### Joint commissioning bulletin

Promoting personalisation and access to personal budgets

### 1. Introduction

### 1.1 Introduction to the Joint Commissioning Bulletin

The Council for Disabled Children regularly receives questions from SEND Regional Leads and delegates from the regional SEND workshops on a whole series of issues relating to the SEND reforms and joint commissioning. The joint commissioning bulletins are designed to share the learning from those discussions to a broader audience.

# 2. What do we mean by the term "personalisation" and how can we promote it?

### 2.1 What do we mean by personalisation?

### Think Local Act Personal defines personalisation as:

'A way of thinking about care and support services that puts you at the centre of the process of working out what your needs are, choosing what support you need and having control over your life'.

Promoting personalisation in health, education and social care is at the heart of the government's transformation programme to improve the quality and effectiveness of services and the experience of individuals who use them. It is a key part of the government's SEND reforms and its approach to promoting early intervention and prevention through Early Help.





#### 2.2 Where do we start?

Figure 1: Ladder of engagement and participation

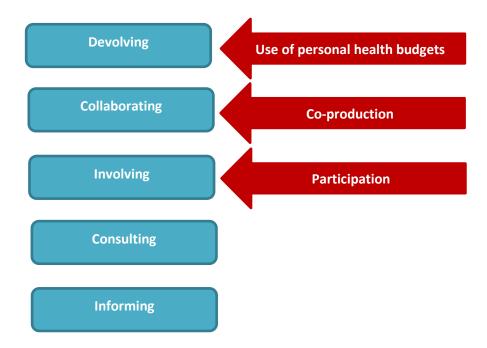


Figure 1 above shows the ladder of engagement and participation that is based on the work of Arnstein's Ladder of Citizen Participation<sup>1</sup>. It recognises that there is a hierarchy of engagement with informing at the bottom and devolving at the top. As you progress up the ladder the power relationships between the professional / commissioner and the individual begin to change, with the individual being empowered to have a greater say on key issues that are affecting them, or about how services are commissioned in the future.

Promoting personalisation starts with commissioners and providers of services having an honest discussion with children, young people, young adults, parent carers and their staff about where they think their organisation is on the ladder of engagement and participation and what may need to change.

# 2.3 Promoting personalisation through an effective approach to coproduction

#### The SE7 SEND Pathfinder defined coproduction as:

Co-production is about trust and builds upon transparency, open communication and equal value being given to each participant's contribution. Co-production happens when all team members together agree outcomes, co-produce recommendations, plans, actions and materials as a collective. It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing<sup>2</sup>.

<sup>1</sup> Arnstein, Sherry R. "A Ladder of Citizen Participation", JAIP, Vol. 35, No.4 July 1969 pp 216-224.
2 Brittan C. & Taylor J. (2013) Co-production with parent carers: the SE7 experience, Mott MacDonald & SE7 SEND Pathfinder

Co-production changes the power relationship between professionals/ commissioners and members of the public, where professionals/ commissioners value and acknowledge that children, young people and parent carers are experts by experience and should have an equal role in any assessment and support planning process or in the process of understanding local need and developing innovative solutions to address them.

The SEND Parent Carer Forums have played a leading role in championing the co-production of parent carers within local areas and there is a growing evidence base that even though co-production is more resource and time intensive, it plays a key role in promoting transformational change. Many local authorities and CCGs have promoted the co-production of children and young people and parent carers in the review and development of their SEND Local Offer and SEND Strategies.

NHS England regards promoting strong and effective participation and coproduction and bold and brave clinical leadership as the two foundational principles for delivering transformational change. See web-link below for more information.

## Commissioning for effective service transformation: What we have learnt

https://www.england.nhs.uk/wp-content/uploads/2014/03/serv-trans-quide.pdf

The findings from the Ofsted/CQC's Local Area inspections has also evidenced that progress has been made in promoting the co-production of parent carers in the assessment and planning process leading to the creation of EHC plans, as well as progress in involving children, young people and parent carers strategically. In Stoke-on-Trent Ofsted/CQC outcome letter notes that:

- The parents' forum is involved at a strategic level in implementing the reforms. This group seeks the opinions of a wide range of parents and uses this valuable information to help to improve the provision in the local area.
- There are positive examples of co-production, where parents, children and young people and professionals work together to decide how to meet the needs of individuals. Parents value many aspects of the support that they receive.

