key point of contact for parent carers should remain the same when possible

😊 The Parent Carer Forum has contributed proactively to workforce development in supporting practitioners to understand how to facilitate parent carer voice

😊 There is commitment by individual services, and some services working together, to young people having a meaningful voice, for example the Advocacy Service

😊 There have been some innovative pieces of work commissioned involving young people with disabilities communicating some key experiences, for example a Social Care assessment, to help prepare other young people for the same

😊 Early Help is working creatively with families to enable their voice and the voices of their children
There is ongoing work taking place to refresh the Local Offer in response to feedback, and there are individuals who have responsibility for overseeing and updating it.

Wikis are being successfully used for teams (e.g. The Choice Team) and individual children and young people.

In Health different options for communication are carefully considered (e.g. text, phone call) to ensure they are the most appropriate for the occasion and the individual.

Creative methods of consultation are used with parents and young people to find out how they feel about the service they receive; patient questionnaires are on Survey Monkey for the first time this year.
Could be better

- Young people suggest social media could be used more widely to reach out and engage them in communication; initiatives are taking place to look at the possibilities of using social media to share and convey information
- Some parent carers feel there is an absence of practitioners guiding or signposting them to the right support, so they have to be determined in researching and sourcing their own
- Communicating the history of their child or young person is something parent carers have to repeat, and can mean revisiting traumatic experiences; this is difficult
- It can leave parent carers feeling judged, that there is something they have done, and that practitioners are looking to blame them for their child or young person's needs
- Practitioners seeking information are not thought to be 'deliberately cruel', rather they do not always have awareness of the difficulty of relating these experiences
- When provision and transport is being organised for a child, parent carers should be consulted right from the beginning
- Communication depends on being willing to engage in lots of positive dialogue with parent carers who may have concerns, for example about the level of support for their child in school (which is sometimes justifiable) and in managing their expectations
- Parent carers want practitioners to be more human, honest, transparent and consistent in their communication
- Trust can be lost when a piece of work changes direction, and if the possibility of this happening is not discussed openly at the start and contingencies planned
- Practitioners in schools need to actively listen and try to understand, not defend
- There is still more work to do to make the Local Offer fully work for families and young people
- Some of the innovative tools and positive practice taking place in West Sussex has not been communicated consistently across all SEND areas, even within services (e.g. use of Wikis)
- Information is not always passed on where it needs to be
- Although email is a quick and efficient method of sharing information, there are confidentiality issues that can make it inappropriate
- In Health, there are logistical issues around using electronic techniques to gather responses from families about the service
WORK IN PARTNERSHIP

YOUNG PEOPLE: “...it feels like people with disabilities and issues can actually be heard again and not silenced by a bunch of people that don’t understand what people with disabilities can do ...”

PARENT CARERS: “...I sat down with the senior social worker and she said, ‘I don’t know about this...’ and she was quite human and we went through it together, and I thought ‘Oh, there is a future.’”

LA EDUCATION: “We work with the parents consistently and continually over the course of however long that child is with us ...”

CARE: “…this year’s Listening Event...focused on the young people and their PAs*... not just their views within their assessment and...personal budget, but actually get their view on how it works for them...”

HEALTH: “The Barnardo’s model is a very good model of working in partnership; they work with 16-25 year olds and are hosted by Sussex Community Foundation Trust;...”

*PAs – Personal Assistants

Going well

😊 Young people are beginning to trust that adults really want to work with them
😊 They believe that working together is important and that including them helps them feel empowered
😊 To truly work in partnership young people need to feel listened to
😊 There are some good examples of involving young people in processes that affect them, for example the one page profile, which is felt to be completely young person led, and young people are often involved in interview panels
😊 The Care Leaver’s Forum has a strong voice that feeds back into the service
😊 Parent carers feel that experiences are a journey that involves learning and partnership is experienced when it is recognised this is a learning journey for both parent carers and practitioners; it makes a difference when practitioners indicate it is something to be completed together
😊 Working in partnership with parent carers is more about listening than talking
😊 Some Early Years settings have opened their doors to partnership working, and trust, with services and schools
😊 School placements for children and young people are more effective if a variety of guidance from different teams is sought
😊 LA Education services perceive that parent carers should be key partners throughout a child or young person’s journey and there is commitment to ensuring everyone is involved equally
Parent carers are a key element when working in partnership at a strategic level and planning for this should incorporate their needs.

