



An In-Depth Evaluation of the Integrated Service for Children with Additional Needs (ISCAN)

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Executive Summary

The following report outlines key findings from an in-depth evaluation of the Integrated Service for Children with Additional Needs (ISCAN), conducted between 12th March and 31st July 2020.

ISCAN is a single point of access referral pathway for children and young people displaying multiple developmental concerns, or possible ASD or ADHD, funded by the Regional Partnership Board in Gwent.

The limited previous published research into single point of access models has found they result in timely and appropriate support for children and young people, however models need to be monitored and developed routinely to provide an effective service.

The aim of this evaluation was to determine the effectiveness of the current ISCAN referral pathway, and the views of parents and professionals on this pathway.

I would definitely say communication is one of the strengths of ISCAN.
(Professional)

We still don't really know what ISCAN is for...and we're two years down the line and three referrals in.
(Family)

Interviews were conducted with families who had been referred to services via ISCAN, and with professionals in North and South Gwent.

The interview transcripts were analysed thematically and four key themes were found: communication, efficiency, coordinated approach to care, and family involvement. The cost effectiveness of ISCAN was estimated and a summary of case studies is also presented.

Many benefits of ISCAN were identified, as well as a number of areas for improvement. Recommendations for service development have been made based on the views of both families and professionals.

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Introduction

Aneurin Bevan University Health Board's (ABUHB) Integrated Service for Children with Additional Needs (ISCAN) is a single point of access referral pathway for children and young people (CYP), aged 0 to 18 years, who are displaying concerns in two or more elements of their development, and/or are presenting with possible Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). Following development work by Janet Kelly and colleagues within ABUHB, ISCAN was introduced in October 2016 (see Figure 1), funded by the Regional Partnership Board in Gwent; there are three regional ISCAN boards, in the North, West and South respectively. ISCAN panel meetings are attended by the ISCAN Coordinator, ISCAN Administrator and ISCAN Care Coordinator, as well as representatives from Paediatrics,

Physiotherapy, Specialist Nurses, Dietetics, Occupational Therapy, Speech and Language Therapy, Health Visitors, Child Development Advisors, education and social care (including Children with Disabilities Team).

Panel meetings are held weekly for each region, North, South and West (ISCAN South holds an additional monthly panel meeting). Referrals are accepted from all professionals, however the majority of referrers are general practitioners (GPs) or professionals from education. Referrals are discussed at a multi-disciplinary panel meeting, which includes representatives from health, education and social care. The panel decides the most appropriate services and support for each case, and whether a neurodevelopmental (ND) assessment for ASD or ADHD is necessary.



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Timeline of Services

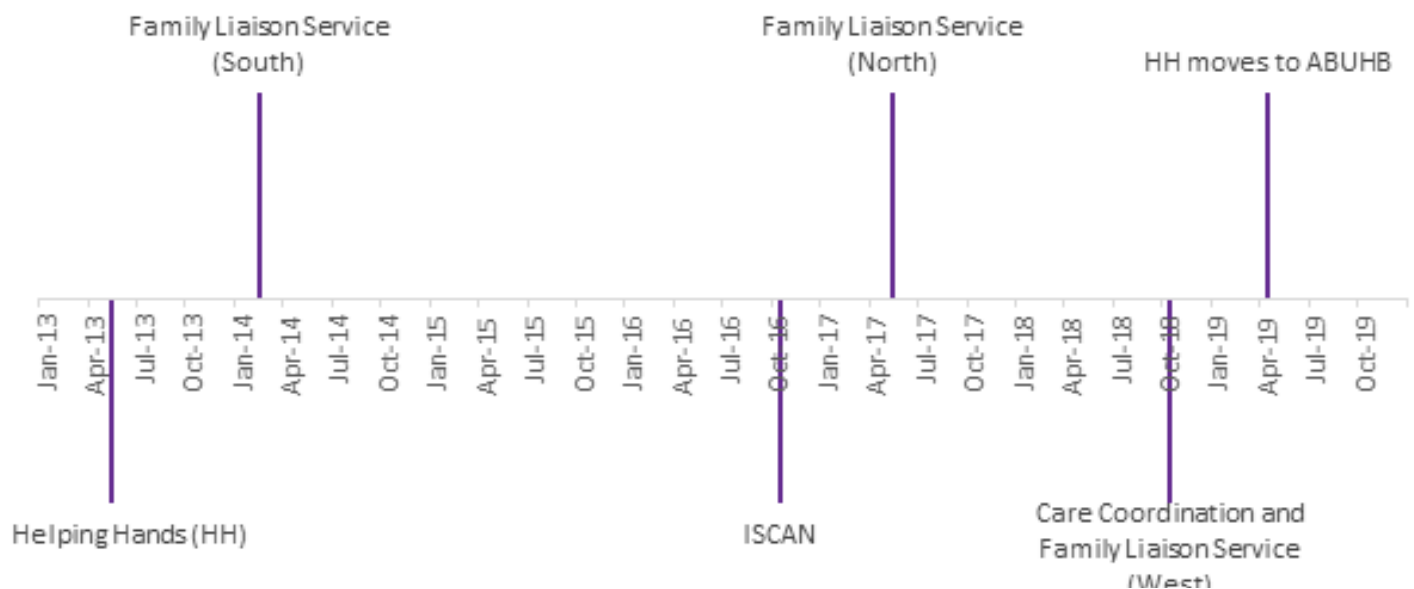


Figure 1: Timeline of Services, including the introduction of ISCAN.

