Progress Report	LOIP Project 8.6 Increase by 20% the number of families of children with autism or awaiting diagnosis accessing support prior to diagnosis and reduce the interval between referral and diagnosis by 2024.
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Purpose of the Report
This report presents the results of the LOIP Improvement Project 8.6 which sought to Increase by 20% the number of families of children with autism or awaiting diagnosis accessing support prior to diagnosis and reduce the interval between referral and diagnosis by 2024 and seeks approval to close this project. The overarching elements of the project were achieved as detailed in 1.1.

Summary of Key Information

1. BACKGROUND

1.1 The aim of this project was to engage children and families awaiting an autism diagnosis and bring together the key stakeholders who have a role to play in referral, assessment, diagnosis, and support (pre and post referral) to deliver the following aims:

- That children and families would have access to information and a range of supports suitable to their needs, when they need it. They would know who the professionals are that can provide support, and what to expect of them, resulting in children and families reporting a good experience.

- By simplifying the referral process and providing accessible tools we would improve the confidence and competence of our workforce and realise efficiencies across the current system. Encouraging the referrer to consider early intervention and/or concurrent support to help to ensure that children and family's needs are appropriately met at the earliest opportunity and reduce unnecessary referrals. The defining of roles and responsibilities across the workforce would allow colleagues to recognise the value of their contribution and promote professional satisfaction.

- By identifying the unmet need for children with neurodevelopmental profiles as a result of trauma and adverse childhood experiences, and by developing recommendations for a model to address this need, to highlight the opportunity to improve long term outcomes for a significant number of children, young people, and families.

2. IMPROVEMENT PROJECT AIM

2.1 The purpose of the project was to create a new pathway for the implementation of the National Neurodevelopmental Specification for children and young people. The objective of the specification was to ensure that children, young people, and families receive neurodevelopmental assessment, associated support, and access to services, that meet their needs at the earliest opportunity. With this in mind, the following aim was established:

Increase by 20% the number of families of children with autism or awaiting diagnosis accessing support prior to diagnosis and reduce the interval between referral and diagnosis by 2024.

3. WHAT CHANGES DID WE MAKE?

3.1 The project was based at Woodside Primary and Nursery. This was agreed through extensive engagement with partners across Aberdeen City Council and NHS Grampian. We engaged partners in reflection on data from existing systems and considered the efficacy and appropriateness of current systems for children and families in the Neurodevelopmental (ND) context.

3.2 We gathered data on the current ND pathways in the City and referral data from CAMHS. We were keen to learn how children and families experienced the current systems.

3.3 The key design features of the test of change included:

- Creating a change team within the school that reflected key stakeholders (Discovery Team).
- Understanding potential prevalence within the school and nursery (levels of dysregulation and children already referred to services).
- Understanding how equipped school and nursery staff felt to support these children.
- Understanding how equipped parents felt to support their children thrive.
- Delivering training, modelling, and reflective practice with school staff to upskill them. This was supported by our partner SensationALL.
- Embedding a part time multi-disciplinary team (mainly 0.2 whole time equivalent because of the limitations in funding) *within* the school to accept referrals to assess/diagnose children whose parents and the school felt could be neurodivergent.
- Create support plans for those children post diagnosis to share with school and parents.
- Created posts (Family Health Link Practitioners) to 'hold' families through the referral and assessment process and to support both school and home implement the support plans.

4. HAVE OUR CHANGES RESULTED IN IMPROVEMENT?

4.1 Overall, yes for 10 families of children either with autism or awaiting diagnosis within the pilot at Woodside School. There was an improvement in the number of children with either autism or awaiting diagnosis accessing support prior to diagnosis, and some demonstrated reduction in the interval between referral and diagnosis.

4.2 The Improvement aim was to "*Increase by 20% the number of families of children with autism or awaiting diagnosis accessing support prior to diagnosis and reduce the interval between referral and diagnosis by 2024".* The target of 20% was not measurable, given the lack of pre-existing data prior to the project, however all of the families of children with autism or awaiting diagnosis engaging in the pilot had positive outcomes in relation accessing support.

4.3 The Project showed significant potential benefit to the children and their families. The key benefits were measured via data from case records, qualitative interview feedback from parents, interview and survey data from school and interviews with the Multi-Disciplinary Team (MDT). A summary is provided below:

Efficiency of the school-based MDT:

4.4 Within the timeframe that MDT were based within the school, ten children (of the 17 referred) received a full holistic assessment and the outcomes were shared with parents and the school. Two additional referrals were accepted but the parents disengaged during the assessment. The following information is based on the ten cases completed. Efficiency of MDT based on wait times:

- Consent to first assessment (most cases FNDQ completion with FLW): 11.5 days.
- ESSENCE-d sent to parent to ESSENCE-D being completed: 1 day.
- Consent to first clinician observation of the child: 13.5 days.
- Consent to parent feedback (overall time parents had to wait for outcome) 43.5 days (6 weeks approx.)
- Consent to school feedback (overall time teacher/headteacher had to wait for outcome): 80 days (approx. 11 weeks)

N.B due to the complexities of the reporting processes it is not possible to provide direct wait times comparisons between those involved in the project compared to those that were not.