Further examples highlighted within the joint inspection outcome letters can be seen in **Appendix 1** $^3$ .

<sup>3</sup> It's important to note that whilst the examples in Appendix 1 were highlighted as strengths within the joint inspection outcome letters, they do not necessarily reflect the entire report for each area, where provision, outcomes and quality of services vary.

However, in some areas there is more that needs to be done to promote the effective co-production of children, young people and young adults in the development and review of EHC plans.

### 2.4 Promoting personalisation through using I Statements

### My Life My Support, My Choice

Think Local Act Personal and National Voices developed the I Statements which are set out in My Life, My Support, My Choice

http://www.nationalvoices.org.uk/sites/default/files/public/publications/my-life-my-support-my-choice.pdf

The regional workshops have both promoted the use of the I statements for children and young people with complex lives and have heard how they are being used to promote personalisation. I Statements have been used by local authorities and CCGs in the following ways:

- To support co-production events in identifying the outcomes that are significant and meaningful for children, young people, parent carers and professionals for a new strategy or integrated pathway.
- To support co-production events in identifying the core principles to promote personalisation within a new integrated pathway / model of care.
- To inform questionaires and audits on the SEND Local Offer.
- To inform questionaires to create a baseline on how children, young people and parent carers are experiencing the SEND reforms in their areas.
- To develop quality indicators in new outcome based service specifications.
- To inform co-production events and strategic planning linked to reviewing and updating the local SEND strategy.

At a recent workshop in Wolverhampton, there was a discussion around how the I statements could also inform the development of quality indicators for a multi-agency SEND dashboard.

### 2.5 Promoting personalisation through patient activation

## Supporting people to manage their health: An introduction to patient activation

https://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf

Patient activation is a widely used concept. It describes the knowledge, skills and confidence an individual has in managing their own health and healthcare<sup>4</sup>. Patient activation as an approach has been developed in the US and used successfully to support health professionals to effectively tailor their interventions around the needs of the individual. It recognises that children, young people and parent carers will have varying degrees of knowledge, skills and confidence in being able to navigate the system, be an effective advocate, and manage their own health and wellbeing and the support that is available to them across health, education and social care. The Council for Disabled Children's *Expert Parent Programme* is a really good example where trained parents deliver the Expert Parent Programme to other parents to improve their skills, knowledge and confidence in getting the most out of their engagement with health professionals, being an effective advocate for their child and understanding how to navigate the health system.

CCGs in Peterborough have commissioned their Parent Carer Forum to deliver the Expert Parent Programme for those parents whose children are on the CAMHS waiting list.

CCGs in Kent have commissioned delivery of the Expert Parent Programme to 178 parents of children with SEND. The feedback from parents was that the Expert Parent Programme had a significant impact in:

- Improving parents' knowledge in navigating the health system, section
- 19 principles, their rights, person centred planning and what was available locally.
- Improving parents' skills in engaging with professionals, acting as experts by experience and getting the best outcomes for their child.
- Improving parents' confidence in being an effective advocate for their child and celebrating their child's strengths and abilities.
- Building parents' resilience and reducing a sense of isolation.

The Kings Fund Report Supporting people to manage their health: An introduction to patient activation identified above, has been used by NHS England as the evidence base to support the role out of Patient Activation

<sup>4</sup> Hibbard J. & Gilburt H. (2014) Supporting people to manage their health. An introduction to patient activation Kings Fund

Measures through the Integrated Personalised Commissioning Programme. There is certainly an opportunity for Integrated Personal Commissioning early adopter sites and other areas to explore how patient activation can be used to enhance personalisation within the SEND reforms, the CAMHS transformation programme and the Transforming Care Programme. A Patient Activation Measure creates a score that falls into one of four categories. Someone with a low activation score will lack the knowledge, skills and confidence to manage their health and healthcare. Someone with a high activation score will be highly motivated, empowered and skilled in working in partnership with professionals; will be aware what is available and how to access it. They will be confident in taking forward key aspects of a person centred plan.

LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4
Predisposed to be passive	Building knowledge and confidence	Taking action	Maintaining behaviors, pushing further
Patients lack the confidence to play an active role in their health.	Patients have some knowledge but large gaps remain. They can set simple goals.	Patients have the key facts and are building skills. They are goal-oriented.	Patients have adopted new behaviors but may struggle in times of stress or change. Healthy lifestyle is a key focus.  1'm my own advocate.'
'My doctor is in charge of my health.'	'I could be doing more.'	'I'm part of my health- care team.'	
10-15%	20-25%	25-30%	20-25%

Understanding the activation levels of parent carers and children and young people can be very helpful when considering how to promote personalisation for those eligible for SEN Support, Early Help or an Education Health and Care plan. It also helps professionals consider how they can best support a child and family. The research suggests that child or parent carer who has a low activation level may well benefit from a coaching approach to enable them to develop the knowledge, skills and confidence required to manage their own health and wellbeing and the support that could be available to them.

# 3. Strategic approach to promoting personalisation and access to personal budgets

# 3.1 Developing a strategic approach to personalisation and the roll out of personal budgets

It is recommended that local authorities and CCGs work collaboratively to develop a multi-agency strategic approach to promoting personalisation and the roll out of personal budgets over a 3-4 year period. To enable systems to

be developed and expanded and contracts amended. At a high level this could be described through the Sustainability and Transformation Plan or Health and Wellbeing Strategy and then described in more detail in the following:

- SEND Strategy and SEND Local Offer
- Early Help strategy
- CAMHS Transformation Plan
- Transforming Care Plan
- Autism Strategy (adults)
- CCG Operating Plan

It is recommended that the strategic approach to personalisation and the roll out of personal budgets is considered within the context of:

- People children, young people and parent carers who will benefit from this approach
- Workforce those will be tasked with delivering the transformational change
- Organisation the policies, procedures and governance structures that need to be put in place to achieve the transformational change

Local areas may also want to consider a strategic approach to implementing the Integrated Personal Commissioning Programme's emerging framework based on the five key shifts:

- a) Proactive co-ordination of care
- b) Community capacity and peer support
- c) Personalised care and support planning
- d) Choice and control
- e) Personalised commissioning and payment

For more information on this and other resources from the Integrated Personal Commissioning programme please go to the website below:

### **Integrated Personal Commissioning Programme**

https://www.england.nhs.uk/commissioning/ipc/

KIDS, through its DfE funded Making it Personal Programme developed a series of resources for commissioners, providers, families and family information services on promoting personalisation and the roll out of personal budgets. It is recommended that commissioners, providers and parent carers refer to these resources to inform local discussions on developing a local strategic

approach to promoting personalisation and the roll out of personal budgets. The resources can be found at the following web-link:

### **Making it Personal 2 resources**

https://www.kids.org.uk/mip2

# 3.2 Key learning points from the regional workshops and discussions with commissioners, providers and parent carers

### a) Graduated pathway of Early Help and Support

A number of local authorities and CCGs have expressed an interest in developing a graduated pathway of Early Help and Support similar to the one created by Gloucestershire County Council – see web-link below:

### **Gloucestershire's Graduated Pathway of Early Help and Support**

http://www.glosfamiliesdirectory.org.uk/kb5/gloucs/glosfamilies/family.page?familychannel=2

Gloucestershire County Council and their partners have worked collaboratively to bring together the assessment, planning and support processes of Early Help, SEN Support and the specialist support required through an EHC plan into a single personalised integrated process based on 7 stages. This also includes the offer of a personal budget for those who are eligible for an EHC plan. This is a good example of how children, young people and families are encouraged to access the services that are available to them through the SEND Local Offer and then if there is a need for additional help and support this is undertaken through a single personalised assessment and planning process.

### b) Workforce training and development

When implementing a strategic approach to promoting personalisation and the roll out of personal budgets, it is essential that time and resources are identified to deliver the workforce training and development that are required to successfully implement it.

The workforce training and development programme needs to consider the skills, knowledge and capabilities required to implement:

- A locally identified personalised care and support planning process, including the creation of a "my profile" and the measurable outcomes that will be used in the plan.
- Local policies and procedures for identifying the indicative budget.

- Local governance processes for agreeing the plan and the personal budget.
- Local financial governance processes for issuing a personal budget and monitoring how the money is being spent.

Local workforce training and development programmes may also require providers of services to consider how their services need to change to accommodate the choices of children, young people and parent carers who are commissioning their services via a personal budget.

