

National Commissioning Board Wales

Integrated services for children and young people with a disability in Conwy

A case study

February 2019

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1 Introduction

This case study has been written for the National Commissioning Board Wales, to be published alongside the Good Practice Guidance for Regional Partnership Boards on the Integrated Commissioning of Services for Families, Children and Young People with complex needs, (IPC 2018).¹

The guidance is designed to assist the seven Regional Partnership Boards in Wales to develop an integrated approach to the commissioning and delivery of services for children and young people with complex needs. Local authorities and health boards are legally required² to work in partnership to provide the range of services that need to be put in place for children with complex needs.

This case study provides an example of effective integration both at 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 a range of care and support services that respond to complex needs and improve outcomes for children and their families.

2 What are the services and how do they work?

Conwy benefits from a wide range of services for children and young people with disabilities and complex needs provided by social services, health, education and the community and voluntary sectors. The services selected for this case study, shown in the diagram below are exploring different approaches to integration, with the common purpose of “unlocking potential and creating better lives”³ for children with disabilities.

This is facilitated through:

- Co-location
- Multidisciplinary teams
- Staff and projects that are funded through the Integrated Care Fund⁴

¹ Institute of Public Care (September 2018) *Good Practice Guidance for Regional Partnership Boards on the Integrated Commissioning of Services for Families, Children and Young People with complex needs.*

² Section 13, Part 9, statutory guidance under Social Services and Wellbeing (Wales) Act, 2014

³ From: *Vision Statement for Disability Services in Conwy*

⁴ The Integrated Care Fund is a pot of money from Welsh government that helps health boards and partners in local authorities, housing, the voluntary and independent sectors to work together to support frail and older people; people with a learning disability; children with complex needs due to disability or illness; and carers, including young carers.



2.1 Children and Young Adults with Disabilities under 25 - Conwy County Borough Council

Four years ago, in response to the Social Services and Wellbeing Act (2014), Conwy Council restructured its provision for people with disabilities as part of their Social Services Transformation Programme. Three new teams were created: children and young adults under 25, adults over 25, early intervention and prevention and community support services working within **one integrated disability service**. In addition, closer links have been made to the local health services with the aim of providing equality of access to support and resources across the age range based on assessed need.

Recognising that a new way of working was required in keeping with the 2014 Act, the Service “helps people work out ‘What Matters’ to them, for example where they want to be and what they want to achieve; how they’re going to do that; what they need to do; what others can help them with and what help they need from us” (*Vision for Disability Services in Conwy*).

In terms of children and young people, the service is available to those who have a significant and substantial long term disability as defined in the Equality Act (2010).⁵ In line with the Social Services and Wellbeing Act (2014) the team ensure that the 4 stage eligibility criteria is applied, exploring universal and community based activities if appropriate to meet individuals outcomes. From the outset, services work together to support parents and children. Referrals are made by a range of professionals eg community paediatricians, schools, children’s social care, as well as parents - all contributing to an initial ‘simple assessment’ that informs a joint plan focusing on outcomes and progression. Packages of care provided by the Diana Nursing Service are usually funded 50/50 by health and social services. Plans also include support to access universal services and community and voluntary sector run activities to improve health and wellbeing eg sports and leisure, music and drama. Carers assessments are also carried out and support for families to enable children to live at home is a key part of the package.

⁵ Equality Act (2010) Section 6 (1)

Key benefits of being part of an all age service include:

- Greater profile for children's service, equality of access and resources across the age range
- Skills and knowledge transfer between children and adult teams, flexible workforce and greater shared understanding of legislation, policy and practice across the whole lifespan
- Children and families can access Community Support services including sessional workers who are registered for domiciliary care
- Children can access the Early Intervention and Prevention team which includes a Progression Service that works with a person to identify what is important to them and develops plans to achieve their personal outcomes eg learning to travel independently
- Young people can keep the same social workers and support workers when they transfer to the adults service, providing consistency for individuals at key points in their lives e.g. moving from school to college
- Creative use of direct payments – families can access a pool of (all age) direct payment workers to deliver tailored support eg early morning help to get children ready for school; accompanying a young person on the bus to college (instead of expensive taxi) to build confidence and independence
- Investment in children and families early on benefits adult services ('spend to save') – more likely they will be able to stay living with family/progress to independent living rather than expensive residential placements