Partnership working with the Parent Carer Forum is strong.

Services and schools are being encouraged to work with each other as well as parent carers, and systems and processes are being promoted to support this; it is especially important during times of transition.

The Pathways to Adulthood Strategy supports young people into adulthood by involving all partners from an early stage.

The North Disability Teams’ Listening Event is a creative way of enabling young people with a range of needs, and the people around them, to raise issues concerning them and to have some impact on service delivery.

PEPs (Personal Education Plans) help people get together to hone in on the individual educational needs of children coming into the care system.

Adult Services invest in, and feel empowered by, the contribution of people with Asperger's in addressing the Autism Act.

It is felt that in Health opportunities for partnership are being actioned to maximise the best outcome for young people, for example through the collaborative approach being adopted by the 9 school nurses working in the County’s special schools, and the IPEH* Hub.

The positive working relationship between Health and Education is viewed to be very important.

Other examples of working in collaboration that contribute to young people reaching their potential are also cited, such as the Barnardo’s model.

* IPEH - Integrated Prevention and Earliest Help
Could be better

- Genuine co-production has to happen from the beginning; there is more to do here
- Everyone needs to have a clearer understanding of when co-production is necessary, and wanted
- Young people suggest that because of the world we live in, there is the need for continuous development
- They also ask that space needs to be created to celebrate the successes achieved from working together
- Parent carers explain that when practitioners do not know about their young person's need or 'condition', or want to learn about it by working with them, they try to find a different appropriate person, but the right support for their child or young person can be limited
- Parent carers are not necessarily given the central role to which they are entitled in contributing to decisions about their children's provision
- Practitioners indicate that it is sometimes difficult and time-consuming to find, and signpost, routes forward for parent carers and families because information is not always easy to find
- There can be tension between support and independence; making sure each child has the right level of support and working with parent carers on when the child or young person is ready to progress
- Services and schools need to develop a more consistent understanding of different experiences and perspectives; they could work with each other better to relate to parent carers, teachers in the classroom and other frontline staff so that relationships become stronger all round
- Work on transitions is ongoing; a Lifelong Service has been developed but the range of partners, and scale, can seem daunting, there is more to do, one strand at a time
- Better partnerships to support young people post 16 are being created but there has been a capacity issue, for example with EHCP*s going into adulthood
- There could be better collaborative working between some services, and consideration of the impact of the needs of one service on another, especially on front-line workers
- It is felt there have been missed opportunities for services in supporting individual voices to influence their wider context in a more collaborative way because roles entail considerable other pressures, some stemming from changes of direction and/or restructure, which can then lead to silo working
- Health services seem to be sometimes placed in the role of communication facilitator in the middle of a conflict of resources and priorities
## West Sussex Co-production Action Planning

(stars next to priorities agreed by the participants)

### Going well

- A passionate and active Parent Carer Forum ✫
- GP’s inclusive practice - Have a Go Awards ✫
- Early/Pre meetings with families with children going into preschool ✫
- Help and support for young people to build confidence
- Advocacy services for children in West Sussex
- Youth participation officer
- Drivers, escorts and their rapport with families and children
- An independent support service valued by families
- Good care and support after diagnosis

### Could be better

- Mental health/CAMHS* - waiting times, approach by staff ✫
- Developing Young Inspectors ✫
- Consistency: how welcoming? Schools/IPEH hubs/delivery point
- All GP practices inclusive: lack of consistency
- Keep going to hear young people from West Sussex at strategic level
- Transitions at all phase (ages)
- Listening events for Early Help
- Joining the dots between services
- Communication between services
- Transport imposed on family, no welcome and care through process of placement for young person; transport tagged on the end and excludes young person with ASC**
- Following up on important accessibility: equipment, do people know how to use it?

