

National Commissioning Board Wales

**Good Practice Guidance for Regional Partnership Boards on
the Integrated Commissioning of Services for Families,
Children and Young People with complex needs.**

September 2018



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1 Introduction

This guidance is the first produced by the National Commissioning Board in Wales targeted at Children's Commissioning. The focus of the guidance is in recognition of the increasing challenges facing public sector commissioners of children's services at the highest end of the continuum of need. This is where an integrated approach from partner agencies is essential to successfully negotiate a path through the potential barriers and complexities of creating a cohesive child centred package of care and support that delivers positive outcomes for the child / young person and their family.

The unique and specific legislative framework in Wales provides some real opportunities to achieve truly integrated approaches to commissioning and service delivery across a regional footprint. The Social Services & Well-being (Wales) Act 2014, the Additional Learning Needs and Educational Tribunal (Wales) Act 2018 and their accompanying codes of practice facilitate integrated approaches between agencies to respond to the needs of children, young people and their families. The Welsh Government's forthcoming review of continuing care for children and young people offers the opportunity to consolidate these positive developments.

1.1 Who the guidance is for and what it aims to do

The intended audience for the guidance are Children's Services Commissioners, Local Health Board Commissioners, CAMHS Commissioners, Local Education Authority Commissioners, other service delivery partners (such as youth offending teams) and specifically Regional Partnership Boards in Wales.

The guidance is designed to assist the seven Regional Partnership Boards in Wales to develop an integrated approach to the commissioning of services for children and young people with complex needs. Section 13 of Part 9 of the statutory guidance for partnership arrangements under the Social Services & Wellbeing (Wales) Act 2014 requires local authorities and local health boards to establish regional partnership boards, based upon the local health board footprint, to manage and develop services and to secure strategic planning and partnership working to ensure that an appropriate range of services are in place to meet the needs of their respective population. Section 17 states that "Regional Partnership Boards will need to ensure that all partners work effectively together to improve outcomes for people in their region. They will need to ensure that services and resources are used in the most effective and efficient way to enable this."

Regional Partnership Boards have arguably been heavily adult care focussed. There is a need to rebalance this focus and to tackle the children's agenda. The guidance requires Regional Partnership Boards to prioritise the integration of services in relation to children with complex needs due to disability or illness. This guidance is designed to support Regional Partnership Boards with this work.

With writing any guidance there is the challenge of producing a balanced document that discusses the underpinning principles, offers a structured framework to approach challenges and will be a useful tool for implementing changes in practice. When producing this guidance, we are mindful that it in itself, cannot be a solution to the challenges of integrated commissioning in Children's Services, but the hope is that it sets out a clear approach that can be taken forward by the Regional Partnership Boards to implement change. The challenge in terms of developing this guidance and the much greater challenge for Regional Partnership Boards in terms of service delivery is the diverse range of needs involved. This will range from those of individuals with a severe physical impairment (requiring a complex range of services (adaptations, community equipment, communication equipment, wheelchair including personal care) which require effective coordination; to those with palliative care needs, to those with emotional and behavioural problems together with many others with special needs. The challenge for Regional Partnership Boards is to develop an integrated approach to responding to such a diverse range of needs involving so many professionals and services. For children / young people and parents an integrated approach is essential.

The Appendix to the guidance (toolkit) provides practical tools that can be used to health check where you are in your region and consider the next steps required to implement changes that can deliver best practice. For each Region it's likely the planning for what needs to happen next will be different as each is at a different stage of planning and delivery.

The case studies are intended to illustrate good practice but also give a clear understanding of what level of complexities need to be faced. An important message to take forward is that we should not label individuals or families as complex, certainly no more than each of us are complex as individuals, instead the real complexity is the development and delivery of a package of care and support that is person centred and delivers meaningful outcomes. Once we accept the complexity is in the integrated response required then we can collectively address the challenge of commissioning.

This guidance is based upon the principles of the legislation that supports early intervention and prevention to avoid the escalation of needs.

1.2 Typologies of Complex Needs

This guidance covers a wide range of complex needs, the typologies of which are listed below:

- Complex due to chronic health conditions (including life-limiting conditions)
- Complex due to sensory impairment (e.g. blind, deaf)

- Complex due to physical disability and associated conditions such as learning disability and / or autism
- Complex due to the display of risky, challenging and or harmful behaviours
- Complex due to mental ill health
- Complex due to learning disability and/or autism
- Complex due to context (e.g. abuse, neglect, growing up with domestic violence, growing up as a refugee/asylum seeker). The circumstances of some young people will become complex because in addition to their original needs they have also become involved in the youth justice system.

It should be noted that the needs of some children will straddle more than one typology.

It should also be noted that not all children with one typology will be complex. For example, a child with autism may or may not have complex needs, it depends on how their autism impacts on them and/or the co-existence of other complexities such as health conditions. In less complex cases where the child or young person requires care and support the Regional Partnership Board should ensure effective referral pathways to meet needs (e.g effective pathways between health and social care after the identification of sensory impairment). This will prevent needs from escalating and becoming more complex.

Whilst we have described typologies above the term 'complex' should refer more to the complex service provision required, rather than a way of labelling children and young people.

Key Message

Complex is not a label we should give a child. We should recognise that it is a description of the complex service response needed to meet their needs. The service response is complex in nature because it requires collaboration from at least two, if not three or four services and often cross-border provision.



2 **Question: What values underpin the guidance? Answer: Children's Rights Approach, Best Interests and Corporate Parenting**

The Welsh Government believes every child and young person is important. Each one should have the best start in life, the best possible chance to grow up free from poverty or harm and with the support they need to reach their full potential. The United Nations Convention on the Rights of the Child (UNCRC) is an international agreement that protects the human rights of children under the age

of 18. It was ratified by the UN General Assembly in 1989 and two years later the United Kingdom formally agreed to ensure that every child in the UK has all the rights listed in the convention. The Welsh Government adopted the Convention as the basis for policy making for children and young people in Wales in 2004. There are 54 articles in the Convention. Articles 1-42 set out how children should be treated while Articles 43-45 are about how adults and governments should work together to make sure all children are entitled to their rights.

The 'Rights of Children and Young Persons (Wales) Measure' 2011, received unanimous cross-party support when it was passed at the National Assembly for Wales in January 2011. The Measure strengthened and built on the rights-based approach of the Welsh Government. It placed a duty on all Welsh Ministers to have due regard to the substantive rights and obligations within the UNCRC and its optional protocols when making decisions about proposed legislation and policies for children and young people. By placing children's rights at the heart of policy and legislation, The Measure influences the delivery of services and improves the outcomes for all Children and Young People including disabled children/young people and those with complex needs.

Another United Nations Convention which is relevant in this context is the United Nations Convention on the Rights of Disabled People. In the Convention disabled people are not viewed as subjects of charity but as subjects with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent and are active members of society. The convention covers all disabled people, but Article 7 which refers explicitly to children states that "Disabled children are supported to express their views and those views must be listened to and taken seriously. They should enjoy all their human rights on the same basis as non-disabled children"

Disabled children are however very vulnerable, and this is compounded by their complex needs *Disabled children also have the same human rights to be safe from abuse and neglect, to be protected from harm and achieve the same Social Services and Well Being Act 2014 (Wales) outcomes as non-disabled children. Disabled children do however require additional action. This is because they experience greater vulnerability as a result of negative attitudes about disabled children and unequal access to services and resources, and because they may have additional needs relating to physical, sensory, cognitive and/ or communication impairments. It is therefore important that any services commissioned for disabled children recognise this.*

The Social Services and Well-being (Wales) Act 2014, the Well-being of Future Generations (Wales) Act 2015 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018 establish duties on public authorities that contribute toward the realisation of children's rights. A Children's Rights Approach is consistent with these duties and will help public sector bodies to meet their statutory duties. Similarly, a range of organisations in the private and non-governmental sectors in Wales have a significant part to play in the implementation of children services, and therefore have an obligation to contribute toward better realisation of children's rights in Wales. A Children's Rights Approach will help organisations in the private and public sectors give effect to children's rights.

In 2017 the Children's Commissioner for Wales published 'The Right Way. A Children's Rights Approach in Wales'. A Children's Rights Approach is a principled and practical framework for working with children, grounded in the UN Convention on the Rights of the Child.

2.1 The principles of a Children's Rights Approach

- **Embedding children's rights** – putting children's rights at the core of planning and service delivery
- **Equality and non-discrimination** – ensuring that every child has an equal opportunity to be the best they can be
- **Empowering children** – enhancing children's capabilities as individuals so they're better able to take advantage of rights, and engage with and hold accountable the institutions and individuals that affect their lives
- **Participation** – listening to children and taking their views meaningfully into account
- **Accountability** – authorities should be accountable to children for decisions and actions that affect their lives

2.2 A Children's Rights Approach means that....

- Organisations will prioritise children's rights in their work with children and families to improve children's lives
- All children are given opportunities to make the most of their talents and potential
- All children are given access to information and resources to enable them to take full advantage of their rights
- Children are provided with meaningful opportunities to influence decisions about their lives
- Authorities and individuals are accountable to children for decisions, and for outcomes that affect children's lives

2.3 Why should I use a Children's Rights framework?

Investing in children's rights has real benefits for organisations:

- It will help public bodies to meet their statutory duties

- It contributes to enabling more children and young people to be better involved in public services; leading to better decision making
- It ensures there's a real focus on the particular needs of children whose voices can be lost or silenced
- It helps to create an environment where public services are accountable to all of its service users

Children and Young People's National Participation Standards

The participation standards identify seven key topics that all workers should be aware of when working with children and young people in Wales. These are:-

- Information – this must be easy for children and young people to understand and make an informed decision
- Choice – children and young people have the right to choose to be involved in and work on things that are important to them
- No Discrimination - children and young people are all different and you have the right to be treated fairly
- Respect – children and young people have the right to have a say. Their opinions are important and must be respected.
- Children and young people will get something out of it - they have the right to learn and be the best they can be
- Feedback – children and young people have the right to know what difference their involvement has made
- Working better - those who make decisions that affect children and young people should put children's rights at the centre of everything they do.

The standards have been ratified by the Welsh Government and are underpinned by the UNCRC and the Well-being of Future Generations (Wales) Act 2015 that puts the involvement of children at the heart of improving their well-being. The full version of the standards are available [Children and Young People's National Participation Standards](#)

The standards have been adapted to make them more accessible for disabled children and young people under the name of [Having a voice, having a choice](#)

Social work and the work of other professionals is grounded in theories of child development. Its assessments of children and young people are based on a model that charts children's development through stages of their immaturity. In contrast, much of children's rights theory on which advocacy practice is based, regards children and young people as competent and autonomous. These opposing principles may account for some of the tensions in practice between Rights and Best Interests.

In reality there must be a balance between the two whilst always maintaining a focus on the young person. There is a need for all professionals to respect children and young people as individuals, but it is also crucial that professionals take account of the child's relationships and connections. In so doing professionals are more able to develop a sophisticated and insightful view, recognising that children and young people are not always autonomous when forming their opinions or in their decision making and that rights must be balanced against best interests.¹

The Social Services and Well-being (Wales) Act 2014 requires local authorities support people to fully participate in decisions made about their care and support and be helped to express their views wishes and feelings and support to make decisions about their personal outcomes. Some individuals are able to express their views themselves. Others need the support of an "appropriate individual" such as carer, friend or relative to do this. If no one is able to do this, the local authority must arrange for an independent professional advocate to support and represent the individual. There is a shortage of professional advocates to support some individuals' especially disabled children and young people. Commissioning of specific independent professional advocacy services for this group will overcome this shortage to ensure that the voice of disabled children and young people is heard during the assessment process. The use of appropriate tools will also help social workers ensure the individual's view is heard. As there is a shortage of these, some social workers are devising their own and it would be helpful if appropriate tools are commissioned. This requires further discussion.

One project that ensures that the voice of disabled young people is heard, and their rights are upheld is Vale Youth Speak Up. This is a group of up to young learning-disabled children and young people aged between 16- 25 who work to highlight and tackle the issues of discrimination and bullying facing young people with disabilities. A major objective of the project is to empower and facilitate young people's involvement in decision making processes. They consult with other young people, promote the UNCRC Rights of the Child in schools and deliver disability equality / awareness training to other young people in school and professionals on disability. The group has made 2 community films about scenarios they've experienced. The first film was The Rights Fighters for which they were awarded the prestigious Philip Lawrence award and the sequel Rights Fighters II which was short listed for the Zoom Young Filmmakers Awards 2013. These can be viewed on the groups [YouTube Channel](#)

¹ Barnes,V. (2012) Social Work and Advocacy with Young People: Rights and Care in Practice. *British Journal of Social Work* 42, p1275-1292

Key Message

A range of organisations in the private and non-governmental sectors in Wales have a significant part to play in the implementation of children services, and therefore have an obligation to contribute toward better realisation of children's rights in Wales.



TOOL

Use the Policy Mapping Tool to map the legislative levers for collaboration from the Social Services Well-being (Wales) Act 2014 (SSWBA), the Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET), the Well-being of Future Generations Act 2015 (WBFGA) and the Regulation and Inspection of Social Care (Wales) Act 2016 (RISCA). Use the tool to identify the key responsibilities for partners across education, health, social care and housing to satisfy legal requirements and achieve well-being outcomes.



3 Question: What is strategic commissioning? Answer: The Commissioning Cycle

At its most basic, commissioning involves understanding need and then ensuring there is a supply of services to meet that need.

Commissioning is a set of activities by which local authorities and partners ensure that services are planned and organised to best meet the ... outcomes required by their citizens. It involves understanding the population need, best practice and local resources and using these to plan, implement and review changes in services. It requires a whole system perspective and applies to services provided by local authorities, as well as public, private and third sector services.

Fulfilled Lives and Supportive Communities Commissioning Framework Guidance and Good Practice (2010)

The Welsh Government Fulfilled Lives and Supportive Communities commissioning cycle and its associated Commissioning Framework Guidance and Good Practice no longer have a statutory status, but do still represent good practice and are relevant today. The Commissioning Cycle (shown below) describes a range of activities and illustrates the relationship between them. It is underpinned by six key principles, namely:

1. Focus on client group needs across agencies.
2. All four activities are equally important.
3. The activities follow sequentially.
4. Commissioning drives procurement.
5. The procurement experience informs the ongoing development commissioning strategy.
6. There is an on-going dialogue with service users/parent carers, managers, providers and the third sector.



of the
case/care

For further information see ['Leading Integrated and Collaborative Commissioning' \(2017\) National Commissioning Board.](#)

Key Message

Commissioners across Wales should be using the Commissioning Cycle to ensure they engage in good commissioning practice.



TOOLKIT



Use the commissioning arrangements self-assessment tool to evaluate the strengths and weaknesses of the commissioning arrangements for children with complex needs and to determine whether your Regional Partnership Board arrangements promote effective commissioning.

4 Question: What should your commissioning activities achieve for children and young people? **Answer: Well-being**

For the purposes of this guidance we will use the definition of well-being outlined in the Social Services and Well-being (Wales) Act 2014. In the Act well-being is defined with eight common aspects:

- physical and mental health and emotional well-being;
- protection from abuse and neglect;
- education, training and recreation;
- domestic, family and personal relationships;
- contribution made to society;
- securing rights and entitlements;
- social and economic well-being; and
- suitability of living accommodation.

