

National Commissioning Board Wales

The Integrated Service for Children with Additional Needs (ISCAN) in Gwent

A case study

January 2019

National Commissioning Board Wales

The Integrated Service for Children with Additional Needs (ISCAN) in Gwent

A case study

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 is the Integrated Service for Children with Additional Needs (ISCAN)?

The Gwent ISCAN service covers the whole of the region and provides a single point of access to services for children and young people aged 0-18 years who have two or more developmental needs and those with suspected Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). The service is divided into three sectors: West (Caerphilly), North (Blaenau Gwent, North Monmouthshire and North Torfaen) and South (Newport, South Monmouthshire and South Torfaen). The three ISCAN teams are centred around the children's centres in each area – Caerphilly in the West, Nevill Hall in the North and Serennu in the South, each one acting as the single point of access for referrals in that area. Each team consists of an ISCAN co-ordinator, an administrator, a care co-ordinator, a family support worker and a family liaison officer. The service is headed up by an Integrated Children's Services Manager, who is also the Head of Occupational Therapy services and manages the Neurodevelopmental Service (which includes ASD and ADHD services), the Child and Adolescent Learning Disability Service and the continuing healthcare elements of these services. What is

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

immediately striking is the broad spectrum of roles included within the ISCAN service, which support both health and social care needs. The weekly ISCAN referral meeting brings together professionals from Health, Social Care and the voluntary sector and facilitates effective communication, information sharing and decision making across all the partner agencies and resulting in better outcomes for children and young people.

But things haven't always been this way. Over the last few years, services for children with additional needs in Gwent have been on an 'integration journey'. Faced with evidence that agencies were working in silos, resulting in duplication of services, long waiting lists and poor outcomes for children, senior managers from the Health Board, Children's Social Care and the Sparkle charity realised that things needed to change.

They began by listening to parents. In 2014, a parent and professional care co-ordination forum was established, and parents were able to express their frustrations with being given the 'run around' as they saw it, when they tried to get help for their children. Professionals listened to what families said was important to them and together they worked on developing a charter that families and professionals both agreed to sign up to and became the blueprint for a new approach to service delivery.

The Serennu charter (see [appendix one](#)) represents the underpinning values that parents said were important, for example, working in partnership, families being listened to, being able to speak to a person rather than an answerphone, and professionals giving open and honest responses. The values that staff highlighted as being most important were empowering parents, collaboration and the child's voice.

3 How has ISCAN developed over time?

3.1 Phase One of integration

The purpose of the first phase of re-organisation, launched in October 2016, was to streamline the referral process.

Once the ISCAN co-ordination recruitment process had taken place, the team began to look at how the 'single point of access' could be implemented effectively and seamlessly.

Previously, referrals had been made separately to different services resulting in a fragmented and siloed approach. Children were placed on multiple waiting lists, underwent several different assessment processes resulting in numerous plans, appointments in different places, and no-one to help them understand and navigate the system. Not surprisingly, the whole experience was described as 'overwhelming'³.

For the last two years, the new system has directed all referrals to one place to be considered by a weekly multi-agency panel in each of the three sectors comprising paediatricians, consultant psychiatrists, members of the neuro developmental team, representatives from across therapy services, educational psychology, care co-ordination and social services. The ISCAN co-ordination team ensures that all the

³ Interview with parents at Serennu Children's Centre, 30th November 2018

relevant information is gathered before the meeting so that an informed decision can be made without delay.

Outcomes may include a full neurodevelopmental assessment for children suspected to have ASD or ADHD or referral onto multiple services for those with physical disabilities. The ISCAN team is responsible for recording decisions, sending paperwork onto the relevant service and making sure that the outcome report is sent to the family, the referrer, the school/early years setting and the GP. They continue to follow up cases and track progress, so that nobody falls through the net. The result is a streamlined and rapid process that avoids duplication, ensures professionals consider the child's needs holistically and provides a transparent and managed allocation of resources.

A key message from the ISCAN co-ordination staff is that 'ISCAN is not a closed door'. Their 'no bounce approach' means that even if a child is not accepted for a statutory service, the family can be offered other options including a referral to a voluntary sector organisation such as Families First or to a Family Liaison Officer (one based in each of the three centres) who can help with practical and emotional support. For example, help with filling in forms for disability living allowance, applying for grants, accessing support groups, workshops and courses, leisure activities and clubs (both specialist and in the community). In the spirit of 'no bounce', referrals can also be redirected to specialist CAMHS or primary care mental health as appropriate.

One of the key challenges during the first phase of integration was for health professionals to relinquish the chairing role that they held previously at referral meetings. Taking on board input from a much broader range of professionals and agencies was a big change, but one that is now seen as beneficial and helpful for families and professionals. Co-location where possible, joint assessments and joint appointments are all helping to 'oil the wheels' so that what families experience now, is a seamless, joined up response to their children's needs.

The commitment and passion of the ISCAN co-ordination team, under the guidance of the Integrated Children's Services Manager, in ensuring that the single point of access has been well embedded in only two years has meant that Phase II of Integration has been implemented sooner than was planned.

3.2 Phase Two of Integration

Following a successful bid to the Gwent Children & Families Partnership Board for funding from the Integrated Care Fund,⁴ two new initiatives have started to be rolled out from October 2018 to support the next stage of integration:

- Integrated Assessment and Planning (IAP)
- Care Co-ordination

Informed by a 12 month research project funded by Sparkle to investigate what parents wanted as well as models of best practice in other areas, a new **Care Co-ordination**

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.