*CAMHS - Child and Adolescent Mental Health Services
**ASC - Autistic Spectrum Disorder

### Including young people in training

- Some mainstream school will give the help and support you need ✫
- Community nursing: teaching and upskilling practitioners to allow more inclusion/access
- Strategies to include all children to access local preschool/school
- Early identification and good EHCP work is good for families; it values and includes parents voice
- Some good Early Help plans
- PATHS, MAPS, WIKIS and training around person centred approach
- Index for Inclusion [pilot] and schools taking it up

### Local Offer not family friendly: some work with Forum but less with young people ✫
- Young people need to be more involved ✫
- Mainstream schools should more inclusive of young people with SEND ✫
- Everyone knowing about Index of Inclusion and difference it’s making for ALL
- Attachment awareness and training for schools ✫
- Post 16 and transition ✫
- Including young people in training
- If practitioners had time to develop and train and work together, that would be better (schools)
- Still feels to be distance between family and decision makers, and review process (EHCP)
### Going well

- Communication between parents and practitioners in Early Years settings
- Increased communication to families about transport families
- SENAT* during assessment (EHCNA**)
- Local Offer: a good example and passionately supported by West Sussex Parent Carer Forum (WSPCF) and Local Offer officer
- Social media use by WSPCF
- WIKIS
- Communication library: ‘Understand me’
- Disabled Children’s Partnership Board  
  *SENAT – Special Educational Needs Assessment Team  
  **EHCNA – Education, Health, Care Needs Assessment

### Could be better

- Getting the basics right
- Services communicating better between each other
- Disabled children’s Partnership board - but it’s not always joined up with Adult Services and other boards
- IT systems can be barrier
- Less emails, more personal contact
- More personal links in school
- ‘Joining the dots’: helping families know what is available for them
- EHCPS: who is doing what and when
- Local Offer: not enough use or awareness
- Awareness of Disability Register
- About what’s available post-16
- Lack of communication between transport and parents: all areas
- Children and young people are now being present but we need more progress
- Some services are listening and adapting: needs to be more openness to listen and respond
- Smarter communication

### Youth participation developing e.g. young people at events

- Co-production with Parent Carer Forum
- Parents and young people: opportunities to speak out at different training
- Asperger’s group: Adults
- Therapies in Schools partnerships
- Supported lodging placement for care leavers
- DofE* offer: partnerships with schools and DofE
- EHCPs work – PATHS
- Working well with schools and colleges
- Joint working: multi agency and parent carers/young people
  *Duke of Edinburgh Award scheme

### Partnership

- Commitment to co-production
- Accountability could be more robust
- Different definitions of ‘safe’ and ‘good’ (quality standards)
- Start earlier in process
- Co-production from very start of EHCP process
- Consistency across schools: EHCPs
- Accessibility of Local Offer and making it even more user friendly
- People knowing what they don’t know
- More of what works/awareness of what’s working well
- Moving from having young person officer at all school meetings, to having young person
- Joint working: multi agency and parent carers/young people
Summary of Strengths and Next Steps

Strengths

It is to be celebrated that West Sussex is enabling parent carers, young people and practitioners to continue strengthening relationships and communicate about co-production in open, honest and creative ways. A Framework for the Development and Sustainability of Co-Production in SEND, drawing upon the SE7 (pathfinder) good practice guide and suggested framework, was co-produced by West Sussex Parent Carer Forum and partners from the Local Authority and Health in February last year. A self-evaluation tool for strategic co-production is available for services and the VOICES event in March this year took place during a month of co-production activity.

This event has highlighted that an overarching strength for this large County Local Area is the willingness, commitment and aspiration of key partners to engage in meaningful co-production with parent carers and young people. The Parent Carer Forum is confident, skilled and pro-active, and highly valued within SEND strategy. Positive relationships exist between the Forum and current SEND leadership. In turn, the Forum has high expectations of partners when it comes to co-production.

West Sussex has also invested in the appointment of a SEND Youth Participation Officer, and worked with the Council of Disabled Children and In-Control Youth, and more recently Kids, to develop a SEND Youth Forum to enable young people’s co-production at a strategic level, as well as to introduce Young Inspectors. There is evidence of rich activity promoting person-centred planning, and Wikis are being used not only with some individual young people, but also teams.

The ethos that permeated the Voices event was one of warm and friendly relationships and positive engagement in joint activity and partnership working. The team felt this was reflective of some established practice as well as a cultural drive to sustain and build upon good foundations. Opportunities for further development are now being sought, which illustrates recognition that co-production is dynamic; necessarily an ongoing process.