In relation to a child, well-being also includes:

- their physical, intellectual, emotional, social and behavioural development; and

- their welfare as that word is interpreted for the purposes of the Children Act 1989 – ensuring that they are kept safe from harm.

Whilst all aspects of well-being in the definition have equal importance, it is likely that some aspects of well-being will be more relevant to one person than another.

4.1 Children with complex needs are at greater risk of poor mental health and emotional well-being

- Public Health Wales has recently undertaken a wave of research in understanding adverse childhood experiences and the impact these have on adulthood. They discovered that people who have experienced abuse, neglect and other adverse childhood experiences (ACEs) such as living with domestic violence during their childhood are at much greater risk of mental illness throughout life.²
- Research undertaken by Emerson and Hatton (2007)³ focused on children with learning disabilities and found that children with learning disabilities are more at risk of mental health problems than their non-disabled peers.
- CARP Collaborations and the Building Bridges Project completed a research project that involved working with peer researchers to explore patterns of friendships and social isolation with young people with a learning difficulty in transition to adulthood. The report entitled “Young People and Friendships: What matters to us?” details findings of qualitative research undertaken across Gwent with 14- 25 year olds with learning disabilities. Participants spoke about different types of bullying behaviours - verbal and physical bullying, cyber bullying and spreading rumours and lies, manipulation, exploitation and mate crime. Suggested ways of tackling bullying suggested by participants include increased facilitated social inclusion; better links between hate crime and bullying being undertaken in relation to disability and the production of information about how to manage bullying in easy read and audio formats so it can be easily understood. The full report which includes information on the risk of social isolation and how to overcome it and the role of the family and professional agencies can be accessed [Download Report](#).
- A report from a survey on parents' and young peoples' experiences found that many children with autism were not getting the education they need and deserve. A quarter of children were not happy at school, and one in five did not feel safe. 34% of children on the autism spectrum said that the worst thing about being at school was being picked on. 17% of autistic children had

² Public Health Wales (2018) ‘Sources of resilience and their moderating relationships with harms from adverse childhood experiences’

³ Emerson, E. and Hatton, C. (2007) ‘The mental health of children and adolescents with learning disabilities in Britain,’ British Journal of Psychiatry, 191(1): 439-499

been suspended from school; 48% of these had been suspended three or more times; 4% had been expelled from one or more schools.⁴

- For those with a chronic health condition it is a similar picture. A chronic illness in childhood is associated with an increased risk of psychological and behavioural problems. Research has shown that children with chronic illnesses sustain more emotional trauma. The main difficulties faced in school were the implications of school absence, exclusion from school life, teachers' reactions to illness, and peer relationships. Common psychosocial problems encountered include low self-esteem, feelings of isolation and poor academic performance.⁵

4.1.1 Accessing support

Young Minds (2018)⁶ conducted two major surveys with more than 2,700 young people who have looked for support for their mental health and more than 1,600 parents whose children have looked for support.

The findings show that:

- Only 9% of young people and 6% of parents reported that they had found it easy to get the support they needed. 66% of young people and 84% of parents reported they had found it difficult.
- Only 6% of young people and 3% of parents agreed that there is enough support for children and young people with mental health problems. 81% of young people and 94% of parents disagreed.

Young people and parents reported barriers at every stage in their search for help. When asked what barriers they had faced, if any, to getting support for their mental health:

- 51% of young people said that they hadn't understood what they were going through
- 23% of parents said that their child hadn't told them what they were going through
- 42% of parents reported problems getting help from school or college
- 29% reported having problems getting help from their GP

⁴ Reid, B. (2011). Great Expectations. London: The National Autistic Society, p8

⁵ Northam EA. 'Psychosocial impact of chronic illness in children'. Journal of Paediatric Child Health. 1997 Oct;33(5):369-72

⁶ Young Minds (2018) 'Fighting For'.

Key message

Children with complex needs are at greater risk of poor mental health and emotional well-being than their peers. Children, young people and their families find it difficult to access mental health support.



4.2 The key to good mental health and emotional well-being

Not all children with the same condition develop the same psychosocial problems. This suggests that moderating factors have a role in determining the outcome. Four key factors seem to be important in fostering good mental health and emotional well-being:

- **A positive sense of self** – asset-based approaches that support children and young people to have a positive identity.
- **A sense of belonging** – support to develop positive relationships with others.
- **A sense of competency** – support to learn new skills.
- **A sense of purpose** – support to contribute to and feel valued by their community.

CASE STUDY

Bethan became known to children's social services in 2001. The Local Authority has remained involved since that time and in October 2016 her name was placed on the Child Protection Register. The core concern for social care during this time has been the need for mental health assessments, supporting Bethan with emotional regulation, the management of self-harming behaviour and suicidal ideation. Bethan has had several periods from 2014 to 2018 where she has required hospital admission under Section 2 and Section 3 of the Mental Health Act. Bethan has also had repeat and frequent admissions to A&E wards and contact with emergency services due to cutting herself, use of ligatures, and the swallowing of foreign objects. Bethan has been considered a risk to others, as she has sought to incite self-harm or suicide in the community and with fellow inpatients.

Social Services offered intensive support to Bethan through child in need and child protection plans, which included a range of interventions through specialist and intensive family support services. CAMHS have also had long term involvement to offer DBT (dialectical behaviour therapy) and behavioural support.



In November 2016 Bethan became looked after when she was discharged from a mental health inpatient ward after a 5 month admission. During this admission social services sought fostering and residential placements for Bethan as her family could no longer support her at home, but searches were unsuccessful due to the complexity of meeting her high -risk needs. Following 3 months of searches it was agreed via Multi-Disciplinary Team meetings that Bethan would be discharged to a supported living provider in the local community.

Bethan's behaviour proved unmanageable in the community and the risks re-emerged. The provider tried to offer a bespoke and specialised placement which could adapt to Bethan's needs. There were regular placement meetings and clear guidance about safe care, placement planning, behaviour management, risk assessing, and the improvement of care standards. Bethan received 2-1 care at all times and there were frequent multi-agency meetings to try and explore opportunities for therapy, harm reduction, and reduced admissions to hospital.

In January 2018 the Local Authority needed to issue an application for a Secure Order as Bethan had repeat admissions to hospital for swallowing batteries and glass. Whilst the application was being submitted the lead clinician discharged Bethan to her mother's care as he felt he could not detain her under the Mental Health Act. Bethan immediately absconded and sought to hang herself from a tree.

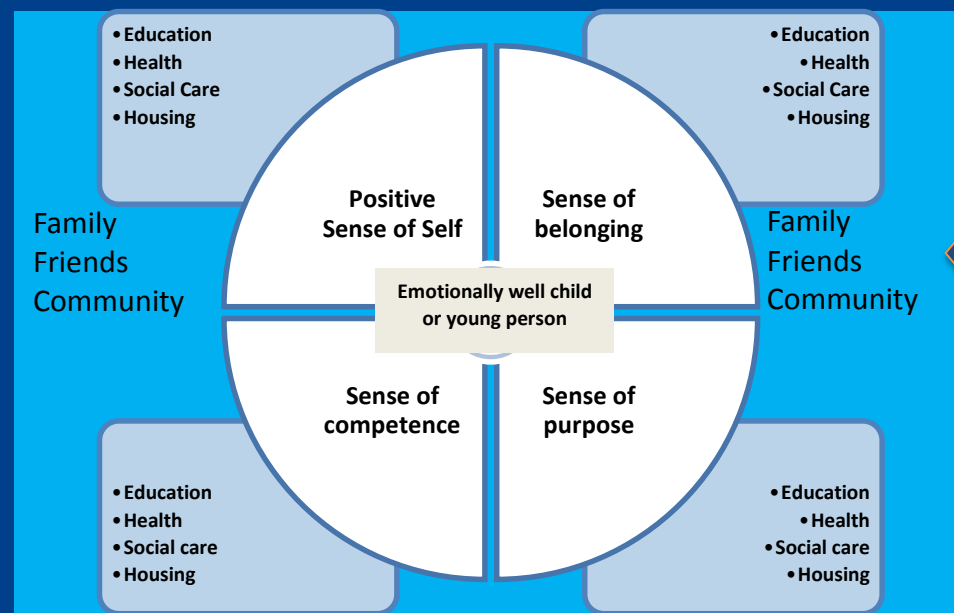
Whilst in Court, social services again could not match Bethan to a safe placement and asked the Health Board to assist by keeping her safe in a health provision, pending the identification of a Secure Welfare bed. Bethan remained on a Mental Health Ward until April 2018, because no Secure Welfare bed was available to manage her needs. In April Bethan moved to Hillside Secure Unit and since that time expert assessments have been completed which offer clearer understanding of her needs. Social Services, Health and partner agencies are now collaborating to identify a move-on provision when the Secure Order ends, in October 2018.

Impact on young person: *When Bethan was living in the community it was difficult to manage her needs in a way which prevented repeat hospitalisations and ensured her immediate safety. Bethan is considered to have emotional and social difficulties by CAMHS and therefore not Sectionable under the Mental Health Act. On the other hand, her emotional and social needs are so great that the identification of a Social Care placement which can meet her needs has proved highly challenging. The level of risk for any Provider is almost too high to bear. So, Bethan was ineligible for health placements and not matched to social care placements. There was then drift and delay in meeting her needs appropriately when a lack of integrated commissioning was evident.*

The result for Bethan has been lengthy stays in secure hospitals or secure welfare beds to ensure her safety, whilst searches for more appropriate placements were exhausted. It could be argued that the unavailability of secure provision was such that this heightened her needs whilst she was in hospital settings. Equally, the Local Authority has had worry that her ineligibility for health services, has meant she has not always received the specialist health input she has required.

In court in recent months the Health Board and Local Authority have worked together to try and overcome these challenges by commissioning an integrated solution, but it has been difficult to ensure that Bethan's needs have remained the focus of all professionals and that case management has not become politicised. Given the complexity of the care and support package required for Bethan the only possible solution to deliver good outcomes will have to be a truly innovative partnership arrangement.

Key Message



Regional Partnership Boards **must commission integrated services** that optimise

opportunities for children and young people to experience the protective factors that will support them to experience good mental health and emotional wellbeing.



When integrated services are not commissioned the system adds to the risk factors and the mental health of children, young people and their families can significantly deteriorate.

Example: Llanrwst Family Centre

Llanrwst Family Centre provides an important example of a service designed to support the needs of a rural community facing the different challenges of limited facilities and accessible transport. It has been open for several years and has been the model for the development of family centres in Conwy.

The Centre works with a range of partners to provide an integrated whole family approach. This is based upon the belief that all issues that affect the family will have an effect on the child. The Centre works to ensure that families are supported to give their children the best possible start in life.

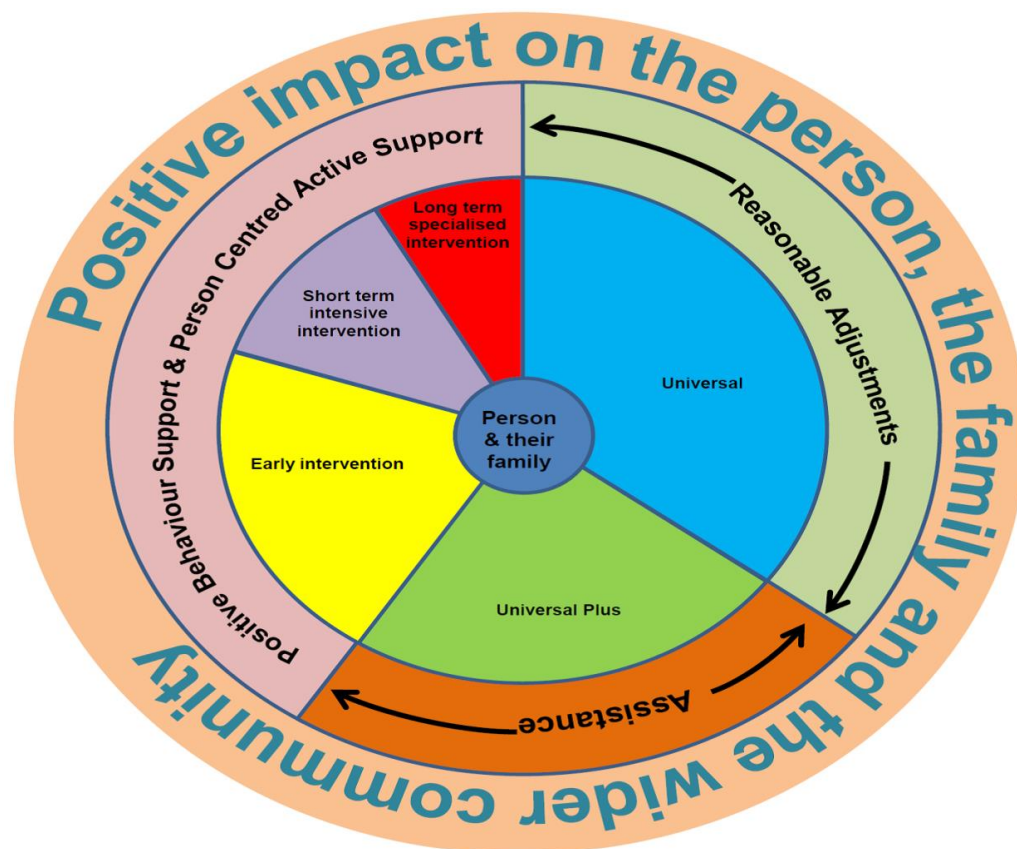
The Centre provides a hub of support to parents offering a base for multiagency activities/ services as well as providing one to one support as required. The Centre is working to integrate services to ensure families only need to tell their story once to get the support they need. This will be managed with a variety of agencies through the day to day co-ordination of the Family Centre.

It places a clear emphasis on early intervention for families making it easier for families to access the supported needed. Promoting positive parenting is embedded throughout the service enabling families to help themselves. Each Family Centre in Conwy provides a support group for families with additional needs. Services are designed to respond to individual need.

<http://www.conwy.gov.uk/en/Resident/Social-Care-and-Wellbeing/Children-and-families/Family-Support-Services/Rural-Families-First/Rural-Families-First.aspx>



4.3 Commissioning Good Lives in Community Settings - The Welsh Good Practice Guidance for Commissioning Services for people (including children and young people) with learning disabilities and/or autism



The Welsh Good Practice Guidance for Commissioning Services for people (including children and young people) with learning disabilities and/or autism describes an approach to commissioning good lives in ordinary settings. It is based on the concept that people with learning disabilities and/or autism have the right to equal opportunities, to live in the community and to access the same services as the rest of the community. The approach suggests that commissioners should view universal services as the starting point and that any person with a learning disability and/or autism (no matter how complex) needs access to universal services. Many will also need specialist support to achieve particular outcomes or to get specific needs met.

Universal

The Welsh government and therefore all of the partners support the social model of disability which recognises that people with impairments are disabled by the barriers that commonly exist in a society. The social model is a positive approach to disability and focuses on removing barriers to equality. This means that Regional Partnership Boards and their partners should be working to make

reasonable adjustments to make their services accessible and enable children and young people and their families experience 'ordinary lives'.