4.5 All parents were enthusiastic about the speed of the assessment, reporting that the reduced waiting time helped to reduce their anxiety and better helped them to support their child and to make decisions within their lives; all of which was why they sought referral in the first place. Feedback from parents is detailed in section 5 below.

Child Outcomes:

4.6 All ten of the 'regularly dysregulated' children assessed by the Project were neurodiverse and, in most cases, more than one neurotype (neurodevelopmental condition) was identified. The most frequent diagnoses made were, Autism and ADHD followed by Intellectual Disability. The median age of the children assessed and diagnosed within the Project was 9 years old.

4.7 Some of the ten children assessed had been seen previously by services. For a small number of the ten children, their neurodivergence had been missed. In the remaining children, additional diagnoses had either been missed or the picture had since evolved, and additional diagnoses were now warranted.

4.8 The positive outcomes highlight the benefit of the holistic approach being taken by the Project team. Please see the full evaluation report (link below at paragraph 4.9) for further details of the holistic approach taken and the diagnostic screening tool (ESSENCE-D) used at the point of referral to support a holistic approach.

4.9 Following on from the pilot, we now have a better understanding of what it is that staff need within universal services and in health care need to be able to support children who are neurodivergent and/or who have experienced childhood trauma. We also have insight into what this population of children need to be able to succeed within school and beyond. As a result, we have significantly improved our understanding of the opportunities, barriers, and constraints to the creation of a whole systems neurodivergent affirming pathway. Specific areas of action are described in the Test of Change final report which can be found here: Aberdeen City Test of Change

4.10 The early data we gathered from the engagement we had with children and families with lived experience illustrated that a web space was not on their list of priorities. They had experienced being 'signposted' to various web spaces and had not found this to meet their needs. They were looking for more specific and tailored information relating to their child's needs, such as would be described within the child's care plan.

4.11 Feedback from staff was also positive. Twenty school staff members, including Nursery Teachers, Primary Teachers, Pupil Support Assistants (PSA) and senior management (deputy and headteacher), completed a short survey at the end of initial testing and some teachers completed interviews.

- Sixty percent (n= 12) agreed or strongly agreed that an MDT embedded within the school was more beneficial for the children and 55% (n=11) of individuals felt they were better supported by having access to clinicians in school.
- Of those who did not agree with these assertions, the majority felt they were unable to provide a response either way as they had not had direct experience with the MDT.
- Only 5% (n=1) disagreed. In addition, 60% of individuals agreed or strongly agreed that the Test of Change was a worthwhile service and 40% were unsure; again, largely related to not receiving direct input from MDT, although a few staff attributed their uncertainty to inability to make a judgement of worth for the whole school, stating they could only speak for their individual circumstances.

What did we learn?

4.12 We learned that it is helpful to create a change team within a single school community and that all professionals value this way of working. School staff felt more equipped to support young people with ND needs when there was greater access to health professionals, bespoke training, modelling, and opportunities to reflect with health known professionals.

4.13 Embedding a part time multi-disciplinary team (mainly 0.2 whole time equivalent because of the limitations in funding) within the school to accept referrals to assess, diagnose children who parents and the school felt could be neurodivergent worked well.

4.14 We learned about the level of need within our schools and nurseries is considerable and that many have already been referred for services and on long waiting lists for a diagnosis.

4.15 The volume of need across a single school community is challenging without having physical access to quieter break out spaces for young people who need them.

4.16 We learned that parents and carers value connection more than signposting. Parents told us that they felt more equipped to support their children to thrive and schools felt comfortable implementing agreed plans to support sustainability.

4.17 Creating posts (Family Health Link Practitioners) to 'hold' families through the referral and assessment process, and to support both school and home implement the support plans, worked exceptionally well. However, the short-term nature of the funding and inability to secure the resource to maintain this arrangement compromises the continued and further roll out.