The strong parent carer involvement in preparing for, and participating in, the VOICES event, together with the young people who contributed on the day and later that evening, will hopefully inspire attendees less confident in their understanding of co-production to reflect on what it really means to involve parent carers, children and young people of all ages in the decisions that affect them, at individual, service and strategic levels. Next steps should build on the wealth of good practice identified, which includes activities indicative of individuals and services journeying towards co-production as well as the commitment to this way of working advocated at a strategic level.
The VOICES team recommends that the strengths as well as areas for further development highlighted in this report support moving co-production even further forward in West Sussex, providing the opportunity for a process that enables priorities and actions to be devised, agreed and communicated in equal partnership with parent carers, children and young people.

Given the secure history of co-production in West Sussex, it might have been expected that a wealth of strengths would be described within the narratives voiced under each of the four Cornerstones. The VOICES team asks West Sussex to feel justifiably proud of its achievements, as there are many.

Here are some highlights:

✓ Across West Sussex value is given to working in co-production and listening to all voices
  o partnership working with the Parent Carer Forum is strong and the Forum has contributed pro-actively to workforce development in supporting practitioners to understand how to facilitate parent carer voice
  o parent carers and young people are seen as key elements when working in partnership at a strategic level; it is acknowledged there must be good planning to incorporate needs to ensure their equal involvement
  o young people are beginning to trust that adults really want to work with them
  o a Youth Participation worker has been appointed
  o there is commitment by individual services, and some services working together, to ensuring young people have a voice and that they are included and supported to do so
  o there is a positive working relationship between Health and Education services, and schools are being encouraged to work with each other; systems and processes are being promoted to support this
  o personalisation has been strong and there has been good use of person centred planning tools
  o it is felt the EHCP (Education, Health and Care Plan) process should feel positive for families and the work of SENAT (Special Educational Needs Assessment Team) has been praised
  o Adult Services invest in, and feel empowered by, the contribution of people with Asperger’s in addressing the Autism Act
✓ An inviting initial contact helps parent carers, and their children and young people, feel welcomed and accepted from the start
   o specific individuals play central roles for parent carers in helping them feel welcomed and cared for, projecting that the environment they represent is also welcoming
   o being able to interact with reception staff, and other practitioners who are non-judgemental, can be life-changing
   o their child or young person being included without needing a label is important in this
   o there is some good early identification of need
   o Local Authority (LA) Education services recognise that friendly introductions are important to everybody, reducing anxieties and strengthening relationships that develop; being a human face is encouraged
   o schools have a key role to play in ensuring that everyone is made to feel welcome; some mainstream schools are known for their good practice
   o the Index for Inclusion is being piloted in some schools
   o parent carers can find it difficult to manage the needs of the whole family when they have a child who requires additional support; some individual provisions are recognised as welcoming and caring because they take into account the rest of the family too
   o families appreciate drivers and escorts who develop good rapport with their children and young people, and themselves
   o NHS services in West Sussex try to ensure that everyone introduces themselves before treatment or care: ‘Hello my name is…’ and health practitioners work hard to make sure that families and young people feel comfortable when they are visiting
   o Some GP surgeries are recognised for their really inclusive practice

✓ Young people describe some of the adults working with them who make a positive difference to their lives
   o they are open, welcoming and approachable, which helps young people feel more relaxed and at ease
   o they consider how young people like to be acknowledged
   o they communicate and engage in activities in ways that help them feel comfortable
   o they show respect and understanding of their needs
o they adapt communication to suit individual needs and preferences, which helps young people feel supported.
o they make young people aware of the actions that have then been taken following their contributions.

✓ Young people are passionate about being involved in decision-making at all levels, and for spaces to be created within which their opinions and views can be safely shared.
o they believe working together is important and that including them at strategic meetings helps them feel empowered.
o they believe working in partnership is about listening.
o there are some good examples of involving young people in processes that affect them:
  ▪ young person-led one-page profile
  ▪ young people are often involved in interview panels
  ▪ the Care Leaver’s Forum has a strong voice that feeds back into the service
  ▪ they want to be involved in more training.