Previous research into the effectiveness of Single Point of Access (SPA) referral processes is very limited, with few studies having been conducted. Examples of SPAs include Northamptonshire's Healthcare Referral Management Centre, The Liverpool Model, Nottingham City's Single Point of Access, Bury Council Children and Young Persons Improving Access to Psychological Therapies, and Liverpool Alder Hey Children's Hospital; however, none of these models have been formally evaluated (Maidrag, Brown & Keeble, 2015).

Without a SPA model, inappropriate referrals are sent back to the referrer who then needs to refer to a different service, causing a delay between the initial referral and the CYP receiving much needed support. Therefore, it is believed a lack of a SPA for referrals creates a barrier to achieving equal access to and experience of services for CYP (Sin, Francis & Cook, 2010). SPA models are simpler and more efficient than previous models (Simpson & Stallard, 2004) and ensure appropriate support is received earlier for more CYP, resulting in a better experience for CYP and their families, and preventing poorly managed or disjointed care (Mischenko & Bollom, 2015; Frakking et al., 2018). A SPA for referrals also provides a mechanism through which to signpost to relevant information and other sources of support for CYP and their families, particularly when specialist services are not appropriate (Rocks et al., 2020).

Some studies have found mixed views from professionals regarding the consistency of referrals accepted via SPA pathways (Rocks et al., 2020). Published research demonstrated that some referrers expressed concerns SPA models undermine their relationship with the families they refer, and mean they do not have as much input in the care their patients receive. GPs in particular felt SPA models put a barrier between them and service providers, reducing their understanding of services and opportunities to develop professional relationships (Raine et al., 2005). However, Simpson and Stallard (2004) found SPA pathways actually resulted in greater understanding of professional roles, and created a shared responsibility between referrers and service providers.

Frakking et al. (2018) suggested a SPA referral pathway would improve quality of life outcomes for children with a chronic health condition, however a randomized-controlled trial in Canada, which included 445 CYP, found no significant improvement in psychosocial quality of life for those receiving integrated care than those receiving care through the usual process (Ye, Browne, Beyene & Thabane, 2013).

It may be that an effective SPA referral pathway is one which adapts to changing needs. For example, a SPA pathway for child and adolescent mental health services in England needed to revise their online referral form to ensure sufficient information was collected in order to appropriately triage cases (Rocks et al., 2020). Another study also identified the need for an electronic referral form (Simpson & Stallard, 2004). SPA models increase the number of professionals who are able to refer CYP to services, and some allow for self-referrals from YP or parents/carers. Concerns have been raised that this may lead to more referrals being received than providers have the capacity to cope with (Rocks et al., 2020). One SPA model introduced a fast-track pathway for cases with a clear service need, following concerns high numbers of referrals were resulting in long waiting times and delays for CYP accessing services (Simpson & Stallard, 2004).

Research Aims

The original aims of ISCAN included families with the greatest need receiving support earlier, empowering families, improved service efficiency and cost effectiveness, improved professional moral, and better relationships between families and professionals. Since its inception in 2016, ISCAN in Gwent has evolved (see figure 1) in response to service needs and experience with the model. While data is available regarding the number and type of referrals seen, professionals who are referring in and those to whom ongoing referrals are made, no in-depth evaluation of the overall effectiveness and acceptability of the service has been conducted. This evaluation aims to collate qualitative feedback from families referred via ISCAN and professionals involved in the care of CYP in Gwent, to determine whether the service is meeting its original aims, and to assess the impact a SPA referral pathway has on CYP and their families.



Method

Design

This was a mixed methods evaluation. The primary method used for data collection was semi-structured interviews. This approach to interviewing allows participants the freedom to express their views on a topic; the flexibility to follow topics raised by participants, where appropriate and relevant; and can provide reliable, comparable qualitative data. Interview topic guides were created for parents and professionals, comprised of a list of topics and open-ended questions to be covered during the interview (see Appendices A and B).

In addition, a short, online survey was also created using Survey Monkey for GPs, using a mixture of questions with scaled responses and open-ended questions. This

method was chosen to engage as many GP's as possible, in a relatively short period of time.