### c) Market development

One of the challenges to the roll out of personal budgets has been that the provider market is not sufficiently developed in some areas to provide the choice and control that children, young people and their families want. Therefore, it is recommended that commissioners work collaboratively with children, young people and parent carers to develop a market position statement that describes how the market will need to change to deliver the new strategic approach to promoting personalisation and the roll out of personal budgets. For more information on market position statements see the web-links below:

### Think Local Act Personal resources on developing Market Position Statements

http://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/commissioning-market-shaping/In-more-detail/Market-Position-Statements/

### **Information and resources from Oxford Brooks University**

https://ipc.brookes.ac.uk/what-we-do/market-shaping/market-position-statements.html

However, a key starting point may be to look at how existing providers of health, education and social care services can be incentivised to deliver personalisation and the SEND Local Offer through existing contracts. For NHS providers this could be through agreeing a contract variation or to undertake a service improvement project within the Service Development and Improvement Plan (SDIP) part of the NHS contract.

# d) Create a ring fenced budget for personal budgets through top slicing funding from existing budget lines and block contracts

Personal budgets do not create new funding streams within education, health and social care, but provide a mechanism for enabling children, young people and parent carers to have increased choice and control over an agreed amount of money that is already in the system. Local authorities and CCGs have implemented a number of quick wins to increase the scope and availability of personal budgets. These have included the following:

- Children's continuing care packages
- Short breaks
- Wheelchair vouchers and access to community equipment
- SEN transport and travel training

However, to offer personal budgets at the scale envisaged through the Integrated Personal Commissioning (IPC) programme will require a different approach. This will require commissioners to work with their providers to unblock existing block contracts and consider top slicing a percentage of the existing contract value to fund a ring fenced budget for personal budgets. This is also recommended in the Integrated Personal Commissioning Programme's emerging framework (see web-link below). In addition, the IPC emerging framework recommends commissioners work with providers to:

- Move away from block contracts
- Unbundle existing tariffs
- Set local unit costs

This will take time for different population groups. It is therefore recommended that the strategic approach to promoting personalisation and the roll out of personal budgets identifies a robust implementation plan that is agreed with existing providers. This will help to ensure that there is sufficient capacity in the system to deliver the changes that are required.

## **Integrated Personal Commissioning programme emerging framework**

https://www.england.nhs.uk/healthbudgets/wp-content/uploads/sites/26/2016/05/ipc-emerging-framework.pdf

### e) Planning for implementation

It is recommended that local areas consider the following when planning their roll out of personal budgets to a broader group of children, young people and their parent carers:

- Is there an opportunity to create a Section 75 agreement and a lead agency for overseeing the governance process of issuing and reviewing personal budgets across health, education and social care?
- How will existing contracts with organisations offering brokerage and support planning need to be amended to accommodate the expected increase in activity? How will this be jointly commissioned?
- Is there an opportunity of using a payment card method to improve flexibility and financial accountability of the funding delegated to an

individual through a personal budget?

- What additional staffing resources are required within commissioning organisations/the lead agencies' finance departments to process the increased number of personal budgets?
- How will the new policies and procedures be communicated to staff, children, young people and parent carers?
- How will approval and sign off processes need to change to deal with the expected increase in the number of personal budgets being issued?

### 4. Useful References

A co-production model: Five values and seven steps to make this happen in reality

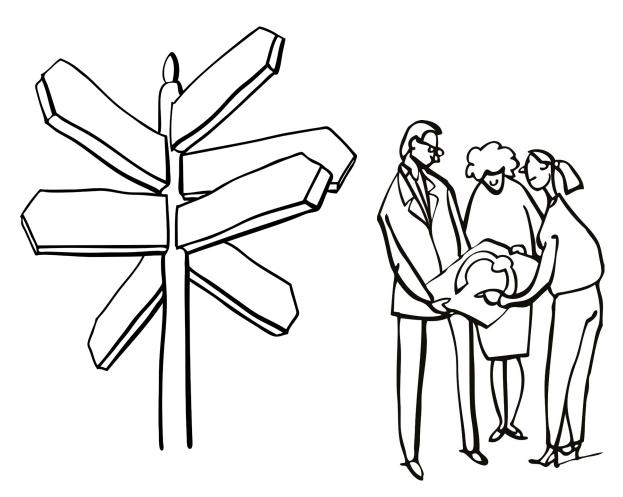
http://coalitionforcollaborativecare.org.uk/wp-content/uploads/2016/07/C4CC-Co-production-Model.pdf