✓ Communication is key for parent carers, and children and young people, who value being encouraged to voice their opinions, and through being heard feel valued.
o communication with young people should be personalised.
o parent carers appreciate it when practitioners take the time to ‘sit down’ with them.
o they have valued increased communication about transport.
o like young people, parent carers feel that working in partnership is more about listening than talking.
o key points of contact need to stay the same when possible.
o the most effective communication is to reflect an honest position.
o young people often find the internet to be the most positive and accessible source of information.
o the constructive use of social media by the Parent Carer Forum is appreciated.
o there is ongoing work taking place to refresh the Local Offer in response to feedback, and there are individuals who have responsibility for overseeing and updating it; it is supported by the Parent Carer Forum.
 Wikis are being successfully used for teams (e.g. The Choice Team) as well as individual children and young people

  - 'Understand Me' – the communication library is innovative and inclusive
  - in Health different options for communication are carefully considered (e.g. text, phone call) to ensure they are the most appropriate for the occasion and the individual

When practitioners recognise that SEND experiences are a journey that involves learning and partnership for both parent carers and practitioners, something to be completed together, it makes a difference

  - some parent carers talk about experiencing good care and support following diagnosis
  - SENDIASS (Special Educational Needs Independent Advice and Support Service) is appreciated by families

When parent carers are actively involved in planning individual futures that are realistic for their children and young people it enables them to feel valued and cared for

  - this includes involving parent carers in the creation of interventions and plans

Co-production is considered to be a central aspect of work in Early Years, and that involving parents from the start and throughout their journey gives families and children the best opportunities

  - teams feel they work hard to ensure that families are given a warm welcome and that they have access to advice whenever they need it
  - it is perceived that higher Early Years staffing ratios are beneficial to the outcomes of the children
  - some settings have opened their doors to partnership working, and greater trust, with services and schools
  - families value meetings to plan and support their child’s transition to pre-school

Feedback is regularly sought to inform Local Area and service development, and several Education, Care and Health services have developed creative strategies and techniques to make tools more meaningful and accessible
there have been some innovative pieces of work commissioned involving young people with disabilities communicating key experiences, for example what happens in a Social Care assessment, to help prepare other young people for the same experience

the North Disability Teams’ Listening Event enables young people with a range of needs, and the people around them, to raise issues concerning them and to have some impact on service delivery

Words and Pictures and a variety of creative strategies are being used by Early Help practitioners to support families and their children to have a voice in order to make Early Help plans more meaningful

My Plan is being implemented by the Choice Team and is viewed positively

there is now a Survey Monkey version of NHS patient questionnaire

the Lifelong Service has been working on Signs of Safety mapping with families in order to create differentiated tools that are easier to access, more child-focused and a more positive experience for children and young people with SEND

when Short Breaks contracts with the Local Authority are up for renewal parent carers are asked for feedback; this information is used to make sure provision is fit for purpose

When there is a genuinely collaborative approach across Education, Health and Care services it brings better outcomes

there is a Disabled Children’s Partnership Board

school placements for children and young people are felt to be more effective when guidance from different teams is sought

the Intensive Planning Team works with schools, services and families to look for solutions that keep young people in West Sussex, even when placements are becoming problematic

collaboration is especially important during times of transition; strategies are being put in place to support all children to access their local preschool or school

therapy services in schools are developing

nine school nurses work across the County’s special schools and have been upskilling practitioners to include children and young people with medical needs and ensure their environment is accessible

the Integrated Prevention and Earliest Help Hub (IPEH) is starting to work effectively
the e-PEP system enables a more holistic approach to supporting children who are Looked After, helping people get together to hone in on the individual educational needs of children coming into the care system.

- It is recognised that supporting and empowering specific groups can be important in enabling relationships, confidence and voice.
  - in Health, strategies have been put in place by the Family Nurse Partnership to support particular groups of people with additional needs, for example young parent carers with learning difficulties.
  - there is an active group for adults with Asperger's Syndrome.
  - there are good Advocacy services for children who are Looked After.

Next Steps

The narratives in this document outline specific areas for development under each of the Four Cornerstones. There is evidence that not everybody is at the same level in respect of understanding, and committing to, co-production. Young people seem impatient to be involved alongside adults in meetings that are about young people's issues and, as described above, parent carers, especially those actively involved in the Parent Carer Forum, expect by now to experience genuine co-production when they engage with Local Area partners at individual, service and strategic levels. However, the VOICES event indicated that some individuals, areas and services may need further support to achieve the same level of understanding, and for this to make a more tangible difference to practice.

Despite the Framework and self-evaluation document, participation and consultation are sometimes referred to as good examples of co-production, suggesting the need for more workforce development as well as opportunities for joint activities that will enable ownership and a more consistent commitment. Schools were not well represented at the VOICES event, although there were some positive examples of good practice cited. There were signs this is inconsistent across the County, however, and that engaging more schools and settings in the agenda at all levels would be beneficial for children and young people with SEND, and their families.