Participant Recruitment

In total, 11,369 CYP have been discussed at ISCAN panel between ISCAN's inception in 2016 and this report (April 2021). Between its inception and the period of data collection for this evaluation (October 2016 – July 2020, inclusive), 9,650 CYP were discussed.

In total, 8 family members and 43 professionals participated in this evaluation between 12th March and 31st July 2020. A purposive sampling approach was used for selecting a sample most appropriate for the purpose of this evaluation. Informed written or verbal consent was obtained from all participants.

	2016 (Oct 16 – Dec 16)	2017	2018	2019	2020
ISCAN North	21	507	565	853	933
ISCAN South	31	734	1473	1181	1358
ISCAN West	23	592	981	1109	1008
TOTAL	75	1833	3019	3143	3299

Figure 2: Number of CYP discussed at panel each year, divided across North, South and West Gwent.

Family Recruitment

Between 16 March and 6th July 2020, 23 families living in the South and North regions of Gwent (South Gwent includes Newport, South Torfaen and South Monmouthshire. North Gwent includes Blaenau Gwent, North Torfaen and North Monmouthshire) were invited to participate in a telephone interview with Sparkle's Research and Development Officer, Fiona Elliott (FE), to share their experience of their child being referred via ISCAN, and their views on the service. Initially, families were sent invitation letters, information sheets about the evaluation, and consent forms in the post, followed by a telephone call to see if the documents had been received and whether or not the family member(s) were interested in participating. In total, eight family members participated in a telephone interview; four parents referred to ISCAN South and four parents referred to ISCAN North. Two parents referred to each regional ISCAN board were part of the same family. These interviews took place between 20th April and 17th July 2020.

Professional Recruitment

All health and social care staff based at Serennu and Nevill Hall Children's Centres (approximately 143; 113 at Serennu and 30 at Nevill Hall) were invited to participate in a telephone interview via email. Recruitment posters were also put up at both Children's Centres. In addition, Health Visitors and professionals working in education, identified as the highest referrers into ISCAN across the South and North of Gwent, were invited to participate. Of those contacted, 10 professionals in the South and six professionals in the North participated in a telephone interview between 12th March and 31st July 2020. Professionals interviewed were from health, social care and education. Professional roles included Health Visitors, Additional Learning Needs Inclusion Advisors, Additional Learning Needs Coordinators, Inclusion and Wellbeing Leaders, Occupational Therapists, and Consultant Paediatricians.

In an attempt to engage GPs in the evaluation, 38 GP Surgery Practice Managers were contacted across 9 of the 12 ABUHB primary care clusters (except for the Caerphilly clusters)*.

*For ABUHB care clusters, please refer to

<http://www.primarycareone.wales.nhs.uk/aneurin-bevan-uhb>

Ethical Approval

This service evaluation was approved by ABUHB Research and Development Department, Research Risk Review Panel on 5th February 2020.

Data Analysis

Interview transcripts were analysed using qualitative data analysis software, NVivo (QSR International). Thematic analysis was used as a method for identifying, analysing and reporting patterns within the data (Braun and Clarke, 2006). Inductive thematic analysis was used; this is a widely used method of analysis which allows for categories to evolve from the data and facilitates the interpretation of themes supported by the data.



Findings

The purpose of this project was to conduct a formal, in-depth evaluation of ISCAN to find out whether the service is meeting its original aims and to assess the impact the ISCAN referral pathway has on CYP and their families. A thematic analysis of the transcripts of the interviews found four key themes: (1) communication, (2) efficiency, (3) coordinated approach to care, and (4) family involvement. These themes are discussed below. Interview participants who were a family member of a CYP are identified by 'F' and a participant number, and participants who were a professional working with CYP are identified by 'P' and a participant number. It is also indicated whether participants were located in South Gwent (S) or North Gwent (N).



Communication

Professionals felt that the introduction of ISCAN had helped improve communication between services.

"Whenever I've communicated with the team, they've always been very quick to respond."
(PS10)

It was commented that the ISCAN panel provided opportunities to share information, which had direct benefits for professionals working with CYP.

"The information that we receive, the written referral with the detailed Proforma from the referrer, and then often information from parents and school nursery is really great, really thorough, really helpful."
(PN2)

This improvement in communication between services seems to have helped build relationships, for example professionals are more aware of each other and their remits.

I would definitely say communication is one of the strengths of ISCAN.
(Professional)

"I think it's great to have contact with other professionals and so they know who you are, they know [what] your roles are so that you're not just in your silos all the time."
(PS4)

Some families also commented on the positive experiences they have had communicating with ISCAN. In particular, communication was timely and clear, which professionals also agreed with.