This good practice guidance for commissioning services for children and young people with complex needs builds on the 'ordinary life approach' in the learning disability and autism guidance. The ordinary life approach is just as relevant for children, young people with complex needs as they and their families all state that they want the same things as their peers but that it can be harder to achieve an 'ordinary life' due to the many challenges they face.

The philosophy underpinning the Welsh legislation is provide appropriate support early to prevent problems escalating with negative impacts upon the child/ young person and the family also leading to more expensive and possibly more intrusive service interventions later. It will be important to attempt to resolve issues in relation to the development of challenging behaviour, for example, when a child is young rather than having to respond to the challenging behaviour of a strong young person. Commissioners should start by making universal services as effective as possible encouraging them to make reasonable adjustments to make them accessible. Specialist services/ resources need to be preserved to focus on the needs of individuals whose needs cannot be met effectively at a lower tier or earlier segment of the diagram above.

The importance of early intervention can be illustrated in relation to support with continence. It requires early support from health visitors and school nurses with education providing a healthy environment with clean toilets and the encouragement of good hydration. Good liaison between health and school staff should manage any toileting issues with referral to a continence advisor where appropriate. The development of appropriate pathways to effective continence advice and support is essential in resolving problems at an early stage.

Example: Provision of intimate care at school

All schools (special or mainstream) catering for children with complex needs due to disability and/or ill-health should have a policy for the provision of intimate care. See example -

<https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1758>

Children with bowel/bladder problems may have soiling accidents at school and require sensitive and immediate support. Welsh government guidance notes that it is 'unacceptable practice to require parents or otherwise to make them feel obliged, to attend the education setting..... To administer medication or provide health care support to the learner, including the toileting issues.'

Appropriate support with intimate care will help support the individual and the family's well-being. Parents having to leave work and being summoned to the school in these circumstances does undermine their sense of well-being and ability to cope. *Welsh*



Government (2017) 'Supporting Learners with healthcare needs' <http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs/?lang=en>

All children and young people from birth to 19 years with bowel bladder dysfunction, including children with learning difficulties and physical disabilities should have access to a paediatric continence service for treatment which should have effective referral and care pathways to secondary care when required. The outcome is to help children and young people to achieve complete continence, or to manage the condition discreetly and effectively if full control is not clinically possible. In areas where we have shortages of paediatric nurses we need to develop an alternative solution with appropriate support.

Paediatric continence forum (2014) 'Paediatric continence commissioning guide: a handbook for the commissioning and running of paediatric continence services'.

Universal Plus

Achieving well-being, including emotional well-being is partly dependent upon the investment made in early intervention and preventative approaches that can be accessed via universal services. A good example of this is how we support and teach children and young people to take care of their mental health by providing access to this support via school.

Example: One-Eighty

One-Eighty is a psychology focused behavioural support charity supporting children, young people and families to have positive changing experiences in order to engage with education. As part of its work One-Eighty runs a program called 'Make Me Smile'. It is a programme aimed at primary school children and aims to promote mental health awareness. Through storytelling, facilitated discussions and a creative exercise, One-Eighty provide a space where the class are able to share their own strategies and recognise the support networks around them. The story creates a sense of resilience as the class helps a little girl, overwhelmed by her worries, to realise that some of her worries are not her own and therefore should not be part of her worry bag. The children, teachers and parents are introduced to the strategy and encouraged to use it at home and in school to help children process and accept their worries.



www.one-eighty.org.uk

Early Intervention

The provision of preventative and early intervention approaches can reduce the escalation of need and risk, improve personal outcomes and build capacity. Identifying need at its earliest point and providing the appropriate information, advice, assistance and, where required, intervention can delay or prevent escalating need that can often be costly. Being responsive to low level needs must be a consistent and collaborative approach across partners, in which the ability to share information and communicate effectively is key.

Example: E-PAtS (Early Positive Approaches to Support)

Example: E-PAtS (Early Positive Approaches to Support)

Mencap NI is delivering the E-PAtS programme which has been co-produced over a period of five years by professionals (TizardCentre) in the learning disabilities field and family caregivers. E PAtS utilises A Positive Behavioural Support (PBS) Framework and comprises 8x2.5 hour sessions for family caregivers of children aged 0 to 5 years with a learning disability. Its main aim is to meet the needs of families at an early stage, prior to or just after the development of any behavioural difficulties. The programme provides parents with information and practical skills to minimise risks associated with challenging behaviour, and support their child's development and life chances. It is routinely co-facilitated by trained family caregivers and professionals working in partnership. It provides an emotionally supportive and sensitive group process that attends closely to care-givers' emotional needs. It utilises high-quality, evidence-based information and strategies specific to the needs of families raising a child with learning disabilities. It can be implemented in a range of settings, is fully manualised and free to use for all organisations who have trained facilitators.

<https://northernireland.mencap.org.uk/blog/celebrating-e-pats-parent-support-programme>



Targeted Intervention

All children and young people with complex needs are likely to require targeted intervention to build skills, prevent crisis and or to recover from significant events such as a stay in hospital. Whilst such intervention is targeted it is important that it sits within a holistic, integrated approach to meeting needs and achieving outcomes.

Example: Caerphilly Children's Centre.

The centre opened in 1990 and now provides a wide range of high quality services to over 1,000 children and young people with disabilities or additional needs and their families. From the very beginning, the families of children with additional needs were saying that they wanted a one stop shop where they could take their children for a variety of



services they need, with one telephone number for all services. The centre hosts the ISCAN team referred to in section 5 of this guidance. Other targeted services include:

Action for Children:

Assessment Nursery for pre-school children with additional needs providing a safe stimulating environment to promote the child's all-round development whilst having fun. It also provides a pleasant environment for professionals to assess the needs of children rather than a hospital clinic.

Play schemes funded by social services are run during some of the school holidays for children up to 8 years old.

Shared Care (Respite) Service provides shared care placements, sitting service, and a supported leisure service. These services provide a range of flexible and appropriate respite to support families of children 0-18 years.

More than just Play Project (Families First) provides weekly home-based support for pre- school children with emerging developmental delay, disabilities and additional needs, aiming to maximise the learning and development of children through the use of developmental journals and play.

Aneurin Bevan Health Board:

Physiotherapists provide treatment at the centre and at schools, nursery playgroup and children's own home.

Orthotic weekly clinics.

Hydrotherapy (the centre has a hydrotherapy pool).

Rebound Therapy (the centre has a rebound therapy trampoline room)

Speech & language therapy

Dietetics,

Portage (Home Advisory Service) for children with learning difficulties or developmental delay. A child development advisor visits the child's home regularly and plans activities for the child and parents to work together. These plans cover a number of areas of development, e.g. self-help, language, play, motor and social skills.

Social Services

Children with disabilities team including social workers, child care support workers, occupational therapists.

The centre has a purpose built outside play area and all-weather canopy.

The Citizens' Advice Service runs drop in sessions at the centre.

The centre provides an environment that promotes collaboration and a coordinated approach to providing services.

<https://www.actionforchildren.org.uk/in-your-area/services/childrens-centres/caerphilly-children-s-centre/>

Although the centre provides a good environment for collaborative and integrated working it has outgrown its existing premises and is hoping to move to new premises in the medium term. ennau

The Serennu Children Centre near Newport provides an example of a new build modern children's centre.

Long-term Intervention

Everyone with eligible care and support needs should have a single person-centred care and support plan, incorporating a range of other plans where appropriate, which they have been involved in developing and of which they have a copy. Plans should focus on what is important to the individual. For children and young people up to the age of 25 with an additional learning need (ALN), this should take the form of an Individual Development Plan (IDP). Supporting children and young people with complex needs requires integrated commissioning and collaborative services that are flexible and resilient enough to meet ongoing needs in a sustainable way.

Example: Ysgol y Gogarth Special School

Ysgol y Gogarth is a day and residential special school situated in the coastal town of Llandudno. All pupils have a statement of special educational needs for moderate and severe learning difficulties, profound and multiple learning difficulties or autistic spectrum disorder. The school manages a residential facility that offers short term placements for pupils who attend school. It also offers a short breaks respite care service but access to this service is dependent upon an assessment of need under the Social Services and Well-being (Wales) Act 2014.



In 2010, Ysgol y Gogarth started a collaborative project with Bangor University to develop evidence-based practice in the field of positive behaviour support. Initially the school employed a behaviour analyst and secured consultancy from the university with the aim of targeting pupils whose challenging behaviours meant that their school placements were at risk of breaking down. Since then, the focus of this work has been extended to include preventative, early intervention approaches within the foundation phase, and to

develop whole school positive behaviour approaches that support individual pupils in managing their own behaviour. The work is based upon effective multi-disciplinary collaboration and addresses the development of pupil's behavioural, social, communication and education skills.

The school's model of positive behaviour support is based on close collaboration between teachers, behaviour analysts and other professionals. The aim is to teach pupils the skills needed to reach their full potential and reduce barriers to learning. Behaviour analysts support teachers to design to improve communication, teach academic skills, and reduce disruptive behaviours that impede learning.

The model has enabled all pupils to maintain their placements successfully at the school. This has meant, for example, that there have been no permanent exclusions from the school for the last three years. Pupils are included within all aspects of the school and a few regularly access mainstream provision.

A behaviour analyst will also provide training and support to parents.

<https://www.estyn.gov.wales/effective-practice/collaborative-approach-supporting-positive-behaviour>

Pembrokeshire provides a family support service for parents and families of children and young people with an additional learning need or disability which includes universal, targeted, support from the children with disabilities team as well as access to specialist services. A clear pathway for Accessing Targeted Support from the Inclusion Support Officers is also available. See an illustration of the service in Annex 1.

Transitions to Adulthood and Pathways

Good Transition recognises the symbiotic relationship between the system, the services, the multiple simultaneous pathways across Education, Health and Social Care and the impact it has on the outcomes for the young person and their family. This needs to be underpinned by a robust and clear transition protocol which cuts across all the relevant pathways to achieve multi agency working.

Good Transition:

- prepares young people for adulthood, with everyone working in a joined-up way, in true partnership, to provide the young person with the best opportunity to achieve their aspirations and outcomes in their lifetime.
- starts with the young person at the centre of the planning process and focuses on their aspirations for adult life, identifying the support and the continued learning required to achieve the outcome.
- is coordinated, with a nominated lead worker e.g. transition key worker, coordinating the different parts of the process for the young person, so that the young person and their family have a single plan which is person centred and includes all of their key

contacts, their role and any actions due to be undertaken. The transition key worker could be employed in the disabled children's team or the relevant adult's team with the aim of achieving a seamless transition to adult services.

Example: Joint Hospice Transition Clinic

An increasing number of children with life-limiting condition are surviving into adulthood and being discharged from Ty Hafan children's hospice service. However, these young adults who 'graduate' from Ty Hafan are often not recognised by the adult hospices and palliative care services. This is because their diagnoses are often unusual or unfamiliar or simply because no referral is being made to them based on assumption that these young people will not meet their criteria i.e. dying within 12 months. As a result, these young people, when they become 18 and leave Ty Hafan hospice service, are at great risk of their palliative and end of life care needs not being met.



The aim of the joint hospice transition clinic is to ensure that these young people who are leaving children's hospice service and specialist palliative care service will continue to receive appropriate palliative care to maintain quality of life and ensure good end of life care. It was set up on a trial basis for a year between Ty Hafan, City Hospice and Marie Curie hospice to cover Cardiff and Vale patients in April 2017. Approximately 20 patients between the ages of 16 and 25 were identified who were being or had been discharged from Ty Hafan hospice service.

The idea of the joint clinic is that those who are still under Ty Hafan hospice service will have the opportunity to meet with adult palliative care team in their familiar environment (i.e. clinic held in Ty Hafan) supported by familiar staff and that those who have been discharged from Ty Hafan will have the opportunity to meet with adult palliative care team in the adult hospice clinic whilst supported by Ty Hafan staff who know them well.

The clinics are run by Ty Hafan consultant (Dr Baba) who is also an All Wales lead for transition in palliative care and City Hospice consultant (Dr Capel), Marie Curie Hospice consultant (Dr Hayes), Ty Hafan transition worker, Ty Hafan Family Support Practitioner, Cardiff and Vale Paediatric Palliative Care Nurse Specialist and City Hospice Nurse Specialist. It runs quarterly and the site alternates between Ty Hafan and City Hospice. A young person is seen together by these professionals along with their parent or carer and a holistic review is carried out. From the assessment it is decided how the young person is going to be followed up e.g.

further clinic appointment, Community Nursing support or simply to be kept on the record by the adult service for future contact should the need arise.

The Regional SEN Transition to Employment Initiative (Real Opportunities) Project run from 2011 to 2014. This worked with young people aged 14-19 years old with a learning disability, severe and complex needs or an autistic spectrum disorder (ASD) to help them become as independent as possible in their adult lives. To do this, the project worked closely with young people and their families and professionals to develop a transition plan that is totally centred on the young person. Real Opportunities' staff helped young people, their families and other professionals to achieve the goals laid out in the plan by providing training, activities, opportunities and support. The project was evaluated repository.edgehill.ac.uk/6499/1/real_opportunities_impact_report_2014.pdf and was shown to increase independence and reduce dependence upon services.

Key message

Definition of a Good Life: Somewhere to live, something to do, someone to love (home, meaningful activity, relationships)



Integrated commissioning and service delivery enables children and young people with complex needs to live a good life in the community no matter what challenges they face in relation to physical disabilities, health problems or behaviour issues.

4.4 Emotional well-being and the importance of a positive, relational and person-centred approach to managing risky, challenging (including self-harming) behaviour

Safeguarding children and young people is a priority under the Social Services and Well-being (Wales) Act 2014. This is a complex area but is made more difficult when the child or young person is disabled. They have exactly the same human rights to be safe from abuse and neglect, to be protected from harm and achieve the Social Services and Well Being Act 2014 (Wales) outcomes as none disabled children. Disabled children do however require additional action. This is because they experience greater vulnerability as a result of negative attitudes about disabled children and unequal access to services and resources, and because they may have additional needs relating to physical, sensory, cognitive and/ or communication impairments. The practice guidance [\[PDF\] Safeguarding Disabled Children Policy - North Wales Safeguarding ...](#) ensures that there is an inclusive safeguarding system which will not only meet the needs of disabled children, it will improve practice for all children

Child protection work is too often focused on deficits. To overcome this, Swansea and Cardiff have adopted Signs of Safety which is a strengths-based approach to child protection casework. Practitioners supporting families work together to look at the strengths (what's going well in the child's life), the worries and concerns identified (who is worried and why), and focus on what needs to be done (outcomes) to build on the strengths, reduce the concerns and keep the child safe. The Signs of Safety approach encourages a strong emphasis in creating opportunities for children to be involved in the process, and so act as a catalyst for change within the family. Further information about this is available Signs of Safety Implementation in Cardiff Children's Services.

We all use behaviour as a means of communication and as a way of getting our needs met. BUT often the behaviour of children with complex needs that challenges services is interpreted as wilful or naughty. Parents are sometimes told the child's behaviour is down to their parenting rather than issues related to their child's condition or disability. Some parents are ashamed of their child's behaviour and are afraid to seek appropriate help. They are often shamed into keeping SILENT when things go wrong which leads them to be suspicious of professionals.