2.2 Early Years Child Development Centre – Betsi Cadwalader Health Board (BCU)

The Conwy Early Years Child Development Centre provides co-ordinated care for children aged 0-5 with complex disabilities. The centre, based on the same site as the special school - Ysgol y Gogarth and the Children's Disability Service, enables families to access support from a range of disciplines. A multi-agency panel including a community paediatrician, clinical psychologist, speech and language therapist, physiotherapist, specialist teacher, educational psychologist, and social worker meet regularly to consider referrals, carry out holistic assessments and decide on interventions. The aim of the holistic approach and early intervention is to reduce or delay the need for managed support. Person centred planning is key. Parents and carers are fully involved with every aspect of care delivery, which promotes confidence and independence in supporting their child. Person Centred approaches ensures that the voice of the child is heard. Examples of interventions include:

- Early support by the team social worker to help families come to terms with a diagnosis, develop trusting relationships and encourage engagement with services
- Behaviour management and play based groups run in the centre
- Home based intensive intervention in the evenings and at weekends such as sleep management
- Early intervention and behavioural support in nurseries and schools
- Training on Positive Behaviour Support for parents/carers

- Partnership working with occupational therapists to support the provision of safe space equipment and housing adaptations

Having an **integrated team** with staff employed by the Health Board and the Local Authority based together and delivering co-ordinated care is successfully setting in motion a vision of developing potential and enabling progression from the very beginning of a child's life, however complex their needs.

2.3 **Child and Adolescent Learning Disability Service (CALDS) - Betsi Cadwalader Health Board (BCU)**

The CALDS service provides support to children and young people with learning disabilities aged 5-18 and their families. The primary purpose of their work is to prevent escalation of crisis and family breakdown, which could lead to loss of placement. The service is underpinned by an **enablement approach**, helping families to feel confident to support young people at home. Families are supported at times they find difficult, this may include early mornings, supporting the child into school and evening and night, including weekends, supporting with sleep routines. The aim is to transfer skills and avoid long term reliance on services.

As well as supporting in the home, CALDS workers enable children to access community activities and workshops to help them integrate in the community and develop skills for daily living. More recently CALDS workers have been going into school and working with the Applied Behaviour Analyst to check that what they are doing with the family at home is consistent with the school approach, for example re-enforcing positive behaviour principles that are being learnt at school. They also liaise with personal assistants working under Direct Payments and sessional support workers employed by Social Services to ensure consistency.

A new and innovative role in the team is the Integrated Social Worker post, funded by the Integrated Care Fund (ICF) working with children from birth to 18 years of age. The purpose of the role is to work in collaboration with Social Services, CALDS, Early Years and the Child Development Centre across Conwy County. The ICF project fits with the ethos of the SSWB Act 2014, making greater use of community based assets and is coherent with the principles of the Act e.g. early intervention and prevention, reducing and delaying reliance on managed support and focusing on empowering children, young people and families to develop resilience. The role helps in breaking down barriers providing a link to Social Services to facilitate the sharing of information and establish a trusting relationship with families who may be wary of statutory interventions. The ICF project promotes prevention of escalating need in that the right support is available at the right time. CALDS, Early Years and Social Services are supporting the wellbeing of the family holistically. The role is a broad one and can include joint visits to introduce CALDS nursing staff; care co-ordination - helping families to understand the network of professionals involved with their child; and support with wider needs such as helping to claim benefits eg disability living allowance, or finding suitable housing. By providing active support at difficult times for example supporting a child into school we are enabling parents/carers to continue with their daily activities including work.

2.4 Ysgol Y Gogarth special school and Llys Gogarth residential facility – Conwy Council Education and Social Services

As part of its Transformation programme, Conwy Council has joined up Education and Social Services in a single directorate. In terms of children with disabilities and complex needs, this has helped to facilitate the development of a **joint residential respite centre**, located within the school grounds, that is available to children attending the school as a rolling education programme as well as providing a respite service to support families.