5. HOW HAVE OUR COMMUNITIES/PROTECTED GROUPS PARTICIPATED IN THE PROJECT AND THE IMPACT OF THIS

5.1 Through the engagement of families (50 parents) we learned how important a diagnosis was to them. This informed how we set up the multi-disciplinary team (MDT) referral, assessment, and diagnosis process. Data was gathered through a variety of methods:

- Staff survey to establish how equipped and confident staff felt to work with neurodivergent children.
- Parent survey to establish how equipped and confident they felt to support their neurodivergent children.
- An environmental audit of the school and nursery
- Data gathering to establish how many children within the school and nursery were described as being regularly dysregulated.
- How many of those had been diagnosed or referred to services for assessment.
- Set up a reflection and supervision process for nursery and teaching staff.

5.2 Pretesting feedback indicated a need for better more focussed support:

"We are not helping them early enough. And without the support they have poorer outcomes… They are seen for one thing, then later something else is apparent and then it's another service. And as needs have been unmet for so long, they need extra additional services…"

"I think from the clinician's point-of-view and the patient's point-of-view, there is this dissatisfaction that things have been done halfway and it's a bit disjointed…."

5.3 From the data from parents and also the study of the existing assessment and diagnosis system we felt that we had to test a completely new approach to referral and assessment to respond to need as part of a holistic pathway. We had no access to the existing system for the project as they were under pressure, operating at capacity with long wait times. We were also informed by NAIT

recommendations, and the previous work of the ND pan Grampian group. We planned to 'insert' a multi-disciplinary team into the school setting for this purpose to respond to this part of the pathway design.

5.4 The following feedback was received during/after the interventions:

From Parents:

Just finally getting the support for our son, which was all we ever wanted, that's the main thing, like, obviously the diagnosis helps because you can't often get supported without a diagnosis, but that wasn't the thing for us, it was getting the support and educating ourselves and being kind of able to help them.

We feel definitely feel like we have more tools and more information now than we ever have, and that is all down to the Test of Change

I'm really grateful for them [Test of Change MDT] kind of fast-tracking [child's] diagnosis, and I'm grateful for the meetings that they set up with [child's] teacher… new IEP is so much more detailed and they've [school] actually put some of the things in into action that we've discussed in the meetings.

To be perfectly honest every aspect of that process entirely exceeded my expectations. So, on quite a few occasions, you know, I was completely astounded at, you know, the interactions, at the efficiency of it, at the, um, just how good the whole thing was and how much of a pressure it took off of me….

So, the official diagnosis was autistic, ADHD, dyspraxia, so it was the dyspraxia part of it, was a little bit of an eye opener and I was, you know, it made sense to me…it helps to inform other things like holding a pen and his fine motor skills. It's so obvious now. A real kind of multidisciplinary perspective. They got to know and see [child] as a whole person and not in isolation...

6. HOW WILL WE SUSTAIN THESE IMPROVEMENTS?

6.1 Having been part of the test of change, and specifically the MDT, the management team at Woodside have developed a universal school wide regulation plan, based on the support plans for individual children, and will implement the Plan to sustain the improvements.

6.2 As a result of the Plan, the school are in the process of creating more targeted resources such as a room that children can engage in heavy work, punch bags, vibration plates etc. The sensory room they had already is being re-imagined based on their learning through the process. In addition, the school has invested in a Barnardo's worker (who is a Play therapist) through Scottish Attainment Challenge funding. The school has also invested in a Place to Be school counsellor through short term grant funding.

6.3 The biggest shift, however, is the implementation of a pro-active dysregulation prevention approach in a sincere attempt to meet the needs of neurodivergent children. This is being met by creating a nurture and life skills development programme and a dedicated room has been identified. This is timetabled for the most distressed children across age groups (which they access in very small

groups) and staffed on a rota basis by the members of the management team supported by PSA's.

6.4 Dedicated health funding is currently being explored. Without this investment the approach will not be sustained.

7. HOW WILL WE MONITOR THESE IMPROVEMENTS?

7.1 Woodside school will oversee the school Regulation Plan and implementation of the dysregulation prevention approach, this will be supported by health colleagues via the ongoing Health Visitor/GP and nursery nurse pathways monitoring of the progress of the children being supported.

7.2 This progress will be reported to the Children's Services Board on an ongoing basis to inform work against the Children's Services Plan and Local Outcome Improvement Plan.

8. OPPORTUNITIES FOR SCALE UP AND SPREAD

8.1 Should there be funding available. A further follow up project within another school supported by health professionals may be beneficial, this would allow for further evaluation of the methods previously used and to build upon the learning points.

8.2 The success of the pilot has helped establish a commitment from the multi-agency pan Grampian steering group to create a new pathway for children that sits outside of CAMHS and CCH. By revolutionising the approach to identifying and supporting neurodivergent children and young people (evidence states that 1 in 5 of the population are neurodivergent). The hope is that the process, if we get the additional funding, will facilitate the expansion of what we have learned from the Project and address several critical needs and gaps within the current system, offering a range of benefits:

The new pathway stands to significantly benefit families with neurodivergent children and the wider community.