Another narrative emerging through the VOICES event was the impact on experience of restructuring within the County. It is perceived this has led to tension between some teams, and stress for individuals, especially frontline workers. It may have also put a strain on opportunities for joint working, and affected communications. A few practitioners talked about not feeling valued, and others were unaware of examples of co-productive good practice occurring within their own area. These issues have impacted on some attitudes, in that several practitioners talked about having to focus
more on surviving the demands of their role during these times of change, acknowledging the resultant increase in silo-working.

The narratives heard, therefore, generated some potential areas for development that could also be used as a platform for next steps:

- **Genuine co-production** has to happen from the beginning; there is more to do
  - to get the basics right
  - openness and listening could be better; more consistent
  - everyone needs to have a clearer commitment to, and understanding of, co-production, including when it is necessary, and wanted
  - services (including the IPEH Hub and Health services such as GP surgeries), and schools, need to develop a more consistent, welcoming approach and understanding of different experiences and perspectives
  - they could work with each other, young people and parent carers better so that positive relationships become stronger all round
  - accountability for co-production could be more robust
  - trust can be lost when a piece of work changes direction, and if the possibility of this happening is not discussed openly at the start and contingencies planned
  - when trust is lost it must be recognised and addressed supportively
  - there is not always enough value placed on the time parent carers and young people give to co-production; it can be taken for granted
  - parent carers also suggest that positive examples might be used to demonstrate to others how to help them feel welcomed and cared for
  - young people suggest that because of the world we live in, there is the need for continuous development
  - it is not all about outcomes; dialogue to review practice should be ongoing
  - they also ask that space be created to celebrate the successes achieved from working together
  - and examples of good practice in schools need to be shared
  - currently some of innovative tools and positive practice taking place in West Sussex have not been communicated consistently across and within all SEND areas

- **Young people feel** that individualised, approachable attitudes need to be displayed by all practitioners, not just those who choose to be approachable
  - they want to feel they can be themselves without being judged
o a personalised approach is required to ensure every child’s voice is heard within a classroom

- Young people believe they should have the opportunity to talk to people who are able to make decisions, and not always rely on the ‘middle man’
  o meetings therefore need to be adapted to make them accessible for young people
  o the development of the Young Inspectors programme is viewed as important
  o there should be a desire to move from having a Young Person’s officer at all school meetings, to having the young person

- Some tools and processes require further development to be effective and inclusive
  o the young people’s Chat Health help line, which allows young people to text if they are embarrassed to ask questions, is not yet inclusive for all users
  o how young people contribute to their EHCP could also be more developed
  o it is questioned whether there is enough follow-up on accessibility equipment, and whether people know how to use it

- Parent carers are not always given a central role in contributing to decisions about their child’s provision and transport
  o it is perceived that decisions can be imposed
  o some children are excluded from access dependent on their needs
  o and there is still felt by some to be a distance between family and decision makers, especially in the EHCP and review process

- Engaging with a new person or service continues to creates anxiety for parent carers because of uncertainty about how the practitioner(s) will respond and the level of support available
  o small comments have a big impact on parent carers as to whether or not they experience a sense of battling; reference has been made to waiting times for CAMHS (Child and Adolescent Mental Health Services) and the approach by some staff
  o positive experiences seem to be left to chance, and relate to individuals or ‘pockets’ of good practice, rather than something purposefully built into services and provisions
  o parent carers explain that when practitioners do not know about their young person’s need or ‘condition’, or want to learn about it by working with them, they try to find a different appropriate person, but the right support for their child or young person can be limited
  o the impression of being thrown ‘back out’ by services gives parent carers a sense of having to start again in their journey to find support for their
child or young person, leading them to feel that they are not cared for despite often already difficult circumstances

- the size of the Local Area is perceived by some parent carers to be an excuse for some of the difficulties experienced by practitioners, and therefore also parent carers, children and young people; it seems to have become a potential limiting factor in practitioner confidence to make improvements which is then conveyed to parent carers

