

STORY OF CHANGE TEMPLATE

Reporting Period	Q2 – 6-month reporting
Strategic Partnership	
Programme Name	West Glamorgan Neurodivergence Programme
Programme Reference	

Programme Overview

The Neurodivergence Programme (ND) is a new Programme that has been established to ensure that people with neurodevelopmental disorders have access to the services and support they need to participate fully within their communities and live fulfilled lives.

The draft aims of the Programme included in the West Glamorgan Action Plan are:

- Ensure groups are formed at a local level to support social interaction, deliver information and advice assistance.
- Reduce the number of people waiting for a diagnostic assessment.
- Develop and enhance the availability of preventative services that would enable autistic people in their daily lives.
- Provide appropriate and timely access to mental health and well-being services.
- Improve child to adult transition services.
- Further planning in terms of the requirements from the ALNWA Act around a fully inclusive education service needs to continue.
- Ensure a common understanding and consistency across the partners in the way the data is recorded and analysed.
- Engagement with people with autism and their carers to inform future developments for autism services.
- Better sharing of information between partner organisations and people, particularly in terms of the services that are available across the region.

Further work is underway to review these aims and develop a more detailed plan which is person centred and focussed on the needs of the people with ND regardless of diagnosis.

The proposed outcomes outlined in the West Glamorgan Action Plan are:

- Sufficient provision of services that meets the needs of people with ND and their families or carers.
- Reduce the number of people waiting for a diagnostic assessment.
- Increased independence and improved outcomes for people with ND.
- More choice of meaningful activities and opportunities to be involved within their local communities.
- Improved emotional health and wellbeing for individuals.
- Reduced social isolation and loneliness.
- Individuals with ND are supported to interact and connect with their local communities which will support their emotional health and wellbeing.
- Enable individuals to live as independently as possible and to develop their daily living skills.

- Increase of representation, voice and influence in governance structure and their local communities.
- People feel more empowered as their voices and opinions are heard.
- A system that supports the modelling of workforce and commissioned services for the future.
- Partners are more informed on trends in demand and able to better plan resources, enabling more effective future planning.
- Improved efficiency / allocation of funds across services.
- Partners have a greater understanding of the quality and impact of support to service users.

Priority Population Group

The population group supported by this programme are neurodivergent children and adults across the region. There are also links to the other following programmes although specific actions around these cohorts may be delivered via the specific programmes:

- Wellbeing & Learning Disabilities Programme, given there are people with ND and LD
- West Glamorgan Carers Partnership Programme, supporting carers and families for people with ND
- Emotional Wellbeing and Mental Health Programme, in relation to MH services for people with ND
- Children and Young People Programme, for children with complex needs and ND including the transition process for children with ND.

The following primary models of care will be developed for people with ND through the development of the programme:

- Community Based Care – Prevention and Community Coordination
- Community Based Care – Complex Care Closer to Home
- Promoting Good Health and Wellbeing

There are links to accommodation solutions model of care and the capital plan given there are people with LD and/or complex needs who have a ND diagnosis who require housing as they are unable to live alone in the community or with their family.

Delivery Partners

The programme brings together statutory services such as Swansea Bay University Health Board, Swansea Council, Neath Port Talbot Council, Third Sector and people representing the voices of people with lived experience and carers.

The Neurodivergence Population Programme Board is chaired by Head of Child and Family in Swansea Council and the vice chair is Group Director for Neath Port Talbot and Singleton, Swansea Bay University Health Board.