Ysgol Y Gogarth is a day school for children aged 3-19 with a wide spectrum of global development delay, physical disability and additional learning needs ranging from Profound and Multiple Learning Difficulties (PMLD) to Moderate Learning Difficulties (MLD) and Autistic Spectrum Disorder (ASD) with a high level of need with associated emotional and behavioural difficulties. The state of the art building overlooking Llandudno Bay combines excellent learning facilities with health clinic and therapy rooms, a climbing wall, therapy pools and two large sensory rooms.

All children from Year 7 as part of the school rolling programme are offered the opportunity to spend time in the residential facility to help them develop confidence, resilience and personal living skills such as cooking, planning and shopping to prepare for living as independently as possible. The facility has ten bedrooms over three flats, with kitchens, living and dining areas and is open throughout the year. The programme is adapted to suit the individual and might consist of a few hours in the day during a holiday period, a tea time visit during the week, 1 or 2 nights over a short time period, progressing to longer stays spread over a year. The ethos of the centre is to provide a positive and caring environment that promotes the development of the whole child.

Assessment is completed by a Social Worker in collaboration with the child/young person and their parents/carers, this will focus on individual's strengths, barriers and risks. From the assessment, individual outcomes will be identified. Where it is agreed that the provision of overnight respite may be required to support the child and family to achieve their wellbeing outcomes local provision is explored. A multi-agency meeting with representatives from social services (including the Looked After Children team), health and the school will determine whether a respite placement at Llys Gogarth or alternative provision will enhance the young person's independence, wellbeing or safeguard them. The provision of respite at Llys Gogarth (or alternative) is part of a wider package of care that includes preventative work. For example, if a child isn't sleeping, the family may desperately need the short term break that the respite centre can provide. However, in order to tackle the problem longer term, part of the holistic response will include CALDS follow up with a sleep programme at home, to teach parents techniques and strategies to improve sleep pattern. Health Care support workers currently funded via the Integrated Care Fund and located with the Diana Nursing Team also support children with complex medical needs to access the facility.

Emergency admissions when care arrangements have broken down are also possible and have proved to be a life line for a number of children who might otherwise have been accommodated out of area. These short term arrangements have enabled children to continue to be around familiar people and family networks and attending school, while more permanent placements are being sought.

3 What has been achieved – for families, for services?

- All children with disabilities in Conwy except one are currently living in county, with their family or foster carer (150 families/carers)
- Additional health support within holiday clubs is successfully enabling children and young people with complex needs to integrate into mainstream activities, have new experiences and develop independence
- Flexible outreach support in the home, including out of hours, supports the wellbeing of the whole family and prevents escalation of need
- Joining up the children's respite service with the school has extended availability to all year round and includes a package of care that includes prevention, so that in the longer term the need for respite is reduced
- The young person is able to access respite at Llys Gogarth until they leave school at the end of year 13 (where appropriate), this is also the case in relation to access to the children's clubs
- The respite service also supports the LAC service whilst they source appropriate local provision, providing a potential stop gap and helping to avoid out of county or country foster or residential care placements
- Smooth transition is achieved by having one lifespan service which gives children and parents continuity, and support from social workers who have a good understanding of options as the young person becomes an adult
- The development of practitioners who have a breadth of knowledge across children and adult service provision supports not only the child and family to understand options and choices but also partners in Health and other organisations who remain focused on a particular age group
- Children are benefiting from extra investment as resources are being spread more equally across the all age service, resulting in improved skills development early on that may lead to reduced support later on in their lives

3.1 What has enabled the achievements?

The key enablers include:

Strong strategic leadership of the Central Area Health and Wellbeing Integrated Service Board. The Chair has a long history of managing services both within the local authority and in health and ensures that there is equal partnership of all members of the Board.

The Integrated Care Fund has been used creatively to pay for joint posts such as the Integrated Social Worker and for additional health support to enable children with complex needs to access both respite provision and mainstream community activities. The Integrated Care Fund provides an opportunity to pilot different approaches, develop proof of concept in preparation for mainstreaming the approach.