We need to move away from attitudes that shame and blame by viewing behaviour that challenges as naughty or attention seeking and in need of punishment, to a more insightful approach that understands behaviour has a function and that the key to managing the behaviour is to find the reason behind the behaviour and meet the needs/function of the behaviour in a different way. Only then will the risky, challenging or harmful behaviour no longer be required, and incidences of challenging behaviour be drastically reduced.

Our approach to supporting children when they display behaviours that are risky, challenging and/or harmful to themselves or others must be based on evidence-informed practice and be person centred. Two approaches are described below: positive behaviour support and attachment- based therapy. They are by no means an exhaustive list but they are two approaches that are based on a significant amount of research and which are widely considered to be effective in supporting children and young people to experience well-being.

4.4.1 Positive Behaviour Support

Positive behaviour support is a good starting point for developing a positive culture of managing behaviour and helps to reduce punitive approaches that only serve to escalate the problem and reduce well-being for all involved.

Positive Behavioural Support (PBS) is an ethical, comprehensive, evidence-based approach developed within the learning disability field. It is person-centred and proactive in that it focuses on improvements in individuals' quality of life and prevention of challenging behaviour. PBS is accepted internationally as current best practice and is specifically recommended by key national government and

professional organisations in numerous recent guidance documents as part of the ambitious transformation agenda across all vulnerable client groups of all ages.^{7 89}

CASE STUDY

My name is Claire and I am the mum of a 16year old boy with learning disabilities and autism. My son Hayden is a caring, friendly, happy boy but he struggles to process what is happening around him, causing him great anxiety and distress. When Hayden is upset he will run around screaming, throwing things and hitting people.



We have never received support to help manage Hayden's behaviour despite our numerous and increasingly desperate requests. The lack of support meant that our physical and mental health suffered with both my husband and myself being prescribed antidepressants and taking time off work.

The most frustrating thing is that Hayden has always behaved like this. His behaviour has not significantly changed since he was 2 years old but age 16 he is almost 6 feet tall, 13 stone and it became impossible for us to keep him or ourselves safe. This year we made the heart-breaking decision that Hayden could no longer live with us. Allowing our son to be taken into care has been the worst moment of our lives. We miss him every day. I truly believe that had we received behaviour support throughout his life our son would still be living with us. Our hearts would not be broken, and the State would not be paying in excess of £3000 a week to care for him.

4.4.2 Attachment Based Therapy

When a child struggles to get their physical and/or emotional needs met by their parent or other primary care giver; if a child is neglected or abused they can become stuck emotionally and have difficulty forming close, affectionate relationships. Psychologists would describe this as poor attachment. Poor attachment can significantly affect the relationships that people have throughout their lives. For some children and young people who struggle to make and sustain relationships, life can be bleak and placement breakdowns are often multiple.¹⁰

⁷ Gore et al (2013) Definition and Scope for Positive Behaviour Support. International Journal of Positive Behavioural Support 3(2), 14-23.

⁸ NICE (2015) Guidelines on prevention, assessment and intervention for Challenging Behaviour and Learning Disabilities

⁹ Royal College of Psychiatrists and the British Psychological Society (April 2016) Challenging behaviour: A unified approach – Update. Joint statement by the Faculties of Intellectual Disability of the Royal College of Psychiatrists, and the Learning Disability Professional Senate of the British Psychological Society

¹⁰ Waycott, L., Carbis, C. and McInnes, K. (2018) Developmental trauma and attachment: An integrative therapeutic approach

Impaired attachment and trauma during childhood can leave a lasting impression on the brain and delay development as this is a contributory factor to young people often displaying challenging behaviour and professionals misinterpreting that behaviour. (Youth Justice).

Early intervention can change attachment patterns, reducing harm to a child and helping them to form positive attachments in adulthood.¹¹ Attachment based therapy aims to help children forge and maintain meaningful reciprocal relationships, have a coherent narrative of their lives and be able to make informed choices for a brighter future enabling them to move on emotionally.

CASE STUDY



Tina is aged 17. Tina was adopted by her parents when she was aged 3. Tina presents as having attachment difficulties as well as having a diagnosed learning disability and ADHD. Tina was accommodated into a children's social care residential home when she was aged 15 due to her risky and significant self-harming behaviour which meant she needed a high level of supervision at all times. Tina's placement broke down after a year because of the difficulties with managing the risk around Tina absconding to the nearby motorway often on a daily basis and threatening to harm herself there which led her to frequently come into contact with emergency and mental health services. Tina was open to CAMHS services and was not diagnosed with any specific mental health issue but was prescribed medication associated with mental health issues to treat the symptoms.

Concerns about Tina's wellbeing escalated in May 2017 to the extent she could not be cared for safely in the community due to her displaying behaviours including attacking staff, ingesting dangerous items, head butting hard surfaces and trying to strangle herself using ligatures. Tina was placed under Section 2 and later Section 3 of the Mental Health Act in May 2017 in a private hospital which is commissioned through Health. There was a plan in place for Tina to move to a children's CAMHS ward to act as a stepping stone to enable her to then transition to a community placement. However the CAMHS ward changed their criteria in April 2018 and could not offer Tina a place which meant the care plan could not move forward.

Tina's previous community psychiatrist has always taken the view that Tina should not be cared for within the mental health estate due to the risk that she will become de-skilled and adopt new behaviours she learns from her inpatient peers and that once this happened it would be very difficult to care for her within the community. The view taken by this psychiatrist is that Tina should be cared for within a social care secure provision if she cannot be cared for safely in the community.

in Archer, C., Drury, C. and Hills, J. (Eds.) Healing the hidden hurts: Transforming attachment and trauma theory into effective practice with families, children and adults. London: Jessica Kingsley Publishers.

¹¹ Howe, D. (2011) Attachment across the lifecourse: A brief introduction. Basingstoke: Palgrave Macmillan.

The Local Authority has a differing view due to concerns that a social care secure setting will not have the experience and knowledge to meet Tina's mental health needs and associated presentation and that the risk would remain that she would adopt new behaviours and will be very vulnerable alongside peers who are resident due to criminal as well as welfare matters. Secure homes across the UK are commonly now rejecting referrals as 'too complex due to mental health needs'. The Local Authority has sought to have a constructive dialogue with mental health services and the local health board in order to find a way forward but this has been problematic.

Impact on Tina: The lack of suitable provision which can meet Tina's complex needs has meant she has been unable to transition from the mental health setting where she has currently been under Section for over a year. This has caused her lots of frustration and at times has led her mental wellbeing and behaviour to deteriorate as a result. Tina has adopted some new behaviour from her peers as anticipated and the thought of her potentially being discharged now can also act as a trigger.

Key message

Our approach to supporting children when they display behaviours that are risky, challenging and/or harmful to themselves or others must be positive (not punitive), person-centred and based on evidence-informed practice.

Support Providers should be commissioned, on the basis, of their commitment and ability to implement approaches such as Positive Behavioural Support (PBS) and Trauma Informed Care.

N.B. Commissioners need to work with providers to develop services with an appropriately trained workforce that can support children and young people when they display behaviours that are challenging and risky. Frontline services may require additional expertise from outside. Parents will also need help to develop these skills. The demand for various levels of training is likely to be extensive and Regional Partnership Boards will need to work with Welsh Government and improvement agencies to develop the capacity to put this training into place.



TOOLKIT



The Positive Behaviour Support Academy has developed a number of useful tools for commissioners including:

- A positive behavioural support specification for contracts
- A guide to identifying positive behavioural support best practice for commissioners and care managers
- A key performance indicator tool to monitor PBS service provision

<http://pbsacademy.org.uk/>

Further information available:

NICE guideline NG93 Learning disabilities and behaviour that challenges: service design and delivery is of particular relevance to commissioning process and specifically recommends a PBS approach. It can be accessed at

<https://www.nice.org.uk/guidance/ng93/evidence/full-guideline-pdf-4788958429>

3 useful PBS Tools for commissioners, organisations and families have been endorsed by the Welsh Government and developed by members of the All Wales Challenging Behaviour Community of Practice. The measures are complementary but can be used independently. Follow this link to access them <http://www.bild.org.uk/about-bild/news-and-views/newpbsguidancewelsh/>

Further information, resources and guidance on PBS can be found at the British Institute of Learning Disabilities Centre for the advancement of PBS website, <http://www.bild.org.uk/capbs/capbs/>

Youth Justice

Over the last 10 years the number of young people being brought into the youth justice system has significantly declined. So, has the number of young people being placed in custody. Youth offending teams are now working with far fewer young people sentenced by the courts with equal time spent providing preventative and diversionary services. The cohort that remains in the system are those young people who repeatedly offend and have a breadth of care and support needs that cannot be met by one single agency. Most often these young people are well known to public services and fall below the threshold for successful referral into CAMHS. It is accepted that ACEs and trauma are prevalent in the youth justice population. The work undertaken by PHW quantifying the impact of ACEs across the life course highlights the risk of future criminal behaviour and victimisation as well as other adverse life outcomes.

The Welsh Government and Youth Justice Board (YJB) share a vision for a rights-based approach to youth justice in Wales that considers young people in contact with the youth justice system as 'children first'. Improving outcomes for young people in contact with the youth justice system must be part of the conversation on developing integrated commissioning of services.

Working towards a trauma-informed youth justice system

Since 2013 the YJB has been working with the Welsh Government and All Wales Forensic Adolescent Consultation and Treatment Service (FACTS) and youth offending teams (YOTs) in Wales to develop and test the Enhanced Case Management (ECM) approach; introducing trauma-informed practice to YOTs. The initial test which took place in three YOTs concluded in 2017 targeted young people whose offending behaviour was considered prolific with complex needs such as adverse childhood experiences (ACEs) and trauma as interlocking factors. Evaluation findings suggest that young people experienced a wide range of complex needs. The most prevalent problems (known or suspected) were drug and alcohol misuse, domestic violence, physical abuse and self-harm. Improvements in the lives of young people following ECM involvement were noted, such as improved resilience to chaotic family life, improved self-confidence, emotion regulation and resilience. There were also notable improvements for several young people across criminal justice indicators such as breach and re-offending rates.

At the same time the YJB has been testing ECM implementation there has been a groundswell of interest in trauma-informed practice and a growing knowledge of the impact of adverse childhood experiences (ACEs). Following the success of the test in Wales our work is continuing over the next few years to trial the ECM and strengthen the focus on ACEs in YOT practice; working in partnership with those mentioned above, Public Health Wales, the South Wales Police and Crime Commissioner and YOTs in South Wales.

The rationale for ECM is to provide a bespoke approach to a small group of young people that are the most difficult to engage due to their entrenched patterns of behaviour and complexity of need. The approach acknowledges the prevalence of trauma in the lives of young people in contact with the youth justice system. It is grounded in a thorough understanding of child development and the impact of poor attachment and trauma in childhood. It also recognises the importance of clinical input from a psychologist to advise and support practitioners in their work. By improving the knowledge, skills and practice of the workforce the impact of ACEs and trauma is better understood and practice is adjusted to tailor and sequence interventions to developmental need.

Significant emphasis is placed on working in a relational way with the goal of connection and to build resilience and provide opportunities for growth. Addressing the underlying cause of offending behaviour rather than solely focusing on the offending and current problems young people can be better supported to make positive life choices and get the right help and support they need. A short film on the ECM can be found here: <https://www.youtube.com/watch?v=3FLv66cX0XY>

5 Question: How do you commission a complex response for complex needs? Answer: Integrated and collaborative commissioning

The legislative drive to commission in partnership suggests that there needs to be a shared understanding of what integrated and collaborative commissioning looks like, and when it is appropriate.

Joint commissioning: *“the process in which two or more organisations act together to co-ordinate the commissioning of services, taking joint responsibility for the translation of strategy into action”*.¹²

Collaborative commissioning is about: *“Improving service user experience by integrating care, extending choice and securing good outcomes; Achieving greater efficiency from minimising duplication and improving co-ordination”*¹³

Integrated and collaborative commissioning is a complex strategic activity combining traditional disciplines of strategic planning, service design, procurement, internal service planning and performance management, and applying these disciplines in a new multi-agency environment. It is not simply about contracting between purchasers and providers but concerns the whole range of ways in which services are developed and secured, including grants, service agreements, voluntary and community contributions. Commissioners should be working towards co-productive commissioning at all times.

As policy places greater emphasis on individual choice and control through coproduction and person-centred care, the role of public agencies as facilitators of service development, rather than only as direct purchasers or suppliers, has become more important. When collaborative and integrated commissioning is undertaken, these activities have to be re-designed, to ensure that they are fit for their purpose in a new environment. Co-productive commissioning requires public agencies not just to work together but to work with citizens and service providers in ways that value all participants' contributions EQUALLY, building relationships of trust and SHARING POWER.

For further information see ['Leading Integrated and Collaborative Commissioning' \(2017\) National Commissioning Board. Co-production Network for Wales \(All in this together\)](#).

¹² <http://prp.gov.wales/planners/social/>

¹³ <http://prp.gov.wales/planners/social/>

Example: Development of appropriate data collection – an opportunity to collaborate

This requires a coordinated approach across Wales. There is a need to build on existing systems to help improve our knowledge of demand and how effective services are in responding to this demand. This is a very demanding task and if we want to share learning and benchmark services across Wales this will require a coordinating role from Welsh Government working in partnership with regional partnership boards and partners in all sectors. This work will include developing our approaches to assessing the needs of children and young people and undertaking market analyses to make some judgements about the quality, appropriateness and capacity of existing service provision.



Effective commissioning for children and young people with complex needs requires collaboration between education, social care, health, housing and Youth Justice partners. This collaboration and the development of Regional services could address some of the support required to meet the high need but low incidence difficulties that some children and young people experience.

There is often a culture of working in silos, but this must be overcome if good outcomes for children and young people with complex needs are to be achieved because they are likely to require services from more than one professional or organisation. Where this is the case, the care and support should be effectively coordinated and delivered to meet their specific needs. This is important because even where families access services they value, they can experience the process of getting appropriate services as being confusing, exhausting and stressful in terms of having to deal with numerous professionals and agencies who may all be working very hard but who are not working effectively together to provide a coordinated response. This means that in addition to the stresses of providing day to day care, parents are often having to operate as their own care coordinators and having to work through a system that professionals themselves often experience as frustrating and confusing. This can serve to undermine the resilience of families. The challenges confronting parents are described in Section 8.

Example: Commissioning the workforce – an opportunity for collaboration

Children and young people with complex needs are likely to require support from specialists. Regional Partnership Boards will need to assess and monitor the range of professional skills required and those of support staff and address any serious deficits.



Regional Partnership Boards can provide a useful vehicle for local authorities to share services. If we take the example of specialist social workers for the deaf, for example, it is unlikely that a small local authority can justify such a post. In some cases, these posts have been replaced with no one providing specialist support. Evidence from research undertaken by Manchester University and commissioned by Welsh Government would indicate that the need for staff with specialist knowledge is important. A profoundly deaf mother of a hearing child or a profoundly deaf child with hearing parents require the support of a professional who understands

deafness and deaf culture and who can communicate directly with them through British Sign Language (BSL). A social worker with no such specialist knowledge working through a BSL interpreter cannot offer the same expertise. Specialist workers could therefore be employed at a regional level. The same principle applies to other specialist posts such as Rehabilitation services for blind people and services for deaf blind people. Demand also appears to outstrip supply in relation to a range of professions – speech & language therapy, paediatric nursing, etc. <https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1756>

There are also opportunities for Regional Partnership Boards and Social Care Wales to undertake some work on an All Wales basis to provide continuing professional development opportunities to those specialist staff employed in very small numbers in each region or local authority area. Approximately eight years ago, for example, the Welsh Government commissioned and funded four two-day blocks of training from Manchester and Birmingham Universities for the provision of training for social workers working with deaf and hard of hearing people. The only way of making such training financially viable was to provide it on an All Wales basis. There will be other groups of specialist workers whose numbers make the provision of specialist training unviable at the regional level.