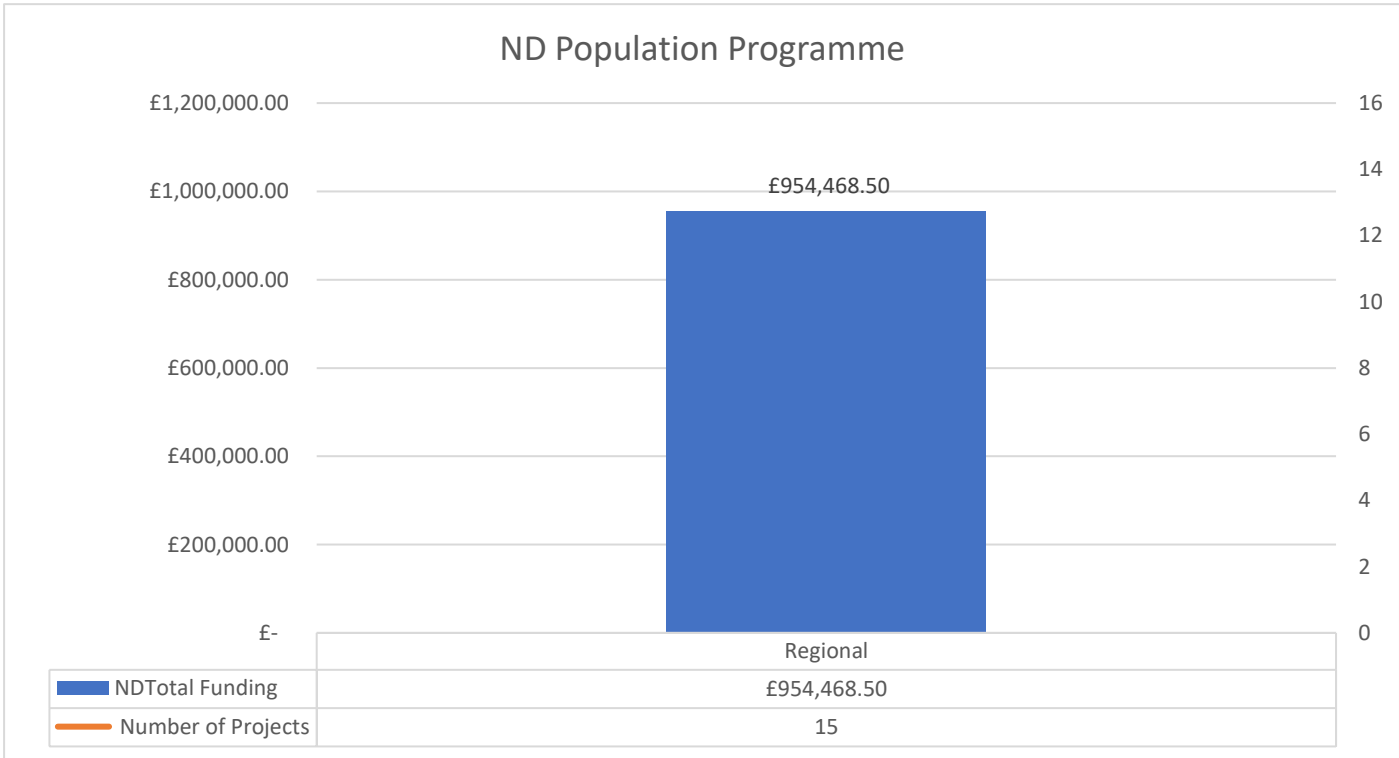
We plan to include people with Lived Experience in all levels of our governance as we believe their voices need to be integral to the work we deliver.

Funding Utilisation

A summary of the ND funding is as follows:

Integrated Autism Service (RIF)	1 regional service	£398,000
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RIF funded schemes	2 regional projects	£16,096
Project Manager (RIF)		£49,977
ND Funded Schemes	8 regional projects	£490,396
Total		£954,469