"When I did need to speak to somebody, the communication was really good. It was quite fast. I got the information I needed straight away." (FN1)

"The families get notified more or less the same day as I do of the decision of the panel." (PN1)

However, there was also a lot of confusion surrounding ISCAN. Some participants were unsure what exactly ISCAN's role was, whilst others were unclear regarding issues such as the referral process.

"I think there's still a little bit of misunderstanding of how they get referrals through to ISCAN [...] because we have such a turnover of staff in schools" (PS1)

Also, some miscommunications were commented on, for example between professionals and families or regarding what an ISCAN referral meant for families.

"She was like, I'm really sorry you've been- not misled but I think not told the truth, but it was just sort of an assumption if you like that it was going to be a lot quicker." (FS1)

"I did not have a clue, because I thought that it was something that the school was going to do to see with his behaviour. That's all I knew about it, to be perfectly honest." (FN5)

We still don't really know what
ISCAN is for...and we're two years
down the line and three referrals
in.
(FS3a)



Efficiency

Overall, professionals felt ISCAN provided an efficient process for CYP to gain access to services. It was suggested that the process was the best route for the CYP to services, and led to efficient outcomes.

“It very much is about professionals working together for the children. That's what we do. When you go to the panel meetings, as you know, you can see that. Everybody's there for the child and the best route for them.” (PN1)

Participants commented that the single point of access for services is what made ISCAN such an efficient process.

“I think the single point of access is excellent and more efficient for patients once referred” (GP)

It was also commented that there is now a clear pathway and criteria which improves the service for both professionals and families.

“Certainly, now that ISCAN is in place, I know that the time that they actually receive the referral on the agenda and then obviously you can see from there to get onto the agenda to that date of the meeting and that has reduced. That is fantastic, the turnaround there is very, very good.” (PS1)

“It's just a lot more streamlined. I find it quite an easy system to use and they just keep me informed of what's going on with that child and that family.” (PS7)

It's great - the main difference is, it is good having that one place you can contact that you send your referral off to. It goes to one team of people. Rather than going off to all the individual people. So, yes, that's helpful.
(PS5)

However, participants also raised a number of issues relating to the referral process. Firstly, it was feared that the current process is resulting in duplicated referrals.

“It's frustrating as professionals because if actually that diagnostic process has been dealt with elsewhere then it's not necessary for me to be seeing them as well, so I could be seeing another patient.”
(PN2)

“I've come across that sometimes where I know that a child's already referred to a service but by the time it's gone to panel...it might be overlapping actually, it might not be at that for example, speech and language therapy. We might be in the process of looking at that. Then by the time the child's gone to be discussed, a referral has already been made to speech and language.” (PN3)

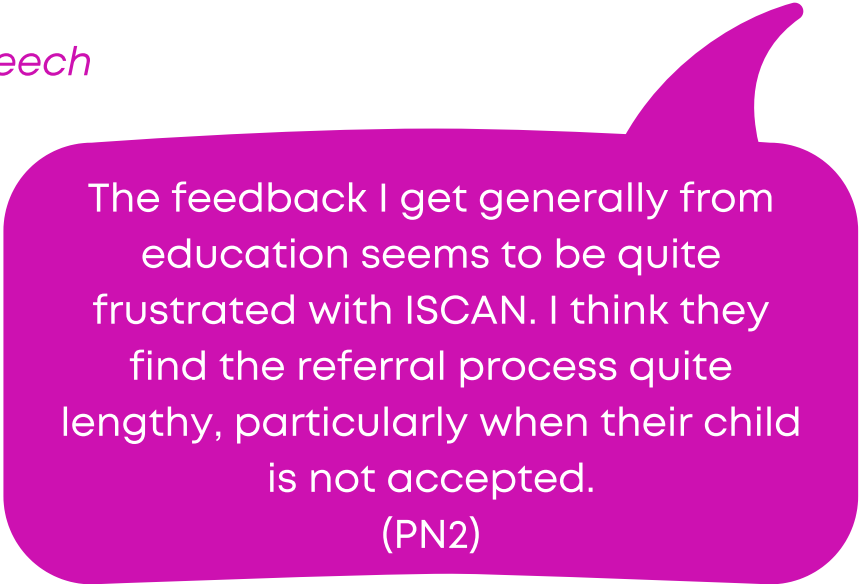
Professionals found the referral form difficult and time-consuming to complete. GPs in particular experienced issues referring CYP via ISCAN, for example they felt they did not always have access to all the information the referral required.

“Lengthy form requesting information that GP's do not generally have available” (GP)

“It seems impossible to get any children assessed, despite very considerable concerns or difficulties.” (GP)

Also, some educational professionals have experienced problems with the referral process.