Effective integration of services is required at both an operational level with professionals and agencies working with individual families to assess need and develop appropriate solutions; and at a strategic level by the integrated commissioning of an appropriate range of services to meet the needs of all children with complex needs. At the operational level this may involve integrated teams, co-located, working with common documentation and record systems reporting to a single manager. It will be up to the Regional Partnership Boards and their partners to design their approach to integrated working and be able to provide a rationale for it. There are several examples in Wales where effective operational arrangements are being developed. In addition to the example of Powys and Pembrokeshire below there is the ISCAN example in Gwent illustrated further on in this section.

A service which seeks to do this are the Powys Integrated Disability Service.



We are an integrated service which co-ordinates care for children and young people aged 0-18 in Powys who have continuing needs as a result of disabilities or illness



Who is in the IDS team?

- Community Nurses
- Neurodevelopmental Nurses
- Learning Disabilities Nurses
- Speech and Language Therapists
- Occupational Therapists
- Physiotherapists
- Portage Workers
- Community Paediatricians
- Educational Psychologists
- Sensory Service Teachers
- Learning Inclusion Support Team
- Social Workers
- Wellbeing Officers
- Action for Children



What can we offer you?

- We offer advice & information
- We assess your child's care and support needs
- We arrange Team Around the Family and Care & Support planning meetings for you
- We run these in a person-centred way, putting the child at the heart of their own care plan
- We can also arrange assessment of your needs as a carer

You may also have contact with us if you access these services:

- Shortbreaks
- Continuing Care
- Transition planning
- Neurodevelopmental diagnosis

Who can refer a child or young person to the IDS?

- The child or young person themselves
- A parent or carer
- A professional working with the child - with the family's consent

For more information:



www.powys.gov.uk/ids

01597 826604

ids@powys.gov.uk

Integrated Disability Service
County Hall
Spa Road East
Llandrindod Wells
Powys LD1 5LG

Family Support for Parents and Families of Children and Young People with Additional Learning Needs and/or Disabilities



Family Support

Within Pembrokeshire there is a range of tiered support for families with children who have additional learning needs and/or disabilities. This is based on the premise that children and families benefit from accessing support as early as possible and a comprehensive range of early help reduces the escalation of needs. The focus of this provision is family facing rather than setting based.

Children with disabilities and additional learning needs often require access to support from a wide range of agencies and professionals. This support may vary depending on the level of need of the child and young person. There is a continuum of support ranging from targeted approaches that families can self-refer or have open access to, through to specialist support available only following social work assessment.



Targeted Approaches

Team around the Family (TAF)

The Team Around the Family approach is a network of practitioners who work together to agree a plan and delivery of support to meet a child or young person's assessed needs. The TAF team workers undertake assessments and coordinate support plans. They work with families who have multiple needs but fall below the threshold for intervention from Children's Social Care – this can include families of children and young people with additional learning needs or disabilities. The emphasis is on the early identification of problems and problem resolution. Telephone 01437 76551 or e mail enquiries@pembrokeshire.gov.uk

Inclusion Support Officers

The Parent Partnership Service provides advice and support to parents and carers of children with additional learning needs or disabilities. The service has Inclusion Support Officers who provide support in the North, South and Central part of the county. This support includes:-

- Information and drop in surgeries on a monthly basis
- Facilitating parent support groups
- Support for individual families

To find out more about Inclusion Support, visit www.pembrokeshire.gov.uk/inclusion or telephone 01437 776354

Action for Children Hawthorn Project

This is a targeted family support service for families with a child or young person with a disability, providing a key worker offering emotional support, service coordination and advocacy. The project works with children or young people aged 4 to 16 years and their families. The child or young person must have moderate or complex needs and have two or more agencies involved with them. Referrals are made via a form that is downloadable from www.hawthornproject.co.uk

Trinity Project

The Trinity Project is a new initiative bringing together short break day provision including after school clubs, weekend clubs and holiday schemes. This is currently under development.

- After School Club – Tots to Teen
Tots to Teens is an afterschool club based at Portfield School for children and young people with a disability aged 4 to 19 years. During term time it takes place three times a week from 3.30pm to 5.30 pm. During the Easter holidays it currently takes place three days a week and during the summer it takes place over 12 days. There is a sessional cost for parents.
- Weekend Clubs
A new programme of fortnightly weekend clubs will be launched at the end of September with clubs taking place in North, South and Centre of the County.
- Holiday Schemes
A new programme of holiday schemes will be launched in the New Year.

Contact – Jon Bell on 01437 776334 or e mail jonathan.bell@pembrokeshire.gov.uk

Children with Disabilities Team

The Children with Disabilities team works with children and young people between the ages of 0 to 18 years who have complex or significant disabilities. This includes substantial or permanent disability, chronic illness and terminal or life threatening illness. Referrals are taken initially by the Child Care Assessment team and then passed on to the Children with Disabilities team – social workers are then able to undertake assessments and develop care and support plans when appropriate.



Community Based Activities

Sports

A range of sports opportunities is available across the County every week for children with disabilities, including wheelchair basketball, swimming, target shooting, gymnastics, boccia and indoor bowls. Contact Angela Miles, Sports Development Officer via angela.miles@pembrokeshire.gov.uk

The Cleddau Warriors Disability Football Club is open to all ages and takes place on the second Sunday of each month, along with a group for those aged 16 or over that takes place every Monday.

Contact ian.eynon@hotmail.com for further information

Specialist Services

The Children with Disabilities team can draw on a range of specialist services when developing care and support plans. These include:-

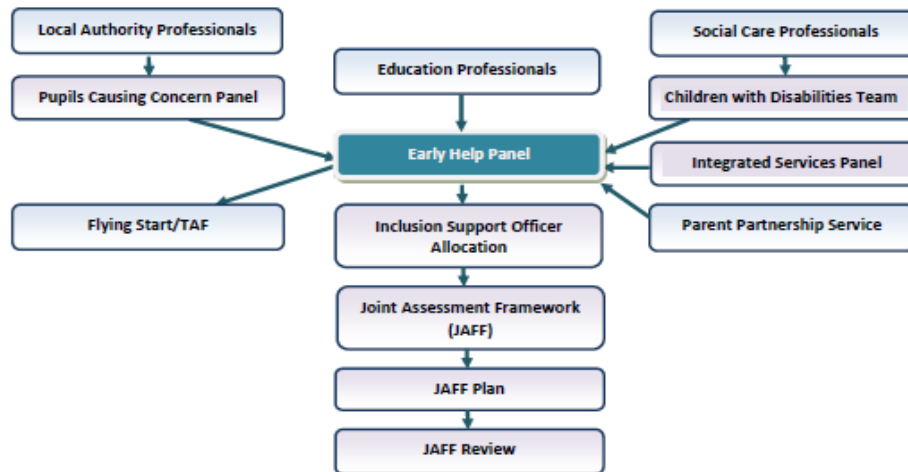
- Short Break Foster Care
This is short term respite care provided in the home of approved foster carers. It is usually overnight and geared to providing short term alternative family care.
- Short Break Residential Care
This is short term respite care that takes place within Holly House, a registered Children's Home situated in Haverfordwest.
- Activity Worker Service
This service provides children and young people with individual sessional support workers to enable the development of independence away from the family unit. It also provides them with the chance to access a variety of social or community activities or experiences.

- Direct Payments

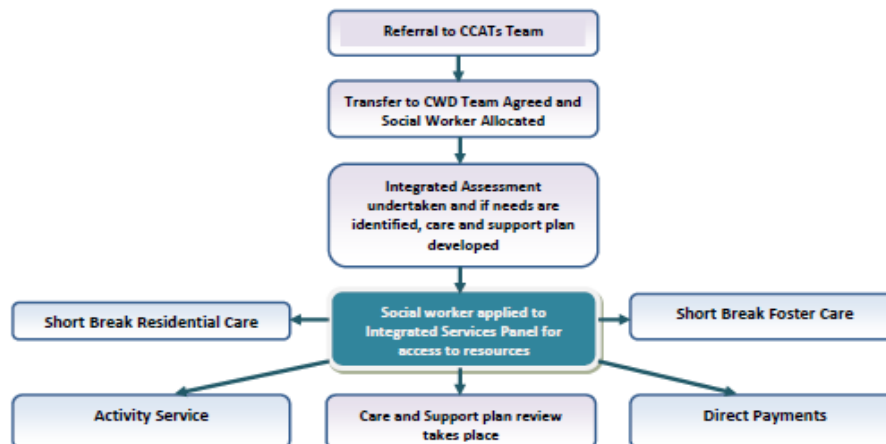
Where the Children with Disabilities team has identified a particular need and would provide a service, it is possible for the parent /carer to receive a direct payment instead. A direct payment enables them to purchase their own care and support, Enabling families to make their own decisions and control their own lives.

Family Support for Parents and Families of Children and Young People with Additional Learning Needs and/or Disabilities

Pathway for Accessing Targeted Support from the Inclusion Support Officers



Pathway for Accessing Specialist Support from the Children with Disabilities Team



Decision Making Panels

There will be times when families with children who have additional learning needs and/or disabilities will require additional targeted or specialist support.

In these circumstances there are two panels that make decisions about support for children and young people.

Panel decision making enables families to be able to access services in a fair and balanced way. It is important for each panel to receive all relevant information, assessments and reports in advance. Each panel considers how best to meet the child's needs by considering support, resources and services. Many resources or services are linked and on occasion may be full to capacity. At times alternative support or plans may therefore need to be considered.

Early Help Panel

This panel takes place weekly at Pennar and brings together managers from Early Help services including Flying Start, Team Around the Family and the Inclusion Support Team. Referrals can be made by any professional and the panel considers whether early intervention is appropriate and the most effective service.

Integrated Services Panel

This panel is chaired by the Integrated Services Manager and it takes place fortnightly. Membership of the panel includes representatives from the Inclusion Support Team, Holly House and the Children with Disability Team. The panel manages access to specialist provision including direct payments, overnight short break provision and activity support workers. It requires a social work assessment and applications can only be made by Social Work Professionals.



Reviewing Integrated Services Targeted and Specialist Family Support

Monthly management meetings take place within the local authority Inclusion Department to review:-

- Inclusion support key working
- After School and Weekend Clubs and Holiday Schemes
- Children with Disability
- Social work
- Activity service
- Direct payments

Data in relation to the number of children and young people accessing these services is collected and analysed. In addition, termly reporting takes place with the senior management team in relation to the above support to set and review targets.

Early Intervention and Family Support Strategic Group

A multi-agency strategic steering group meets every two months to provide strategic direction on early intervention and family support within Pembrokeshire.

This considers the range of support highlighted within this poster alongside additional support from other agencies and other grant funded provision.

The group is chaired by the Head of Children's Services and reports to the Children and Families Executive Group.

Key Message

The integration of services is designed to ensure that professionals and agencies work together to provide a coordinated response to the needs of the child/ young person and the family.



Example: Palliative care – an opportunity for collaboration

When demand rises and resources are strained there is a danger that high volume expensive services dominate the agenda and the significant needs of smaller groups lose out. Regional Partnership Boards need to ensure that they have an integrated approach to working with children who have limiting life-long conditions and within this group those who require palliative care.



Paediatric palliative care services are making progress in Wales and work is well underway to help get a better understanding of demand. Regional Partnership Boards need to work with the Palliative Care Group to continue to develop an appropriate range of services accessible to the children and young people and their families that require them.

Regional Partnership Boards can also draw upon the expertise of children's hospices in Wales who can help them. The hospices deliver an impressive range of services on site and in the community. They see themselves as providing more than just bed based care. They recognize that many families would prefer to be supported with their child at home and that the hospices themselves maybe a long distance from families requiring these services. They have the potential to provide more direct support to families or support to local services in their support for children and families.

Hospices rely in very large measure on charitable funding and their services need to be realistically funded to enable them to contribute to the development of services.

One of the challenges identified is that health professionals believe that social services need to be more involved in supporting these children and families. This requires further discussion between local authority representatives and the palliative care group for social services to get better understanding of how they could contribute given the statutory responsibilities of health and local authorities.

The legal framework prevents local authorities taking on responsibilities for health service provision but this does not mean that there is no role for social services. A discussion is warranted.

Example of Integrated Working.

Megan was 4 years old when her condition suddenly deteriorated, and her clinical team advised her family that they felt she was entering the final phase of her life. Megan had been born with a leukodystrophy which had caused a multitude of complex health needs and disabilities. She lived with her family in a rural part of Pembrokeshire and although she was well known to the local hospital much of her care happened at home. She had a team of community nurses who knew her well and a couple of times a year she would stay at Tŷ Hafan for a break from caring for her family. She and her family had also had regular input from the Tŷ Hafan community team who visited at home to provide play and music therapy and much needed emotional support to parents.

When her family got the devastating news that Megan was dying they were clear that they wanted her to die at home surrounded by her family and familiar surroundings. The entire multi-disciplinary team worked collegiately together to ensure that this could happen, and that Megan and her family would get the practical and emotional support they needed and that clinically Megan would be kept comfortable until her death. This plan relied not just on excellent clinical support and flexible nursing support from their community team which included an on-call rota that parents could use if needed out of hours, but also continued emotional and therapeutic support for Megan and her family.

Tŷ Hafan staff worked alongside health colleagues to ensure that this plan could be supported, and the family got the peaceful death they wanted for their little girl. Because of the support the family had received and the confidence they had been given about how to manage Megan's physical and psychosocial symptoms they were able to care for her at home and just have family around her when she died.

Short Lives have produced a range of useful materials. <https://www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services/research-best-practice/>

Key Message

The use of formal partnerships and pooled funds are important tools for integrating services, but they are a means to an end, not an end in themselves.



Formal partnerships enable health boards and local authorities to delegate functions to each other creating a single management structure for a service or services. The purpose of this guidance is to encourage Regional Partnership Boards to have appropriate discussions with all key stakeholders to identify the actions required to improve the integration of services for the benefit of children, young people and their families. The Toolkit includes a list of questions designed to stimulate discussion. These discussions will also inform decisions concerning the development of formal partnerships and pooled budgets which are designed to support the effective integration of services.

The development of formal partnerships can also improve governance arrangements. Statutory agencies which are part of a formal partnership and or contribute to a pooled fund need assurance that their statutory responsibilities are being fulfilled. Partners will demand good quality management reports to provide this reassurance.

Example: Community Equipment Service – an opportunity for collaboration

Over 10 years ago the Welsh Government made funding available to local authorities and health boards to invest in an appropriate infrastructure to improve the management of community equipment services. This allowed for investment in improved storage, decontamination, refurbishment facilities together with information technology to track equipment and arrange appropriate servicing and maintenance. All social services departments and health boards together with some education departments took advantage of this investment. A condition of the funding was that local authorities and health boards developed formal partnerships and pooled funds to manage the service. These partnerships cover the whole of Wales. With assistance of Value Wales a further development involved the establishment of a framework agreement which covered most of Wales for the purchase of routine equipment which led to improved quality and reduced costs.