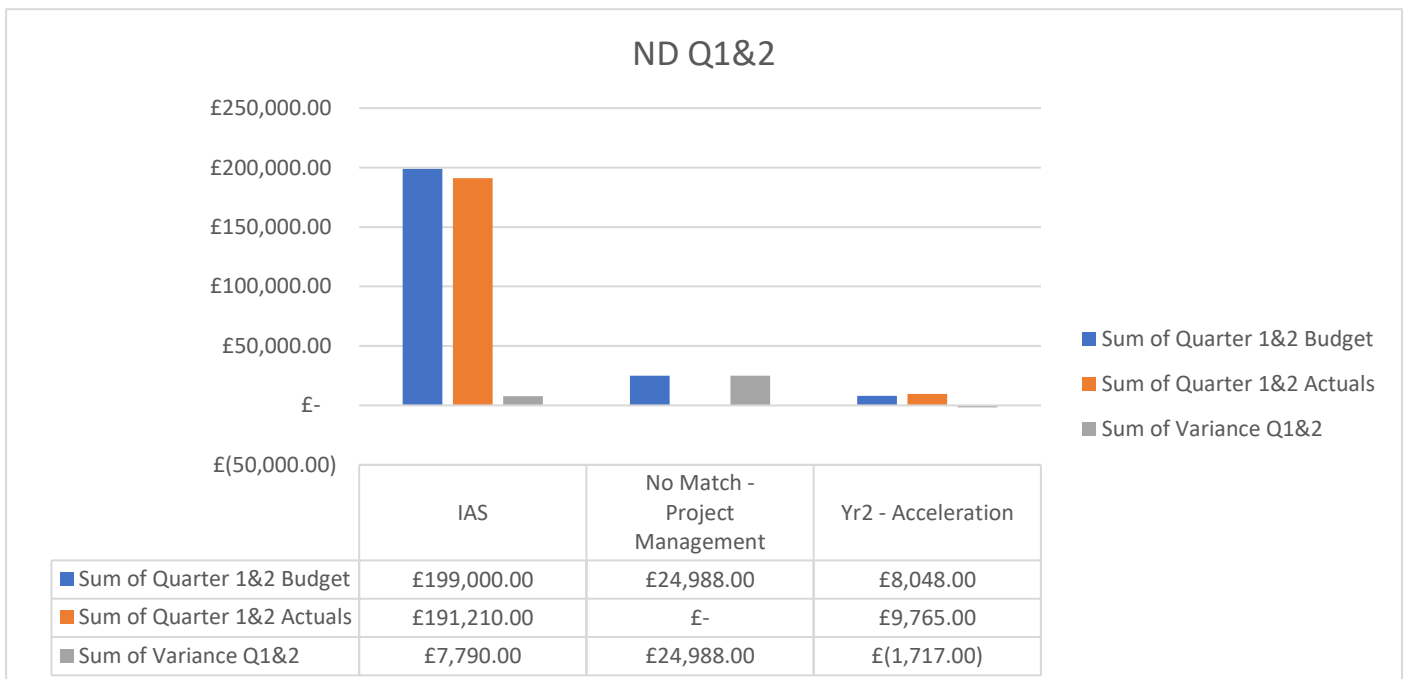


The RIF funds the Integrated Autism Service which is a regional service hosted by Swansea Bay University Health Board. There are also 2 RIF year 2 projects specifically for people with ND, however some projects under CYP, LD and MH do provide services for people with ND but cover a wider cohort of the population. For example, the Interplay Project which sits under EW&LD Programme also includes young people with ND.

RIF Allocations for ND 23-24 (excluding ND funding)



RIF Budget/Spend Position at end of Quarter 2 (excluding ND funding)



As indicated above, Welsh Government allocated some ND funding (separate to RIF). This funding is part of the 3 year programme administered by WG and aligns to the following WG workstreams:

- Workstream 1 - Urgent need and family support
- Workstream 2 - Building sustainable services
- Workstream 3 - Cross cutting themes, workforce, digital, data and monitoring

The following proposals were approved through the governance, details of the proposals are included in below sections of the template.

Sustainability Funding (Demand and Capacity) 3a

Name	Organisation	Funding	
		23/24	24/25
IAS Service	SBUHB	£ 66,185	£ 66,185
Early Years ND	SBUHB	£ 66,213	£ 66,213
ND service 5-18 years old	SBUHB	£ 50,442	£ 50,442
		£ 182,840	£ 182,840

Transformation Funding - 3b

Name	Organisation	Funding 23/24
ND Service 5-18 years old	SBUHB	£ 36,830
ADHD Service, MH Division	SBUHB	£ 107,071
Communication strategy for families about myth busting	Swansea Council and NPT Council	£ 49,655
Additional support for challenging behaviour	Swansea Council and NPT Council	£ 94,000
School Based 'Summer Camp' for complex ND children	Swansea Council and NPT Council	£ 20,000
		£ 307,556

Assessment of Delivery

The new governance arrangements were established in September 2023 and the 1st ND Board took place on 4th November. Some pieces of work that progressed under the Regional Autism Strategy Group previously included:

- Development of the PNA for autism.
- Development of the Action Plan for ND.
- Development of ND proposals for 22-23 and 23-24 in line with the WG criteria for the 3-year programme of ND funding.
- Development of mapping of ND related services / provision for preventative and pre and post diagnostic support.
- Disaggregation of Western Bay IAS, estimated to be completed by April 2024, whereby Bridgend residents will move to Cwm Taf IAS.

Key Enablers

- **Integrated planning and commissioning**

In order to ensure a whole systems approach is developed around the person with ND, mapping work will be needed around all ND services (including prevention and early intervention services and services for pre and post diagnosis support) to provide an overview and identify any gaps.

- **Technology and Digital Solutions**

One of the key issues identified in the Autism PNA was the lack of data available on people with autism which is why one of the key aims for this programme is *ensure a common understanding and consistency across the partners in the way the data is recorded and analysed.*

This work sits under the Digital and Data Programme. One of the aims could be to consider technological developments to enable people to live within their own homes with increased independence.

- **Promoting the Social Value Sector**

Support from Third Sector Services play a crucial role in the whole systems approach given they provide a more preventative approach and this aligns with one of the programme's aims, *ensure groups are formed at a local level to support social interaction, deliver information and advice assistance*

- **Integrated Community Hub**

The development of Hub's is being led by the Regional Strategic Capital Group.

- **Workforce Development and Integration**

Workforce issues are reported in both the statutory services and third sector organisations. One of the supporting programmes is Workforce and can support Programmes in addressing key issues.