“I spoke to another ALNCo recently who told me that she had spent six weeks doing a referral to ISCAN.” (PN1)



The feedback I get generally from education seems to be quite frustrated with ISCAN. I think they find the referral process quite lengthy, particularly when their child is not accepted.
(PN2)

Some participants, particularly families, felt that ISCAN was actually a barrier to accessing services, with one describing ISCAN as “another hoop to jump through” (FS3a). Another participant expressed their frustration that they had to go through another process to access services after being referred by a healthcare professional, and felt this actually introduced a delay between the initial referral and receiving support.

“In [England], when a healthcare professional refers, it was actually GP or health visitor or whatever, you will be seen. There isn't this extra filter of ISCAN. They refer, you get seen. It's simple. [...] It's stopping them access the help that their child needs. It's stopping them getting the right support put in place in school.”
(FS4)

Participants commented that rejections from the ISCAN panel not only stopped CYP who needed support from accessing services, but also could be seen as undermining the professional who made the initial referral.

“I think they're acting as a filtering service which is frankly insulting to professionals who have referred. If a professional thinks they should be seen, that's it, they should be seen.”
(FS4)



Comments were also made by families regarding ISCAN waiting times.

It was quite a long time and that was one of my concerns because it took us so long to get the initial psychology assessment and then the referral. It was getting really close to him leaving primary school and I wanted for us to have things in place ready to support him in secondary school because it is such a big adjustment.

(FN1)

Other participants recognised waiting lists are impacted by the number of CYP who are referred to ISCAN and are in need of services, however it may be that families' expectations need to be managed with regards to the waiting times.

“But when you're being told it's just going to be another month, it's just going to be another month, it's just going to be another month [...] When it doesn't happen, it adds to the stress that's already going on in your house. [...] I think that would be really helpful, to be realistic about the time span that you've got to wait. I know that can't be helped because of how many people, or how many children need this service but the crisis is, things are just getting worse. We didn't know how to deal with him.”

(FS1)

Coordinated Approach to Care

In this section, it is discussed how the introduction of ISCAN has encouraged multi-disciplinary working, resulting in a more coordinated approach to care.

“I think it helps because it offers a more coordinated approach. I suppose obviously, we all want to work together to ensure that a child receives all the required services and we're all specialist in our own role but obviously a child has different needs and different services are there to meet those needs. We all offer something different I suppose.”
(PN3)

Many professionals felt this multi-disciplinary approach led to collaborative decision making between services, and therefore better planned care for CYP.

“From health point of view, I think it's very helpful that there are representatives from most areas in the ISCAN meeting who can talk about the patient and make appropriate decisions about where that patient should be referred to.” (PN2)

However, some professionals found it difficult to continue this joint working following the decisions being made at the ISCAN panel, due to services having different waiting times.

We've got obviously other things that are an issue in the background such as our waiting lists, so sometimes doing joint planning doesn't always work.
(PN6)

The benefits are about having that multi-agency discussion around cases, and that there are other professionals there who are able to look at that decision-making with you.
(PN1)

Well it's really good because they do get a referral to all the services that they need and it is very clear now and as the time has gone on and it's improved it is a much more slick process and the families do get all the services that they need in one go.
(PS2)

A clear benefit of ISCAN was families being able to access all the services they require.

One participant also suggested ISCAN helps families access further support services.

"Definitely for families because they've now got the opportunity of having the signposting to different places as well as to professionals."
(PS1)

However, it was also felt that there were services missing from the ISCAN panel, in particular professionals felt Single Point of Access for Children's Emotional Wellbeing (SPACE) should be involved in ISCAN*.

"There are still services that should be involved that are not involved, for example, SPACE probably being the biggest, I think them sitting in isolation is really not helpful for the families." (PS8)

"What would really be ideal would be to have one point of entry for both of those panels – For SPACE and ISCAN, to work towards that at some point would be beneficial." (PS1)

*As of April 2021, all referrals requesting a neuro-developmental assessment will be processed through a single point of access email: ABB.SPACEWellbeingND@wales.nhs.uk. These will be discussed in a triage multi-disciplinary panel.

The ISCAN panels will continue to discuss children and young people aged 0-18 years presenting with two or more developmental needs. The SPACE wellbeing panels discuss referrals for children and young people aged 0-18 years presenting with emotional and wellbeing needs. All three panels will work closely to ensure that working in silos and duplication of work with families is minimised.

Family Involvement

The data suggests there was a considerable difference in opinion between professionals and families regarding family involvement in ISCAN. Professionals believed that the views of parents are considered as part of the ISCAN process.

"It's just a referral form that is quite good because it gives the parental views as well as professional views." (PS7)

However, many families suggested ISCAN provides an impersonal service, and families are not as involved as professionals believe.

"It was just very- you can tell it was just a standard letter where they just change the name on it basically to whoever it goes to. It wasn't personal to him." (FS1)

It was suggested that this sometimes leads to inappropriate support and advice being given to families.