Service, delivered by three new sector teams each made up of a Care Co-ordinator and Family Support Worker, was agreed by the Partnership Board. This service, which is available to children who have multi-agency complex needs, provides the family with a single point of contact, co-ordinates services involved with the child and facilitates integrated assessment and planning (IAP) in the most complex cases.

Following a successful pilot in 2016-17 in the west sector, children who have multi-agency complex needs and are on several health waiting lists now qualify for **IAP**. This means one assessment process with all the relevant agencies feeding in, resulting in one plan that responds to the needs of the child and family holistically.



Key aims for the service are:

- Fewer children waiting on multiple statutory agency waiting lists
- More children receiving an integrated assessment and planning service
- Earlier intervention on a multi-agency basis
- Improved relationships with families who are in receipt of a co-ordinated and integrated assessment process
- More effective use of scarce agency resources as planning is not done in silos but on a shared and agreed basis
- More empowered families resulting in greater resilience

For more explanation of the care co-ordination model and how it benefits all members of the family see [appendix 2](#).

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

The integrated referral process (phase one) is certainly seen to be a huge improvement by both staff and those amongst them who are also parents of children with complex needs. Key benefits include:

- Fact finding is done before panel meetings, speeding up decision making
- Parent/young person can provide supporting statement
- Attendance at panel by professionals has increased, and papers are read in advance
- Family feedback is gathered via questionnaires and has been positive
- Stakeholders (family, referrer, GP, school) are kept informed
- Decision making is transparent
- Support is given even if criteria not met for a statutory service, e.g. signposting to community and voluntary sector
- Consistency across the three sectors
- ‘First contact is the right contact’
- Tracking of children and young people into the right services
- Children and young people are being seen more quickly – waiting times for neuro developmental assessment have reduced from over 18 months in some cases to within reach of the 26-week target

Feedback from families and professionals is likewise very positive about the family liaison role:

*“The family liaison officer is one of the most sought after people at the centre....
The help both professionals and families get from this role is essential”*

Reception staff

“Thank-you for listening, thank-you for allowing me to cry and thank-you for all your reassurances”

Parent

“The family liaison officer provides a lifeline to these families who are just starting a journey that can be extremely daunting and challenging”

Administrator

“knowledge of where to signpost enables families to access many support networks and activities which we would not be able to offer the family without the service”

Speech and Language Therapist

A successful recruitment process for phase two implementation is now complete and posts have been filled by high calibre staff, with a range of experience including teaching, occupational therapy and family support. One third of the new ISCAN staff members are also parents of children with complex needs and their lived experience adds a very helpful dimension to their new roles.

It is still early days to be able to measure benefits and impact of the phase two developments. However, care co-ordinators have started to collect case studies that are already demonstrating positive outcomes for families. See appendix 3 for examples.

The business case includes several ways that outcomes could be evaluated.

These include:

- measuring the cost of professionals' time saved through not having to invest in care co-ordination activities over and above their core roles
- assessing ISCAN interface with third sector agencies who are part of the overall service delivery model for children who do not need a statutory service provision
- using recognised models (Parent Stress Index and Family Impact Model), record if there has been a reduction in parental stress levels and improved family functionality following intervention by the care co-ordination service

Discussions are ongoing about best methods that will be “paper light” but provide evidence of cost effectiveness and better outcomes for children, young people and their families.

5 Lessons learnt/next steps

Much has been achieved in Gwent to improve services for children with additional needs over the last few years. However, the integration journey has not been without its challenges and these continue. Top of the list are:

- How to manage growing demand (and complexity of cases) and workload challenges, especially the recent growth in neuro-developmental referrals and the current gap in services for children and young people with concerning behaviours / emotional needs
- Improving referral to treatment times for children with ASD/ADHD
- Transition from children's to adult's services remains a huge worry for parents, more work is needed and will be supported by the recent changes in legislation⁵ that will require additional learning needs to be considered up to the age of 25. Sparkle have appointed a research and development officer for 12 months to look at the 'optimum model of transition from child to adult services'. The research will be complete at the end of March 2019
- Interaction with universal services, particularly those that support health promotion and wellbeing is an area for further exploration to reduce health inequalities and premature mortality of people with additional needs
- Ensuring that robust evaluation is carried out, to measure cost effectiveness, quality and impact

⁵ Additional Learning Needs and Education Tribunal Act 2017

Top tips for other areas embarking on the journey:

Listen to the voices of children, young people, parents and carers, let them drive the change at all stages from planning and designing services to evaluating their effectiveness.

Health and social care leaders need to build strong and trusting relationships based on shared vision and values that can 'weather the storms' and keep driving the integration agenda forward.

Get your Partnership Board on side. This requires patience and a commitment to playing the 'long game' and being prepared to go 'out on a limb'.

Carry out pilots and research projects to evidence positive impact.

Don't go for perfection, be prepared to 'try it out', 70% is good enough to start with.

Recruit staff from varied backgrounds for the care co-ordination role – having lived experience is a real bonus.

At the implementation stage, managers need to avoid micro-management and trust staff to be experimental and develop and refine operational procedures and systems that work for families, as they go along.

6 Appendices

Appendix one



Gwent ISCAN Case
Study Appendix 1

Appendix Two



Gwent ISCAN Case
Study Appendix 2