Some education departments remain outside these arrangements and they may wish to consider the benefits of joining these arrangements. If they wish to remain outside of these arrangements they should at least evaluate their community equipment service against the National Standards developed by the Welsh Government (*Guidance Document: Community Equipment services:*

the Introduction of National Minimum Standards 2011) or alternatively a more recent publication – *Code of Practice for Disability Equipment, Wheelchair and Seating Services: A Quality Framework for Procurement and Provision of Services (Brian Donnelly) CECOPS.*

<https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1762>

The Welsh Government also started a project to encourage the sharing of equipment between services for specialist equipment to speed up delivery. This was particularly important for children because the challenges of providing specialist equipment are greater because they are still growing. The project lasted two years and could provide proof of concept but did not continue once funding ended. Regional Partnership Boards should discuss the merits of resurrecting this project with Welsh Government.

The legislation underpinning formal partnerships and pooled budgets offers a considerable range of options. A Regional Partnership Board could decide to include all core services for children with complex needs within a single service with a single management structure operating with a pooled budget within a formal partnership arrangement. Alternatively, it could decide to focus on the creation of a pooled budget for the integrated commissioning of services where statutory responsibilities overlap e.g. specialist placements.

A Regional Partnership Board could decide to develop a statement of purpose outlining its approach to integration and partnership working establishing milestones over the next three to five years whilst establishing a formal pooled-fund arrangement for a specific service. There are numerous options which is why the original measures became known as Health Act Flexibilities.

During the development of this guidance there have been numerous references for the need to establish pooled funds on the basis that a pooled fund would provide for timelier and less contentious decision making.

Pooled funds have several advantages:

- They can reduce the number of separate funding streams that must be accessed providing an opportunity for integrated decision making.
- They can encourage a more joined up approach to working with providers to influence the shape of services to respond more effectively to the range of needs more effectively.

- The development of a pooled budget also encourages greater transparency concerning the use of resources. Partners must be transparent about their expenditure to calculate their contribution to the pooled fund. This encourages partners to scrutinize their total expenditure rather than simply focusing on any new money available – transformation grant, integrated care fund in today's terms or in the past- Wanless money, joint working grant, joint finance. It is important to understand how all resources are being used, the degree of duplication and identify opportunities to deploy resources more effectively.

The use of pooled funds is particularly challenging at a time of financial austerity. One of the barriers is that statutory agencies often fear the loss of control of resources by contributing to a pooled budget but still be held accountable for their statutory responsibilities. They may also fear cross subsidizing other agencies. The construction of an effective pooled fund can address both anxieties if partners are clear about the rationale underpinning their contribution and they receive high quality management reports which provide evidence that their statutory responsibilities are being fulfilled, together with the effective use of resources. Partners from Health Boards and local authorities are members of partnership boards which oversee the management of the pooled fund and as such they are not giving away control of scarce resources.

If Regional Partnership Boards decide to develop a partnership and pooled budget they will need to identify what services should be included within the pooled fund? It may be less challenging to focus on specific services such as specialist placements requiring tripartite or bipartite funding in the first instance. The need to shape specific service provision will play a part in these considerations.

Steps towards a pooled budget for specialist placements.

Step 1

- The first step is to agree the aims, objectives and scope of the pooled fund.

Step 2

- The second step is to examine the expenditure of each partner on placements over the last 12 months together with the rationale for their contributions. This will help to identify the contributions of each agency. This exercise is valuable whether or not partners agree to establish the pooled fund.

Step 3

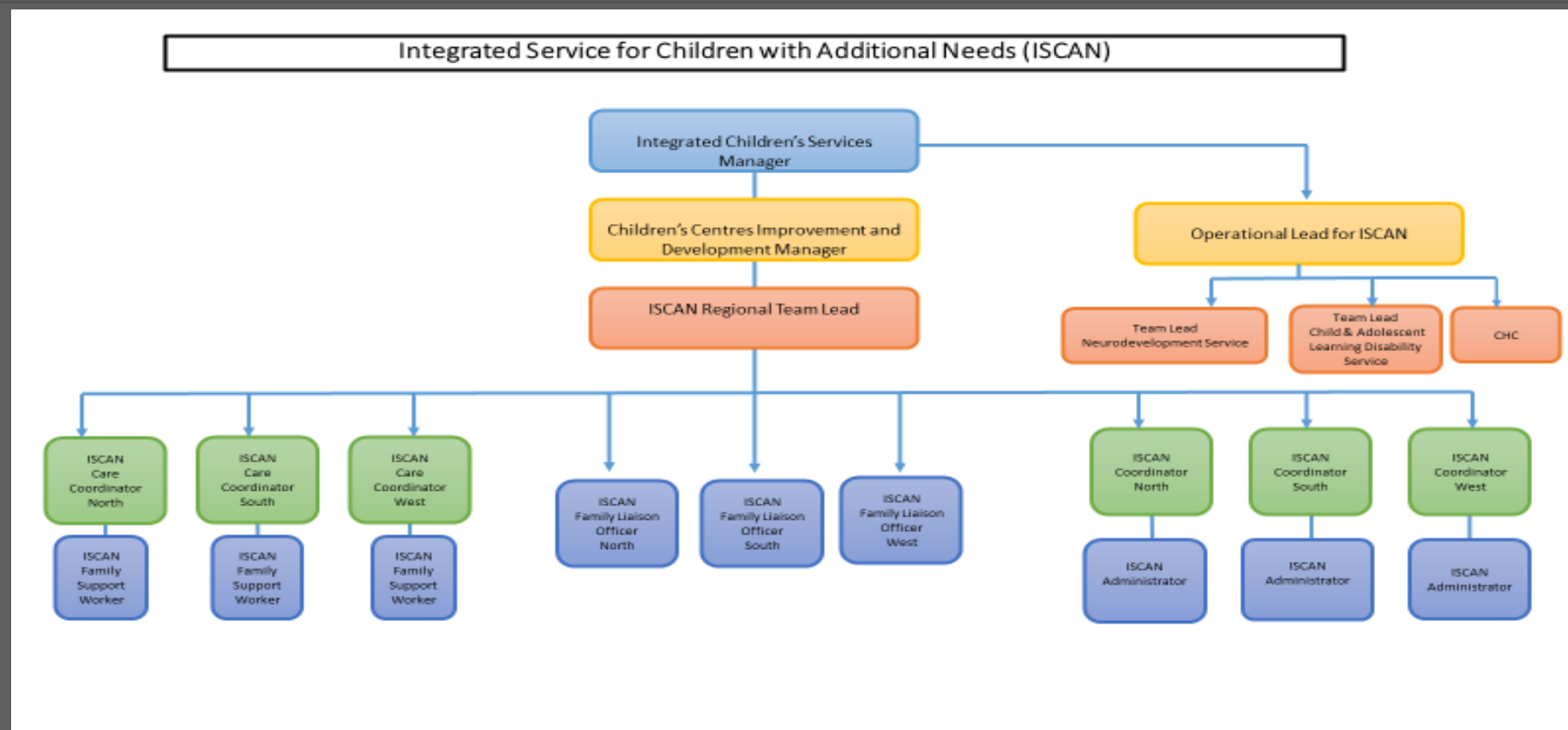
- The third step is to establish a written formal agreement. This will include the details concerning the management of the fund and how it will be monitored.

More detailed guidance on establishing pooled funds is available but the steps identified above are key starting points. Remember, any partnership arrangements must be designed to improve outcomes for children, young people and their families and their success will be measures on the achievement of these outcomes and not on the establishment of the pooled fund.

In addition to formal partnerships under the NHS Wales Act 2006 a pooled fund can also be developed under the provisions of the Childrens Act 2004. This can involve a broader range of partners beyond local authorities and health boards but no functions can be delegated from one agency to another. One use of such a measure could be the establishment of a pooled fund to create resources to manage and coordinate assessments and reviews across agencies. The Welsh Government has developed a template for such agreements - <https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1750>

Example: Gwent Integrated Service for Children with Additional Needs (ISCAN)

In October 2016, ISCAN (Integrated Service for Children with Additional Needs) was launched across three sectors in Gwent. Caerphilly, which already existed as an ISCAN sector in the west, provided the blueprint for the development of the north sector (Blaenau Gwent, north Monmouthshire and north Torfaen) and the south sector (Newport, south Monmouthshire and south Torfaen). The three ISCAN teams are centred around the children's centres in each of the sectors – Caerphilly in the west, Nevill Hall in the north and Serennu in the south. Integral to the development of the three sector ISCAN model was the creation of a single pathway for children and young people with neurodevelopmental disabilities (ND) in line with Welsh Government directive. Each ISCAN team is supported by a full time ISCAN co-ordinator and an administrator.



Referrals for children and young people with two or more developmental needs and also those with potential ASD and or ADHD (ND) are

discussed by the ISCAN sector teams on a weekly basis. Over the past 12 months the ISCAN teams have been focussing on developing effective communication and information sharing across local authority social care and education departments to ensure that all referrals taken to ISCAN meetings are supported with relevant information. All outcomes from the meetings are recorded and an outcome report is sent to parents informing them of the discussion that has taken place and the recommendations that have been made in regard to their child / young person. Parents can phone their local ISCAN co-ordinator at any time to seek or clarify information sent to them about their child.

Integral to the discussions that take place at ISCAN referral meetings is whether each child or young person referred requires access to statutory services or whether the child / young person's needs and the needs of the family can be met by non statutory provision. Referral on to Families First services is an option for ISCAN teams and also referral to the family liaison service based in two out of the three children's centres. Family Liaison Officers provide families with support and information, signposting appropriately to leisure and other community based services. Each ISCAN sector is support by a local board which is made up of all the statutory agencies, parent representative, voluntary sector and the charity which supports the local children's centre. A key aim of each board is the development of a range of enhanced service provision such as swimming sessions for families and a wide range of leisure groups for disabled children and young people who do not wish to access local community groups.

A recent bid for ICF funding to develop Phase 2 ISCAN was successful via the Gwent Children and Families Partnership Board. Phase 2 involves the development of a care co-ordination service which will be embedded within each of the three sector ISCAN teams, delivering integrated assessment and planning for children who need this on a health only or multiagency basis. This aspiration to deliver integrated single plans for children with complex needs involving a range of services and or agencies is integral to streamlining service provision for families, reducing complaints about silo working and delivering efficiencies for all partner agencies through improved allocation of scarce resources.

The ISCAN model (see attached) is being commissioned through the Children and Families Partnership Board to deliver three essential elements:

- A single point of access for referrals for the client group
- Family liaison and support
- Care co-ordination delivering integrated assessment and planning

The final element of the model, Phase 3, will aim to build in psychological support for children, young people and families. Where services like this are present, for example the Family Intervention Team (FIT) in Caerphilly, the benefits in terms of appropriate referral management are evident i.e. referrals for an ISCAN ND assessment are reduced in favour of a more appropriate family intervention.

CASE STUDY



Steven is 13. He became looked after at the age of 11. When in his mother's care Steven had witnessed considerable violence to his mother and been exposed to harm from unsafe adults including being burned by a cigarette and drinking alcohol himself. Steven has significant attachment issues, is not able to display empathy and is unable to understand consequences from his behaviour. Steven struggles to form and maintain appropriate relationships, whether that is with carers', family or peers. Steven is becoming increasingly isolated and increasingly violent. He is very controlling in his behaviour as he seeks stability of care on his own terms. Steven's emotional wellbeing is a significant concern. Steven is diagnosed with ADHD and prescribed medication for this. He does not always take his medication. His medication suppresses his appetite and impacts his sleep which is why he doesn't like taking it. Steven has had an assessment that recommended therapy to address his early childhood trauma.

Initially when in care Steven was placed with relatives but this was not successful leading to an escalation in harmful and destructive behaviours. Steven then experienced care by three successive foster care families and during this period concerns about his violence and threats of violence to others increased. For example, he had threatened to stick a fork in his foster carers' eyes, smother a carer with a pillow whilst she slept and had become increasingly controlling refusing to attend education and for a period not leaving his bedroom. When his placement had to end for the safety of the carers', police assistance and secure transport was required.

A residential care home was next identified as the most suitable package of care, with attendance at local school maintained as part of the package, albeit on a reduced timetable, and with a CAMHS assessment of his needs arranged. This placement ended with staff at the provision being hurt due to Steven's aggression. In an emergency and in the absence of a suitable alternative Steven was supported in residing with his sister. This was also short-lived and ended amidst concerns about his sister's safety (he has put his hands around her neck); Steven's controlling of the home situation and not attending the limited education package available to him.

Steven was moved again with secure transport to a solo residential placement in a three-bedded home whilst a suitable long term plan is developed by social services but an integrated approach with education and health will be crucial to creating a package that can deliver better outcomes for Steven.

The current home does not offer onsite education and no LEA education package is currently in place should Steven be persuaded to engage. The timeliness of availability of education plus the detail of the package will be critical to re-engaging him in education. Education does not want to pay for a package in advance of Steven agreeing to engage or it will waste resource.

The current home does not offer therapy on site. Steven will not attend therapy sessions outside the home offered via health. If Steven does not engage in the therapy offered at this time, the timeliness of availability of the offer will be critical to engaging him in therapy, should Steven be persuaded to engage.

Steven wants to live with his sister again. He is not accessing education. He is not taking prescribed medication. He is not accessing therapy. He has limited peer interaction. Steven requires an integrated commissioning response which means that social care, education and health are integral components of a responsive package that will be accessible when Steven is able to engage and correctly supports his individual needs. The window of opportunity for engagement when there is a motivation for change can be very short, the concern is that without an integrated approach the pace of response won't be sufficient to take advantage of that opportunity.

Key Message

The purposes of integrating services are to:

- Improve outcomes for children, young people and their families who need care and support by improving the coordination of services with agencies achieving more by working together than working in isolation.
- Improve the quality and timeliness of decision making. This will help children and their families, but it will also improve staff morale reducing the number of hoops professionals have to jump through to get a decision.
- Make more effective use of resources by removing inappropriate bureaucracy and duplication of processes. Greater transparency concerning the use of resources will also inform discussions as to how they can be used more effectively.



- Enable staff from different professional backgrounds to share their expertise which should lead to the creation of more creative solutions to help children and families achieve the outcomes important to them.

TOOLKIT

Use the Steps to Integration tool to help a Regional Partnership Board discuss and address the challenges of integration.



6 Question: How do you make sure you meet the needs of children with complex needs and their families? Answer: Co-productive commissioning and person-centred services

6.1 Co-productive commissioning with children, young people and their families

Co-production is a process – a way of working based on equal and reciprocal relationships between citizens and professionals.

“Co-production enables citizens and professionals to share power and work together in equal partnership, to create opportunities for people to access support when they need it and to contribute to social change.”