"When they came back and said go to parenting classes it was a bit of a slap in the face really because it was like, well you haven't looked at his history. [...] But again, when we did the ISCAN referral there was no place for that to be put on there, which is why they've gone 'get him counselling', 'have parenting classes'. We've already been down this route." (FS3a)

Families felt that this could be rectified by more involvement from parents, CYP and the initial referrer. For example, one participant suggested a parent or the initial referrer should be included in the panel meetings to provide more detailed information.

I think the parents should be entitled to attend that meeting. [...] Yes, either the parent or the referrer ought to be attending. [...] Because if there are any extra questions, they could answer them there and then.

(FS4)

Another suggested having face-to-face meetings or conversations would be more beneficial than relying on the referral form.

“Maybe having a face-to-face assessment when they get the referral before they have these meetings to assess the child, whether that be in a school setting or a home setting, actually meeting the child to be able to see what is going on because I think when you see these things it’s a lot clearer and you get a better understanding than what somebody writes down. [...] That’s based on how ISCAN communicate, they don’t communicate with the right people. It’s all done in writing and forms which isn’t how these things should work. [...] They should have a conversation with the parents and the teachers. It should be a conversation.” (FS3a)

Estimated Cost Effectiveness of ISCAN

Figure 3: Estimated cost effective of ISCAN.

	GP referral cost (Assuming GPs generally refer 3 CYP a year to 3 services)	Seconding care cost
Pre-ISCAN	£29,700	£135.55 per child (Assessment and follow up, assuming a referral to Paediatrics and two therapies)
ISCAN	£13,500	£40 per child (Average cost of ISCAN meetings per CYP)
Total cost saving	£10,200	£95.55 per child

Educational professionals can also refer via ISCAN, and it is estimated the total yearly cost of these professionals time is £77,280, based on the number of average referrals made between 2017 and 2019. A full breakdown of costs associated with the ISCAN team is also provided (see Appendix C).

Meeting the Aims

Of the original aims, some have evidently been met. According to professionals, ISCAN has increased efficiency by providing a clear pathway and coordinated approach to accessing services for CYP, and the estimated costs suggest ISCAN is cost effective compared to the previous process. Also, professionals felt they were working more collaboratively and relationships between professionals were improved, leading to the best possible outcomes for CYP.

However, many families felt differently and saw ISCAN as a barrier to accessing services. There is clearly a failure to communicate to families what ISCAN is, and is not. For many families, who still have months to wait before their child is seen by a professional, the ISCAN process did not appear productive. Clearly, the lengthy waiting lists for individual professionals remain an area of considerable concern.

It is important to note that families accessing ISCAN have nothing to compare to, as unlike the professionals they did not experience the previous service model, which was more disjointed, and involved far less communication with families.

Families did not seem to be empowered by ISCAN, as many participants

expressed a lack of family involvement and felt the service was impersonal. Clearly, the form and content of communication with families is not achieving its aims.



Recommendations

Based on the findings of this evaluation, the following recommendations for service development are made:

Professionals who have worked in the old model of referrals identify a clear improvement, greater multidisciplinary engagement, and a far higher quality of information available to professionals to make decisions regarding next steps. It is recommended these improvements are maintained as the service continues to develop.

The service offers considerable savings, in terms of professional time, and overall is cost effective.

Communication between the ISCAN team and professionals and families was commended. However, there was also some confusion regarding the role of ISCAN and the process, therefore it is recommended this is clearly defined and communicated to both families and professionals, prior to a referral being made.

Professionals identified many benefits to a SPA referral pathway with clear criteria, although some referrers found the ISCAN referral form difficult to complete. It is suggested this is reviewed and an online referral form is considered, the benefits of which are outlined in Rocks et al. (2020) and Simpson and Stallard (2004). An online referral process may also prevent duplicated referrals.

There were mixed views regarding whether ISCAN signposts families to other sources of information and support, such as third sector support. It is recommended this is included in the process routinely so that families receive support whilst on waiting lists, and they do not feel as though ISCAN is a 'barrier' to services.

The multi-disciplinary approach was praised by participants and many professionals found value in joint working. It would be beneficial to consider how joint working can be facilitated following the ISCAN panel meeting, and to include more services within ISCAN, particularly wellbeing services.

Clearly the extremely long waiting times for individual services is a concern, and certainly joint appointments between professionals would avoid duplication and offer a more effective, and time efficient, outcome for families.

It is recommended the feedback regarding family involvement in ISCAN is reviewed and options to improve family involvement are considered to provide a more personal service. Consideration should be given to verbal feedback following the ISCAN meeting, with an outline of next steps.

The service has already developed considerably since the data was collected for this evaluation. It is recommended an in-depth evaluation is conducted again in 2023, once further developments have been implemented, to provide a valid assessment of the service.