Early Identification and Support: By focusing on the school and nursery as the key setting, the pathway would aim to identify the needs of children, young people, and their families at the earliest possible stage. Early support, irrespective of diagnosis, ensures that interventions can be implemented at a time when they are most effective, setting the foundation for improved long-term outcomes.

Streamlined Referral Process: Establishing a single point of referral simplifies the pathway for families, reducing the confusion, delays, and frustrations currently experienced. This streamlined process will make the system more accessible and user-friendly, thereby enhancing the overall experience of care.

Enhanced Quality of Assessment: Promoting and enabling good quality assessment by a confident and supported MDT staff ensures that assessments and subsequent interventions are appropriate and targeted. This approach

minimises unnecessary assessments and interventions, making the system more efficient.

Reduction in Waiting Times: By optimising the referral and assessment process, the project aims to significantly reduce waiting times for assessments and interventions. This not only improves the child and family experience but also contributes to better outcomes by providing timely support, reducing the risk of missed opportunities.

Improved Family Experience: The initiative aims to prevent families from having to repeatedly tell their story, a process that can be distressing and inefficient. By creating a more cohesive and integrated system, families will receive more empathetic and effective support.

Improved Outcomes: The ultimate goal of the programme is to improve outcomes for children, young people, and their families. By providing early, appropriate, and streamlined support, the project will contribute to the well-being, educational attainment, and life prospects of neurodivergent children.

Workforce Development: Providing scaffolding to the multiagency workforce through knowledge and skills development and expertise from specialist multidisciplinary teams (MDTs) ensures that the workforce is better equipped to support neurodivergent children. This investment in workforce development will enhance the quality of care provided to children and their families.

Legal Compliance and Rights Promotion: The pathway would ensure that NHS Grampian fulfils its legal responsibilities and promotes the rights of children as required in the UNCRC Incorporation (Scotland) Act 2024. This not only benefits patients directly but also strengthen the trust and accountability of the health service.

Community and Systemic Impact: By integrating innovative approaches and creating partnerships across councils and with the University of Glasgow for evaluation and research, the pathway would generate insights and models that could benefit not just NHS Grampian but potentially be adapted and applied in other regions, thereby extending the impact beyond the immediate community, with Grampian seen as a leading organisation in this important arena.

8.3 In essence, the new pathway would enable a transformative change in the way NDs are identified, assessed, and supported within Grampian, leading to a more inclusive, effective, and rights-based healthcare system. The ripple effects of these improvements will be felt not only by the children and their families but also by the wider community, through the creation of a more resilient, supportive, and efficient healthcare ecosystem.

8.4 By identifying the unmet need for children with ND profiles and those who have experienced trauma and adverse childhood experiences, and by developing recommendations for a model to address this need, we will highlight the opportunity to improve long term outcomes for a significant number of children, young people, and families.

8.5 A multi-agency working group has been created to facilitate this and the process is underway. We are also hoping to bid for funds from the NHS Grampian Charity to create the additional elements of a new design and to implement the learning from the project on a pan Grampian basis. If we do not receive additional resources this will significantly limit the ambition of the design.

8.6 In the interim period while efforts are made to secure additional funding, the learning points and experience gained through this project would benefit from wider sharing to other schools across Aberdeen City. Which will include multi agency support and guidance for staff as well as looking at how the environmental assessment mechanisms established in Woodside can be adapted to other schools.

Recommendations for Action
i) Agree to recommend to the CPA Board in March 2025 that initial testing is concluded and that this Improvement Project is ended on the basis that the changes tested in Woodside have been effective however funding is to be secured to enable the pilot to upscaled and spread as detailed in section 8, and ii) To agree that the Community Planning Board be updated on the securing of funding for the pathway and note thar systems are proposed to continue the work going forward subject to capacity.

Opportunities and Risks
Opportunities: • There is an opportunity to inform and scale up some of the learning points gained through participation within this project. This would potentially benefit other schools, and in turn assist with improving outcomes for children and families. Risks: • Placement of the Multi-Disciplinary Team within the school and its associated nursery was significantly delayed due to a retraction of funds in March 2023 which had been earmarked for recruitment of a dedicated MDT to the project. alternative funding was secured in November 2023, but because of the funding issue was only able to recruit clinicians on secondment for 1 day per week. Both the time delay and the reduced capacity of the MDT had impact on the outcomes achievable as the MDT were only based within the school for one day per week for 3.5 months (Mid-December 2023-ed of March 2024) before the project funding ended. This had and will continue to impact on the ability of the project to scale up the work
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