SEND Code of Practice

https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

NHS England site on Personal Health Budgets

https://www.england.nhs.uk/healthbudgets/



### Appendix 1

Strengths in co-production and involvement of children and young people, parents and carers – as identified with the Ofsted/CQC joint inspection outcome letters

#### **Established**

<u>Brighton and Hove</u> – co-production, where services and families work together to review and plan provision, is well embedded and co-production of individual EHC plans is very effective. Children, young people and parents attend local area planning meetings and have a clear voice.

Stoke-on-Trent – the views of parents and carers are gathered routinely and used well to inform strategic planning and the assessment of children and young people's individual needs. Strong support from the advocacy service, the SEN and Disability Information, Advice and Support Service and the parents' forum/local parents' groups helps this process. The views of parents are responded to more effectively since the reforms were introduced and co-production is improving.

### **Developing**

<u>Bolton</u> – the views of parents and carers are taken into account in the early identification of need, special educational needs support and the development and co-production of EHC plans. The vast majority of parents felt their views and those of their children were listened to and that their children's needs were identified well. But the local area has not done enough to ensure parents, carers and children and young people are aware of the role they could play in helping to shape the Local Offer.

<u>Enfield</u> – representatives from parent/carer forums are actively engaged in improving the Local Offer. The Independent Advice and Support Service (the term which inspectors us to describe the SEN and Disability Information, Advice and Support Service) and Our Voice forum are effectively supporting activity.

Gloucestershire – effective co-production of EHC plans is a characteristic of the local area's work. The Ambassadors group of young adults, which meets leaders regularly, is highly effective at influencing and developing local provision made by colleges and employers. Some parents felt their views were not being sufficiently taken into account, for example in relation to school placements, and described their frustration at having to fight for a joined up approach involving education, health and social care.

Hertfordshire – over the past year parents have been well represented at meetings with senior leaders about improving services but their views are not being used sufficiently. Participation and challenge by children and young people, such as the 16 paid commissioners, help to maintain a strong focus on what matters most to users of services and their suggestions make a difference. Many parents don't know about the Local Offer and parents don't appear to have been involved in its development. Communication between professionals and parents is not as good as it should be. Parents are not convinced that the reforms have improved services and are very frustrated about the quality of information and guidance and the timeliness of responses to their concerns.

<u>North Yorkshire</u> – co-production of EHC plans with parents, children and young people is strong but it is less well developed in respect of commissioning new services or reviewing existing ones, particularly in health and social care. However, young people meet council officers to successfully help shape future provision.

Rochdale – there is some evidence of involving parents, carers and young people in the development and redesign of services (for example, emotional and mental health services for young people). But the local area does not have a thorough understanding of the views of parents in respect of their child or young person's special educational needs and/or disabilities. Co-production at strategic level is developing well; the parent carer forum is firmly established as a partner and has been instrumental in positive changes.

<u>Plymouth</u> – an active young people's forum is working with commissioners to inform planning and development of services. Parents and carers were involved initially in developing the local offer and local provision but the original parent carer forum was dissolved and arrangements for the new one are currently a focus for development.

<u>Derbyshire</u> - stakeholders from across the local area, including children, young people and parents and carers, are well represented and their voices are listened to. Their views are taken into account at a strategic level and to a lesser extent at an operational level (engagement in EHC plans is cited as effective where a SEND officer or facilitator is allocated to the family). However, the further away children, young people, parents, carers and local area staff are located from key partners, the less informed and engaged they are.





### **About the Council for Disabled Children**

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC Council is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provide a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Independent Support
- Making Ourselves Heard
- Special Educational Consortium

### **About NEL Healthcare Consulting**

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Our clients range from CCGs, local authorities and STPs to NHS England, specialised commissioners, voluntary sector organisations, mental health trusts and providers. Our consultants are experts in delivering, supporting and advising complex programmes with different partners and stakeholders across multiple organisations.

Our consultants' expertise includes strategic service review and service reconfiguration planning and delivery, option appraisal, business case development, activity and capacity modelling, impact assessment, management of independent review panel processes and implementation planning and delivery.

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