Conclusions

The findings of this evaluation suggests there are mixed views regarding the impact of ISCAN. Most professionals identified benefits of the service and saw the value of a SPA referral pathway, however a few issues were noted which need to be addressed to optimise the service, particularly regarding how referrals are made. Families generally had a more negative view of ISCAN, believing the process to be a barrier between their child's referral and accessing services. Clearly, there is misunderstanding on the part of families as to what the ISCAN meeting can and cannot achieve. Participants also found issues relating to waiting times for ISCAN meetings and outcomes, and felt the service was impersonal with little opportunity for family involvement. The recommendations that have been made, such as clearly defining and communicating the role of ISCAN, signposting other sources of support, and considering more family involvement in the process, should help improve families' views and experience of ISCAN.

Shortening waiting times for appointments with the individual professionals is also of vital importance here.



The estimated cost effectiveness of ISCAN suggests a SPA referral pathway saves time and costs associated with GP referrals, and ISCAN panel meetings are more efficient compared to multiple assessment and follow up appointments, where key information may be lacking.

Overall, many benefits of ISCAN have been identified and the service clearly has great potential. The views of the family members and professionals included in this evaluation need to be considered to develop the service to enable it to fully meet the original aims. Since the evaluation, the service has already seen new developments, such as coordinating with SPACE and introducing a triage nurse. It is recommended the evaluation is repeated once these new developments have been fully operationalized.

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Appendix A

ISCAN Evaluation Topic Guide: Parents

Clarify: does the parent know what ISCAN is? Who made them aware of it/explained?

1. Experience of being referred to/accessing services for their child
 - a. How concerns were raised/with whom
 - b. How did this person/people help
 - c. Other people involved (health/social/education)
 - d. Describe experience of time between referral and appointment
 - e. Employment (type, impact)
 - f. Satisfaction with timeliness of receiving a decision on referral (Likert scale)
 - g. Satisfaction with waiting times appointments (Likert scale)
2. Communication with professionals involved in the process of being referred to services and decision-making
 - a. Which professionals communicated with (awareness of who to speak to)
 - b. How they communicated
 - c. Information shared
 - d. Feelings about how the parent was communicated with
 - e. Satisfaction with communication (Likert scale – satisfaction)
3. Benefits
 - a. Personal experience – support/informed during the referral process?
 - b. In general for families
 - c. Any other benefits
4. Issues
 - a. Describe any issues experienced
 - b. Resolution of issues
 - c. Being seen by multiple professionals from different services
(How many? Which services?)
 - d. Waiting times (for appointments, to be informed of decisions made)
Likert scale – satisfaction, see visual
5. Overall satisfaction with the process of accessing services for their child?
(Likert scale as above)
6. Any other thoughts/feelings to share