Conwy Council Social Services Transformation Programme has applied a whole system approach to embed change, using change management principles that engage and support staff, resulting in high staff morale and commitment to their work.

Joining up Education and Social Services has facilitated the development of a *Person Centred Practices (PCP) strategy* created by the school, young people, Disability Service and Additional Learning Needs Service which now informs practice across education and social care.

Co-location at Ysgol Gogarth facilitates joint working, enabling strong working relationships to develop and a collective sense of pride in what is being achieved together.

3.2 Challenges

Capacity to work preventatively across all agencies is stretched; demand is growing and there are more children with complex needs.

“Working with people to shift the culture from one of dependency on traditional service models to an approach based on looking at the individual and their resources holistically, focusing on what matters to them and the wellbeing outcomes they want to achieve.”

Disability Service Manager.

Management structure change gets in the way of developing integration plans.

Finding the right support in the community, particularly now at a time when grants to the community and voluntary sector are being reduced.

Health and Social Services not having shared access to records but the hope is that the Welsh Community Care Information System (WCCIS) will change this.

Differences in the age groups that services work with, ie CALDS go up to 18, children and young people’s disability services go up to 25.

Shortage of short break foster carers and difficulties in recruiting social workers for the 0-25 age group as it requires knowledge and skills across children and adults.

4 Next steps

Much has been achieved in the four years since the Council and its partners began their transformation of children’s disability services but there is always more to do. The local authority has scoped a ‘single point of access’ and is in the process of developing options going forward.

Disability services would like to be more joined up with Family Centres. The first centre, at Abergele is up and running and benefiting from co location of health staff. There are plans to establish four more centres and to explore opportunities for early intervention with families who are below threshold for statutory services but would benefit from some early help with coping strategies and self-management. There is the possibility of exploring health professionals working from family centres to provide intensive support around behaviours that challenge, toileting and sleeping, providing training but also outreach support within the family homes to implement strategies. We know that when parents are tired it’s difficult to implement all the strategies suggested within training

sessions, having someone there to provide support at difficult times is key to ensuring consistent application of strategies for some parents. In addition there is a need to develop a resource to provide emotional support to parents and carers around their child's disability.

Conwy's Corporate Plan includes a wellbeing outcome as follows - people with disabilities and chronic conditions will have the best quality of life possible. The Local Authority and partners work together on key priorities to deliver on this outcome. The Disability Service Manager chairs the group associated with delivering on this outcome and it is attended by health and the third sector. We consult with groups to identify key priorities and establish work groups to take priorities forward. Conwy PCP Strategy was developed as a result of consultation. The task group included children from Ysgol Gogarth, Education, Health, Social Services and the third sector working.

Overall, a sense of optimism about continuing progress prevails and is reflected in this quote:

"The parliamentary review and regional transformation bids for Learning Disabilities and Children's Services will assist us in moving forward to scale up good practice and develop new integrated approaches to create seamless services."

Disability Service Manager.

The following story exemplifies the change in individual's lives that is being achieved:

Support worker Sarah works with a young person called Ella. Ella has a mild learning disability and a number of health conditions which has affected her confidence and self-esteem.

When Sarah started to work with Ella, Ella was painfully shy and did not want to go out of the family home, Sarah built a trust with Ella by finding out about the things she enjoyed this included the arts particularly reading and acting.

Sarah started by baking with Ella in the family home and once Ella felt more confident they started to visit art galleries, pottery studios, this led to Ella taking part in photography and writing about the things she had discovered.

Ella then started to write poetry and built the confidence to read her poems to those closest to her including Sarah and myself. This was magical and Ella through her words transported you to the place she was writing about.

Sarah then started to take Ella to a drama group and her talent for the arts and acting was recognised and she was contacted by a film director to take part in the film recently filmed in Llandudno, Ella was over the moon. She played the part as an extra and had hair, make-up and costume fittings to fit the role, was paid for the role and got to meet the stars of the film.