(Seeing is Believing - Co-production Case Studies from Wales, Public Health Wales / Co-production Wales)

What co-production means in practice is acknowledging that everyone is an expert in their own life, everyone has something to contribute, and that enabling people to support each other builds strong, resilient communities, strengthening the relationship between citizens and service providers and improving the outcomes for everyone. The approach is underpinned by a set of key principles:

1. Value all participants and take an asset-based approach
2. Develop peer support networks & social capital
3. Focus on personal outcome - what matters to the individual
4. Build relationships of equality & reciprocity

5. Work in partnership with the people who use our services, as catalysts for change

Co-production is about people from different backgrounds working together as equals. This means children with complex needs and their families, working together with health, education, housing and social care professionals, providers or bosses of services, to change people's lives for the better. Co-production is about building relationships where people respect each other to achieve long term goals. It is more than just talking or asking people what they think, but about doing the work together - from start to finish.

There are four essential features of transformative co-production which together make it different from anything that has preceded it:

- **Relationships of equality and reciprocity:** Co-production is based on a re-alignment of the relationship between service providers, citizens and the state, shifting from paternalism to an equal partnership within which everyone is acknowledged as having something to contribute and something to learn.
- **Whole-system approach:** Co-production isn't an add-on. It requires behaviour and culture change, establishing equal and reciprocal relationships across all aspects of public service provision – commissioning, design, delivery and evaluation.
- **Outcomes-based process:** Much of our public service provision is led by organisational priorities. The co-production process focuses on what's important to the individual, their family, friends and communities.
- **Radical aim:** The operational aim of co-production is shared power and shared decision making.

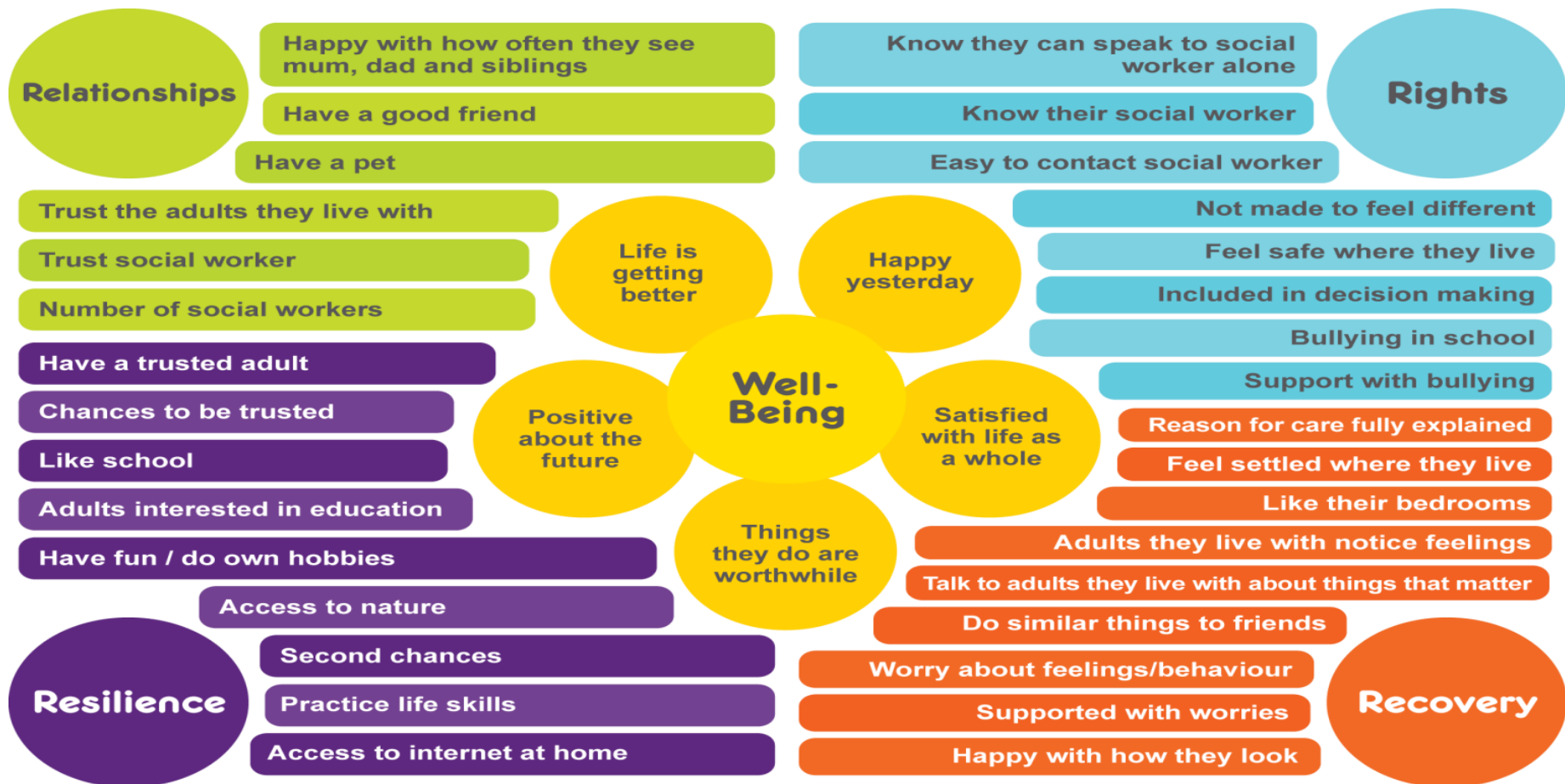
Example: Bright Spots

This research is part of the bright spots programme: a partnership between the University of Bristol and Coram Voice. The programme was originally developed in England with funding from the Hadley Trust. Bright spots in Wales is a pilot with six local authorities funded by the children's Commissioner for Wales and Welsh Government through the work of the 'Improving outcomes for children ministerial advisory group' to measure looked after children's subjective well-being - how they feel about their lives and their care.



Bright spots well-being indicators put children's experience and voices at the heart of how we measure well-being. Well-being is measured using the Your life, Your Care Survey which was developed from literature reviews, roundtable discussions with professionals, focus groups and individual interviews with 140 children and young people. The survey identifies where children feel things are going well and where things could be improved and provides an evidence base to inform service improvements.

www.coramvoice.org.uk/brightspots



Key Message

Children, young people, their families and commissioners are equal leaders in the strategic planning and commissioning of services.



TOOLKIT



The co-productive commissioning tool is a checklist for Regional Partnership Boards. It is based on a similar checklist developed by the Association of Directors of Social Services, Local Government Association and NHS England. The checklist enables Regional Partnerships to self-assess their approach to co-production and gain insight into how they can ensure that children and young people with complex needs and their families are equal partners in the strategic commissioning of services.

6.2 Person-centred services

Co-production supports the delivery of person-centred services. Person-centred services prioritise putting children, young people and their families at the heart of all decisions and plans about care and support. Person-centred services see patients as equal partners in planning, developing and assessing care and support needs to make sure service delivery is appropriate for their needs and will achieve well-being outcomes.

Person-centred services are people focused, promote asset-based approaches, provide choice and control and are based on a collaborative team philosophy. Successful services are individualised in a number of ways and everyone involved recognises the individual's needs. The starting point is the person's strengths and not the way they challenge services. Ways of supporting them to live a full life are the key consideration. Nurturing their friends, family and relationships are central aspects of any care and support plan.

Key Message

Co-productive commissioning on its own is not enough.

Services must be person-centred and built on the strengths of the child or young person and their family.



TOOLKIT



Achieving well-being outcomes is difficult without high quality, asset-based assessment and care planning functions. Regional Partnership Boards need to create the appropriate infrastructure, operational process and good practice to ensure high quality 'What Matters' conversations take place. Use the team reflection tool to support teams to identify the degree to which they are engaging in good practice within the legislative framework of the SSWB Act. The tool draws on recent **practice guidance for social workers registered with Social Care Wales**¹⁴ which describes what is expected of social workers, including codes of professional practice, and provides guidance to help practitioners provide a person-centred, high quality service.

7 Question: How do you commission sustainable, local services for children, young people and families who need a complex response? Answer: Relationship-based commissioning

Children and young people with complex needs require a complex response from services to get their needs met. A complex response is a response that requires input from more than one service area (health, education, social care, housing). Successful outcomes also often require engaging with other partners who can positively influence good commissioning such as the police, youth justice service, etc. Providers that have the skills to meet complex needs must also have the ability to work effectively within a complex system and with the range of wider stakeholders. The ability to work effectively with a complex system is dependent upon the values, attitudes and behaviours that providers, commissioners and other partners across the system bring to the table. Relationship-based commissioning emphasises the need for commissioners and providers/other partners to have trusting, respectful relationships as only then will they be able to work proactively and flexibly with children, young people, families and the community to meet complex needs.

The model for relationship-based commissioning builds on the IPC commissioning cycle. At the heart of relationship-based commissioning is the idea that we do our best work and hence achieve the best outcomes with people when we have good relationships. Good relationships are built on good rapport. We work best with people that we experience as warm, attentive and easy to relate to. Some people are able to do this naturally, while for others it is a skill they choose to develop. Either way, a bureaucratic, complex or challenging system can erode rapport and hence we must be mindful about the processes and procedures we use in our business relationships. The usual way of doing things in the context of commissioning and procurement has not always resulted in good, respectful and hence effective relationships between commissioners and providers.

¹⁴ The Social Worker: Practice guidance for social workers registered with Social Care Wales, 2017

This is due in part because commissioners and providers often see themselves as different, whereas rapport builds itself on features of sameness. Where there is a high degree of sameness we build rapport more easily. Relationship-based commissioning aims to support providers/other partners and commissioners to find common ground and from it to build rapport moving them to relationships of support and trust which in turn enables them to provide complex responses in challenging contexts.

Rapport Building Scale (Starr, 2011)

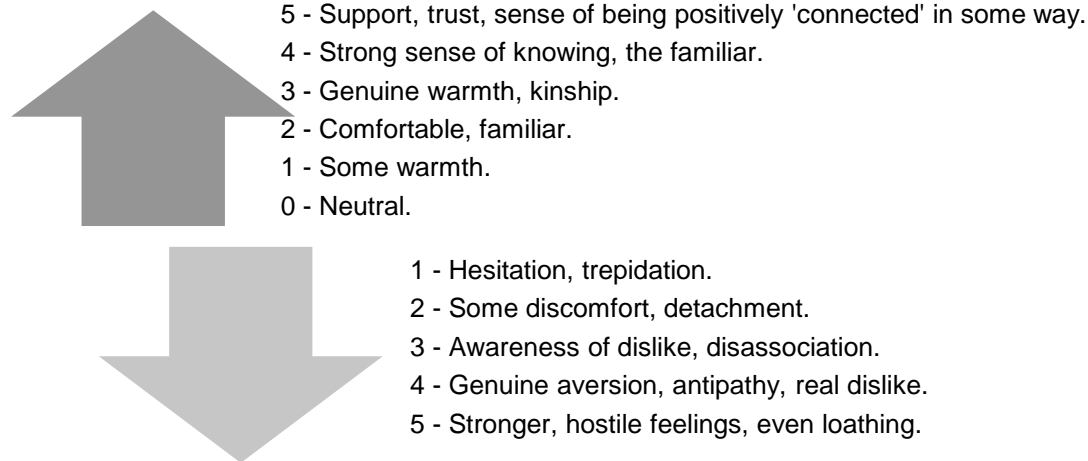
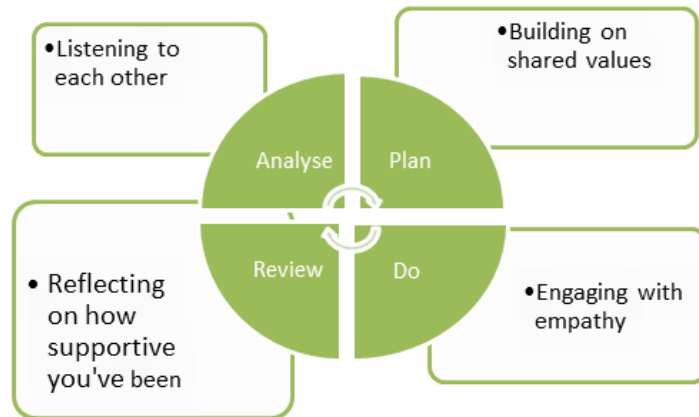


Figure ?? Relationship-based commissioning



7.1 Analyse

Any relationship begins with a first meeting, discovering common ground, and enough rapport to have a desire and agreement to meet again. For commissioners and providers it is important to get the tone of initial conversations right. Too often providers are invited along to meetings, events or forums only to be talked at, told what is required or informed they are currently doing it wrong. Unsurprisingly, this is no way to develop rapport.

The first and most important rule in rapport building is **the ability to listen**. Simply feeling heard creates rapport and by asking questions and really listening to the answers it is more likely that commissioners and providers will find potential common ground that is worth exploring and hence have a genuine desire to meet again.

7.2 Plan

The next step is to explore potential common ground by taking the time to really understand each other's context, wider business, drivers and business relationship needs. By exploring this both commissioners and providers will gain a deeper understanding of each other's values. This is the second rule of rapport building – **shared values**. Our sense of shared values, common aims and intentions are the underlying factors that create real relatedness and rapport. Where we share values we often like each other and feel a sense of rapport, but where we don't we feel detachment or even dislike. If we can't find shared values then we don't have enough common ground and our working relationship will falter down the line and usually at the cost of the children and families we are trying to support.

7.3 Deliver

The positive development of sustainable relationships is affected by principles such as integrity, consistency, openness and trust. Our ability to behave according to these principles impacts upon the sense of rapport we feel and hence the quality of our relationships. Behaving and being perceived as behaving with integrity, consistency, openness and trust when working with children and young people with complex needs within a complex system requires ongoing dialogue between commissioners and providers. Both must be committed to a learning culture rather than a blame culture and both must engage in the third rule of rapport building – **empathy**.

7.4 Review

Long-term relationships succeed because there is a shared common purpose and clarity about who contributes what and how. Achieving this within the context of relationship-based commissioning is about going beyond identifying shared values to co-producing desired outcomes, agreeing how these will be measured and the role each person/organisation has to play in both achieving the outcomes and supporting or enabling the other partner(s) to play their role in achieving them too. It is this ability to both behave in ways that achieve the outcomes AND to behave in ways that support others to play their role which is crucial to maintaining a sense of rapport. The army have a saying when training recruits: 'remember you should not be acting with the sole purpose of protecting yourself, you should be acting with the purpose of protecting the soldier next to you'. This gets to the heart of maintaining rapport. The fourth and final rule of rapport building is **support**.

Key Message

Effective service delivery for children with complex needs necessitates good relationships between commissioners and providers. Achieving this requires engagement in relationship-based commissioning that focuses on rapport building.



TOOLKIT

Use the 'Relationship-based commissioning – Top tips from providers' to reflect on your current interactions with providers and the relationships you have with them. The top tips were collated by a group of providers who provide education, support and care services to people (including children and young people) with complex needs across Wales and England.



8 Question: What support do Parent carers need? Answer: A holistic approach to supporting their well-being.

8.1 What is the experience of parent carers?

Coming to terms with a caring role can be a long and painful process that requires a huge emotional adjustment. The reality for parent carers in terms of the tasks and roles they perform, the emotions they go through and the quality of life outcomes that they experience

are well documented. Recent research undertaken by Contact asked parent carers to identify the 3 main challenges or worries they were facing regarding their child with a disability or additional needs. The most commonly identified challenge for parents was their own Mental health and wellbeing and that of their family. The other two top challenges focused on a lack of support around managing risky, challenging or harmful behaviour, and fighting for support to enable their child to access education.