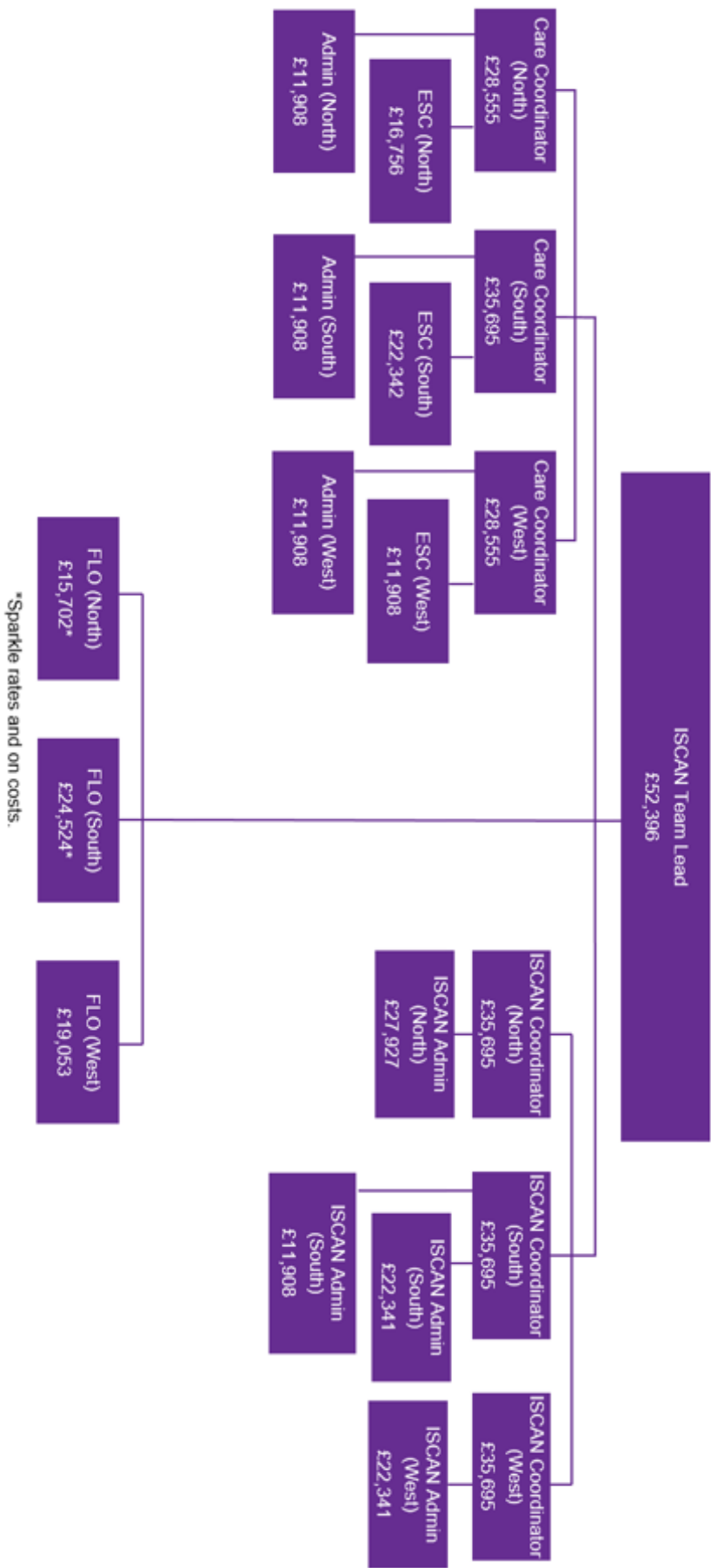
Appendix B

ISCAN Evaluation Topic Guide: Professionals

- 1.Experience of how the referral process worked/works
 - a. Who's involved
 - b. Their involvement/time spent making the referral and attending meetings/ appointments with parents (prior to accessing secondary services, repeated contact)
 - c. CDT/ISCAN meetings
 - d. Quality of referrals (information gathered prior to meeting) – Likert scale
 - e. Efficiency (Likert scale) & elaborate (bounce backs)
 - f. Quality of decision-making by the CDT/ISCAN (Likert scale) & elaborate
- 2.Communication
 - a. With families / what? / how?
 - b. With professionals / what? / how?
 - c. Rate quality of communication on Likert Scale (Very Poor, Poor, Neither poor or good, Good, Very Good) & elaborate
3. Benefits
 - a. For families
 - b. For professionals
 - c. Any other benefits
- 4.Issues
 - a. Describe any issues experienced
 - b. Examples of issues
 - c. Impact of these issues on families/professionals
 - d. Areas for improvement
- 5.Overall effectiveness (Likert scale) & elaborate
- 6.Any other thoughts/views to share

Appendix C

Costs associated with the ISCAN team



Appendix D

The following summary is taken from eight cases referred via ISCAN. The waiting times between referral or re-referral and cases being discussed during an ISCAN panel meeting were between 1 and 8.5 weeks. For cases which were accepted by ISCAN for assessment, the total time from initial referral to acceptance was between 1.5 and 29 weeks.

	Reason for referral	Waiting time from referral/re-referral to ISCAN discussion	Total time from initial referral to ISCAN acceptance	Outcome
Case 1	Aggressive behaviour, family at breaking point, progress at school deteriorating.	1.5 weeks	1.5 weeks	Accepted for ND assessment.
Case 2	Erratic behaviours, dramatic decline of behaviour in school.	Unknown 6 weeks	N/A	Not accepted. Not accepted, re-refer with more information.
Case 3	Speech and language difficulties, behavioural difficulties.	7 weeks	N/A	Referred to Consultant Paediatrician, who advised referral to ND via ISCAN would likely not be accepted.
Case 4	Parents high level of concern, family history of ASD.	4.5 weeks 7 weeks Unknown	Unknown	Not accepted. Not accepted as more detail required. Referred to CP and OT.
Case 5	Signs of ADHD raised by referrer, EP and previous teacher.	7 weeks	7 weeks	Accepted for ND assessment.
Case 6	Continuing social communications concerns.	8 weeks	29 weeks	Not accepted, refer again

		8.5 weeks		following EP review. Accepted for ND assessment.
Case 7	Signs of ASD.	3 weeks 2 weeks 2 weeks	16 weeks	Not accepted. Accepted for ND assessment for ASD, referred to FLS and CC Referred to SALT and OT.
Case 8	Concerns around social/ behavioural difficulties, possible ADHD.	1 week	N/A	Not accepted.

ASD = Autism Spectrum Disorder

ADHD = Attention Deficit Hyperactivity Disorder

ND = Neurodevelopmental

CP = Community Paediatrics

OT = Occupational Therapy

EP = Educational Psychologist

FLS = Family Liaison Service

CC = Care Coordination

SALT = Speech and Language Therapy