- There is general agreement there is more to do to improve communication, which can have a significant impact on experience, relationships and wellbeing
  - young people suggest social media could be used more widely to reach out and engage them in communication; initiatives are taking place to look at this
  - there is still more work to do to make the Local Offer fully work for families and young people
  - some parent carers feel there is an absence of practitioners guiding or signposting them to the right support, so they have to be determined in researching and sourcing their own; they need to know what is available to them
  - practitioners indicate that it is sometimes difficult and time-consuming to find and signpost routes forward for parent carers and families, because information is not always easy to find
  - parent carers want practitioners to be more human, honest, transparent and consistent in their communication
  - there has to be more willingness to engage from the start in lots of positive dialogue with parent carers who may have concerns, for example about the level of support for their child in school (which is sometimes justifiable), and about transport, managing their expectations and anxieties supportively
  - practitioners in schools need to actively listen and try to understand, not defend
  - it is felt by some that information is not always passed on when it needs to be
  - there could be greater awareness of the Disability Register
  - communicating the history of their child or young person is something parent carers still have to repeat, and can mean revisiting traumatic experiences; this is difficult and can leave parent carers feeling judged, that there is something they have done, and that practitioners are looking to blame them for their child or young person's needs
- Parent carers do not think practitioners are being 'deliberately cruel', rather that they do not always have awareness of the impact for parent carers of relating these experiences; there is a need to further training
- An Early Help Listening Event has been suggested
- There need to be fewer emails and more personal contact
- Although email is a quick and efficient method of sharing information, there are also confidentiality concerns that can make it inappropriate
- In Health, there are logistical issues around using electronic techniques to gather responses from families about the service
- Some feel that communication could be smarter

- It is indicated that welcoming, inclusive practice in schools can be inconsistent
  - There is tendency to concentrate time and resources on higher needs children and young people, which can impact on resources for inclusion; there is agreement that practice needs to be more consistent so that children and young people with all levels of need, and their parent carers, are supported
  - Some schools are more successful at being inclusive than others, which puts pressure on schools that are inclusive, and LA transport
  - It is suggested the Index for Inclusion should be extended to all schools
  - Sometimes schools children move on to from Early Years settings do not assist with transition as much as they could
  - Perceived capacity issues mean 1-1 support cannot be guaranteed and this has created tensions with some parent carers
  - There is considerable pressure on special school places, leading to resources being spent on out of County places
  - Young people say they want all the staff in a setting to respond to new initiatives and changes
  - It is indicated there is a need for attachment training in all schools

- There is considerable anxiety around the transition to adulthood
  - There can be tension between support and independence and making sure each child or young person has the right level of support; this involves working closely with parent carers and child or young person in deciding when they are ready to progress
  - It is thought there could be better educational provision for the 19-25 age group
work on transitions is ongoing: a Lifelong Service has been developed but the range of partners, and scale, can seem daunting, there is more to do, one strand at a time
better partnerships to support young people post 16 are being created but there has been a capacity issue, for example with EHCPs going into adulthood
there is concern for the wellbeing of care leavers at the age of eighteen 'cliff-edge': should services be extended to 25?

Restructuring, service boundaries and pressures have led to less collaboration in some respects, and more silo-working
- the Disabled Children's Partnership Board is not always joined up with Adult Services and other Boards
- there could be better consideration of the impact of changes in one service affecting another, especially how this might affect front-line workers
- there have been missed opportunities for services in supporting individual voices to influence their wider context in a more collaborative way because roles entail considerable other pressures, some stemming from changes of direction and/or restructure
- as a result there is some silo working
- different IT systems can be a barrier
- it would be helpful to families, young people and practitioners to know better who is doing what and when during the EHCP process
- some Health practitioners perceive they can be placed in the role of communication facilitator in the middle of a conflict of resources and priorities
- it is felt it would be helpful if practitioners from services and schools had more time to develop, train and work together

Further work will be needed in West Sussex around the Four Cornerstones to make sure everyone's voice is heard and fairly represented in order to provide a truly comprehensive picture that will contribute to a VOICES action plan. Building on the West Sussex tradition of co-production, a key aspect of this work will be involving key partners in further discussions about which of the above are the priority areas, how best they might be approached, and how this is to be communicated to all groups. Enabling and prioritising the voice of parent carers and young people in these discussions will be an essential consideration.
Genuine Partnerships team in partnership with Contact,
members of VOICES: National Alliance for Partnership Working
29th March 2018