Parents were given the option to say more about their concerns. A number of parents took this opportunity to list the impact that their concerns were having on their life.

The situation is causing me severe depression as it's a never ending battle for every crumb of support. Anxiety is a constant state and our whole family struggles because our lives have to revolve around [child]

In addition a number of parents specifically mention the fact that there's not enough services, that the services are inadequate, or that they don't know about what is available, and also their worries about their child's future.

I feel as though we aren't being checked up on enough, and that our struggles with behaviour aren't taken seriously at all. [...] We aren't sign posted enough to where to turn to for any help or second opinions. We also never get told about any activities going on for children and families with disabilities. As a result our family suffers greatly, especially with activities together which rarely happen anymore. His sister never gets any attention as I'm constantly having to deal with his behaviour.

My son has not received any support at all and is deteriorating in all areas of life. He's been seen by the school's Educational Psychologist, ASD TEAM and the Neurodevelopmental Service all outlining that he needs OT and Behaviour support yet no support has been given! I am so frustrated that I cannot find anyone to help me.

In many cases, the detailed comments added by respondents made links between the different issues, e.g. finances or (lack of) respite care affecting health and well-being; or lack of education provision affecting ability to work and therefore finances.

Mental health is affected by the constant fight parents have to get services/needs met. We've had to go to tribunal to get DLA, we are fighting school for support. OT took more than 4 years to get a diagnosis.....we spend our life fighting everyone for help that should be put in place without asking.

My son has very challenging behaviour and we are mostly house bound now, we are seeking the possibility of medication, but of course it's a process that like everything is taking forever, as is the provision of respite as in principal, provision has been agreed but no provision of any sort has yet been forthcoming! Meanwhile as a family we are all suffering, become increasingly isolated [...]

I am concerned about the next level of education for her including transport getting to and from college and access to a one to one as she gets older. I am also worried about being able to adapt my house for her sufficiently as she's getting older and her needs change, the time all this takes to complete if you're lucky enough to get it. I'm also worried about what happens after she leaves high school and having someone to look after her when I have to work, does this mean I have to give up work?

I have to work full time, I'm a single parent, I have no idea if I could get any financial help which would let me reduce my hours. My child has been suicidal [...] Been referred to CAMHS who say it's related to 'high level of anxiety due to autism' and they can't offer her any help. Obviously, all this has an impact on myself and her siblings.

Further research has been undertaken by the Institute of Public Care and the University of Kent. Focus groups with carers identified the following themes:

- **The Scale of the Caring Role:** It was clear from the vast range of tasks each parent carer was engaging in that the things they did with or for the child they cared for covered every aspect of daily living. It was also clear that for many of the Parent carers there wasn't much they didn't do either with or for the child they cared for. The range of tasks and their complexity meant that all the Parent carers performed multiple roles for the child they cared for. For some Parent carers there was an element of being forced to take on roles they didn't want and that fundamentally changed the nature of their relationship with their child. The shift in roles and the impact it had on people's relationships meant that 'being a parent carer' affected every aspect of their lives. The scale of the caring role isn't just the number of tasks Parent carers are doing or the number of hours they care for. The scale of the caring role is related to the range of roles a parent carer ends up playing for their child and the impact this has on the relationship. The enormity of the caring role, the complexity of the tasks involved and the emotional toll of wearing so many hats is seemingly made harder by the onslaught of crisis after crisis, a system that is at breaking point and doesn't successfully involve Parent carers who end up 'picking up the pieces'.
- **The Skilled Helper:** Many people become Parent carers due to negative change in their lives e.g. their child has become physically or mentally ill, had an accident or been born with a disability. Therefore, many Parent carers wish that they were not having to care because they wish the outcome for their child had been different i.e. had not become ill, had an accident or been born with a disability. The nature of the relationship between the parent carer and the child, means that the parent carer naturally becomes THE default carer. When they look around there is no one to hand the caring baton on to because they are the parent who lives with the child and there is an expectation that they will care for them. The love Parent carers have for their child means

that they want to protect and look after them. Yet, taking on the caring role is still less of a choice and more of a default position they find themselves in. Not only do Parent carers find themselves as THE default carer, they become THE skilled helper. This is not least because they tend to be the person who knows the child best. They know the child's likes, dislikes, what's important to them, how they like to do things, etc. The knowledge they have about the child they care for makes them very skilled Parent carers and so they become THE skilled helper. Quite often in the eyes of the child and professionals THE skilled helper is the preferred care option. The role of THE skilled helper takes over from everything else resulting in a loss of identity. Being THE default carer, the one skilled enough to help, demands availability at a moment's notice. For many Parent carers becoming THE skilled helper means that they are very restricted in what they can do and when they can do it which results in a further loss of identity. In summary becoming THE Skilled Helper is less of a choice and more of a default position that results in the loss of other roles and a loss of identity. Ultimately, it results in huge levels of sacrifice.

- **The Hidden World of the Parent Carer:** No one really knows what a parent carer does because most of it occurs behind closed doors, in the family home. From the perspective of service provision and professionals the spot light is on the child. Meanwhile the parent carer moves around the shadowy edges trying to keep all the plates spinning with little recognition of the expertise they have or the job they do in the background. This lack of recognition of the role of the parent carer is compounded by a lack of acknowledgement of the impact the condition of the child has on the parent carer. So not only are the tasks a parent carer performs invisible because they occur, in the main, behind closed doors but Parent carers are often ignored by professionals to the point that they feel invisible and the feelings Parent carers experience remain hidden because no one seems to understand or be able to really listen to them:

'It's just such a dark world, you know, the carer's world is such a dark world because people think they understand but actually until you're put in that position day in, day out, they have no idea what it's like to apply yourself in the same situation over and over again.'

This results in the life of a parent carer becoming increasingly hidden as they isolate themselves more and more:

'You isolate yourself because other people don't understand.'

As the world of the carer becomes smaller and more isolating so their feelings of desperation increase and there is a loss of hope for the future:

‘...you can’t necessarily see an end point, it’s not like, oh well I’ve only got this for a couple of months and then it will all be okay.’

8.2 What is the experience of adoptive parent carers?

Adoptive Parent Carers report similar issues where adoption support packages do not anticipate the level of support required or aren’t delivered effectively. One mother says:

“There’s this pretence that the different services know how to work together, but they constantly prove not to. I was constantly being bandied around between the services. It took an extraordinary amount of resilience to fight with all the services at the same time. It was very difficult.”

As with wider research fighting to access education is a key theme. Adoption UK research has shown that adopted children are 20 times more likely to be permanently excluded from school than their classmates, and they are much more likely to leave school with no qualifications.

8.3 What is the experience of foster parent carers?

There may be a presumption that because a foster carer is a part of the care system around a child that their experience of accessing support and services is better, however, many foster carers’ talk of the challenges they face and the impact that not having the right support at the right time can have on them, their foster child, their ability to care and sustain a placement.

When a child is Looked After the responsibilities of their parents are delegated to a wide number of professionals not only to foster carers but to social workers, specialist nurses, paediatricians and others. This delegation of responsibilities can make it harder for the foster parent carer to co-ordinate services if those services are not commissioned or delivered in an integrated way. The Fostering Network notes that:

“Coordinating the activity between a public authority and the NHS can be a complex task for anyone however foster carers will need to meet these challenges in order to assess, address and promote the health and wellbeing of children in their care.”

8.4 Carers Model of Support

In a time of austerity smart commissioners will pay close attention to carers, exploring how to sustain caring roles by providing access to support that minimises the burden and maximises the wellbeing of this population. Based on the findings from the focus groups, IPC and the University of Kent have worked with carers and carer centres to develop a Carers Model of Support.



8.4.1 Support to navigate their ever-changing relationship with the child they care for

The caring role is time consuming and exhausting. The nature of the tasks and roles a parent carer has to play and the need to be on permanent standby can be overwhelming. This coupled with any behaviour issues can result in a poor relationship between the parent and the child. Furthermore, as the child grows and develops the nature of the relationship between the parent and the child can also change or may need to change. Navigating these changes for any parent can be tricky but doing so when your child has complex needs is even more difficult. Constant battles, feelings of resentment and dislike alongside feelings of love, guilt and sometimes even despair can affect the emotional well-being of parent carers.

8.4.2 Support to manage and cope with the condition(s) the child has and the symptoms they display

Different conditions result in different symptoms, behaviours and complexities. Different parents will cope with different symptoms, behaviours and complexities to lesser or greater degrees depending on their context, family dynamics and individual personalities. Learning what the symptoms, behaviours and complexities are likely to be and potential ways of managing them can be a useful way for parent carers to increase their ability to cope. Parents of disabled children can access support from relevant third sector organisations such as the National Autistic Society or the Downs Syndrome Association. The organisation Contact for families with disabled children also run free workshops for parents of disabled around their child's needs.

8.4.3 Support to maintain their sense of identity past that of parent carer

The overwhelming nature of the caring role and the time it often takes means that many parent carers have to stop other activities. In doing so the roles they engage in outside of parent carer reduce. The more their world shrinks, the more isolated they become and the more roles they give up the harder it is to hold on to their own sense of identity past that of parent carer. Losing other identities is one of the key reasons for reduced emotional well-being. Enabling parent carers to engage in roles outside of their parent carer role is therefore one of the key ingredients to maintaining their well-being and ability to cope.

8.4.4 Support to communicate and work with professionals (individuals and organisations)

The less parent carers are listened to or involved in decision making and the more they have to battle to be heard and understood the poorer the relationship with professionals and the lower their resilience and ability to cope. Definitions of resilience highlight the fact that resilience is not a personal characteristic. The ability to navigate one's way to resources and support that helps and MOST IMPORTANTLY, the willingness of organisations to provide such help and resources has a major impact on a parent carer's well-being and ability to cope. When parent carers do not get access to the things that they state will help, their well-being and ability to cope is undermined.

8.4.5 Support to navigate and manage the changing dynamics with family and friends

Caring for a child can put many pressures on the family dynamics. Parents are more likely to suffer marital problems and there can be a significant impact on other siblings. The wider family can be a source of support or stress as can friends. In many cases parent carers increasingly isolate themselves particularly at times of stress if they do not have family and friends who listen to them, accept their emotions and their opinion of what will make a difference and are willing to help facilitate this. How supportive a parent carers' family and friends network is, will impact on the parent carer's emotional well-being and ability to cope.

8.4.6 Support to ensure the community they live, work and socialise in does not discriminate against them

Parent carers dream of a community that facilitates access to the things they need to keep caring. A community that values their expertise as a parent carer and recognises that they are often the person who knows the child best. A community that sees parent carers as more than that and supports them in a holistic way to engage in a life that is meaningful to them. A community that supports them to adapt to their ever-changing relationship with the child they care for. Creating such communities requires investment in raising the awareness of the issues and challenges parent carers face.

Example: Contact 'Brighter Beginnings'

Brighter Beginnings is Contact's programme of early years' workshops and supports families of young disabled children through dedicated advice, information and resources. It seeks to build parents' skills, knowledge and support networks, to ensure that more families are able to focus on what's most important – being together and growing as a family.

Funded initially by a philanthropic donation, Contact launched the testing and pilot phase for what has become Brighter Beginnings in September 2016. The Development Officer & Parent Advisor worked with families in Wales and the North West of England, to develop and pilot this new series of workshops dedicated to the particular challenges and opportunities of disabled children aged 0-9. The workshops were developed by Contact and an internal working group of Contact's parent advisers across the country. Workshops have now been delivered across Wales and all English regions.

The project has evolved since its inception, and now comprises of a set programme of six workshops that cover the following topics:

- a welcome session and introduction to sources of support;
- understanding sleep;



- building parental confidence;
- encouraging positive behaviour;
- money matters;
- support for you.

It has become clear that families benefit hugely from the additional information, trust and networks they build up by attending a series of meetings with the same group of parents. One example is two mums who over the course of the sessions both acknowledged their guilt at not leaving abusive relationships while pregnant and their fears that this had contributed to their child's condition. The relief both mums felt at sharing their fears, knowing they weren't alone and being reassured by Contact's parent adviser was invaluable and may not have been achieved without the opportunity to build trusting relationships by attending a number of sessions rather than one off events.

Ongoing support, advice and information is available after the workshop series has ended via Contact's Freephone Helpline, online guides and factsheets, and a Helpful Guide which provides ongoing advice and signposting to families with disabled children. In addition, Contact encourage parents who have built relationships during the course to maintain contact with each other. This can include establishing new peer support groups in the area.

Case Study

Sally's three-year-old son Mason has been diagnosed with autism (he is non-verbal) and hypermobility syndrome.

The special needs nurse at Mason's nursery let Sally know about Contact's Early Years workshops and Sally, who was struggling to understand Mason's behaviours and how best to handle them, felt they would be useful for her.

Sally found the workshops welcoming, friendly and professional. "It was really, really good to meet other mums – it made me realise I was not alone."

Thanks to the workshop Sally found there was more support available to her and her son than she was previously aware of. The family had not been awarded the mobility component of Disability Living Allowance as Mason was thought not to have a physical disability, but she is now appealing the original decision "only because the workshop told me which road to go down." In addition,



Sally's family has had to leave their home – Sally was made aware of a charity who could provide support with their move into an unfurnished property.

Sally's confidence has increased significantly since the workshops. Previously she used to feel "like an idiot" when meeting professionals - but the workshop "taught me that I'm the expert on my child. It doesn't matter how many degrees you've got, I know more than you because I live it every day."

This increased confidence has also helped Sally with difficult situations in public. "I understand more about my son's needs and how to deal with them. When Mason had a breakdown in public I used to run away and try and remove him, but now I try and deal with whatever is bothering him at the time. I used to be worried and anxious taking him out. Now I'm not, he needs to be a little boy – if others don't like it, then they don't like it."

In conclusion Sally said "If it wasn't for the workshops I would be anxious and down in myself. They have changed my and my son's life – they have made things better, they really have. I would advise anybody who has a child with additional needs to go."

Key Message

Smart commissioners will pay close attention to parent carers, exploring how to provide access to support that maximises their well-being.



TOOLKIT

Use the carer support model audit tool to benchmark the range and intensity of support in the community for carers.



9 Conclusion

This guidance is not statutory guidance. It has been developed as good practice guidance and its development has involved a wide range of stakeholders. It should stimulate discussion and is designed to help Regional Partnership Boards develop their approach to the integrated commissioning of services for children and young people with complex needs and their families. This will depend on having an integrated approach to information and support services, assessment and care planning, developing shared data systems etc.

The National Commissioning Board (NCB) will include the guidance and the toolkit on its website and will also be including further examples of good practice in terms of service development. We hope that the Regional Partnership Boards will be proactive in sharing good practice with the NCB to facilitate learning across Wales. This equally applies to all partners. Where good practice is identified the NCB wants to work with partners to share learning.

The NCB will hold discussions with colleagues in Welsh Government to discuss options for sharing the guidance in a way that can complement the work of the Ministerial Advisory Group in relation to looked after children.

The development of this guidance has proved to be a very positive experience we are also conscious of its limitations. Inevitably it has not been possible to discuss the needs of specific groups in detail. As the guidance is disseminated we can discuss what further areas of work are required.

Regional Partnership Boards should use the tools in the toolkit to benchmark their current arrangements, identify their strengths and to support them in their improvement journeys.

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ANNEX 1 Diagram from Pembrokeshire.