Successes and Progress

Establishment of a **new ND Population Programme** in order to ensure sufficient strategic focus is allocated to supporting people with ND and their families and carers.

Development of ND proposals through the ND funding with a variety of proposals which cover additional resources to tackle waiting lists, but also some more innovative proposals such as the myth busting communications and additional resources to support both professionals and parents to tackle challenging behaviour.

Disaggregation of the Western Bay Integrated Autism Service (IAS) is progressing well and 300 people have been transferred to the Cym Taff IAS. This disaggregation will be completed by April 2024.

Challenges

Improving Access to Neurodevelopmental (ND) services in Wales has been identified as a key Welsh Government priority. A recent independent review of all-age ND provision identified significant gaps in services and very long waiting times for assessment and support.

There are significant waiting lists for diagnosis of ND conditions both for CYP and Adults in the ND Early Years, ND 5-18 years' service and IAS. Growing rates of referrals for diagnosis seen over the last 2 years. There are challenges around the short term nature of the ND funding.

Gaps in Support Services: There are gaps in services, both pre and post diagnosis, however a clearer picture of all the provision across the region needs to be updated and shared with partners to provide further clarity. There is a need to reinforce the message to people with ND and their families and carers that diagnosis is not critical to receive appropriate support at the right time.

Workforce Issues: Recruitment and retention of staff is proving challenging in both statutory and third sector. When teams are not fully resourced, have significant workloads and long waiting lists, this can affect the morale and wellbeing of existing staff.

Quantitative Measures

There are 2 RIF funded ND projects:

Dynamic Divergent Project delivered by **Anxiety Support Wales CIC** and has funding of £5,296. The project has been developed to provide families with neurodiverse young people (age 8 to 17 years) with additional needs. The project is run on a Friday and Saturday (depending on their education setting), offering parents and caregivers a 2 to 3-hour respite once a month. The project seeks to assist young people deal with anxiety and other mental health challenges while encouraging them to try new activities. Activities include, arts and crafts, farm visits, trampoline, bush craft, water activities etc. **24 young people have been supported through this project this year, with 42 contacts** made to the service.

Gwaith Da Project is delivered by **ASDES** (Autistic Spectrum Disorder Employment Support) and has funding of £10,800. Autistic participants facing hurdles in their employment are able to get immediate support through this project to help them identify, with their team and managers, reasonable adjustments that can be put in place to enable them to maintain their employment. As part of this process participants are supported to apply for long term Access to Work funding that continues the support that they need in employment.

ASDES is able to signpost autistic participants to social based activities that it has running funded by other grants, these include weekly social groups around walking, board games, art based activities and gardening

ASDES is able to support autistic participants into volunteering sessions in their local community that allow them to engage with others and develop an important routine to their week.

25 young people have been supported through this project this year.

The **ND funded proposals** were approved by Welsh Government in June 2023.

Majority of the projects have required set up time in relation to recruiting posts and therefore reported on outputs in quarter 2 rather than outcomes.

There were **3 projects** that had funding until March 2025 under the **sustaining services theme** and all following 3 projects were focussed on targeting the current waiting lists:

- **Integrated Autism Service:** additional resource to directly address the waiting list by supporting the existing IAS service, in particular increasing capacity and therefore improving waiting times for diagnostic assessment. This additional resource would ~~be~~ enable **an additional 8 people being assessed per month**.

Additional resource was also provided to aid in support service development, reviewing referral processes and diagnostic assessment processes and pathways. This will ensure services collaborate and develop to provide early help and early intervention that aims to prevent needs from escalating whilst people are awaiting diagnostic assessments and for those who do not meet diagnostic thresholds.

- **Early Years ND:** additional resource to deal with the waiting lists initiative by offering additional clinics seeing **2 children per clinic**. This includes development of an EYND coordinator role to support change process and provide admin support to the pathway management.

This will provide early contact and support to families and some reduction of waiting time for children requiring an assessment.

- **ND service 5-18 years old:** Additional capacity to **reduce waiting times to 104 weeks** by March 2024.

There are **5 ND funded projects** under the transformation theme and are funded from July to March 2023:

- **ND Service 5-18 years old:** Additional resource to provide additional diagnostic and post diagnostic support which includes advanced practitioners, specialist nursing and speech and language therapy, for assessments.
- **ADHD Service for Diagnostic assessment:** Additional resource for a psychiatrist currently based within the CMHT to undertake **2-3 assessments a day** in order to address the waiting list of approximately 300 individuals.

This will support individuals and their families to have access to timely information and advice which will improve their quality of life, pre, during and any time post diagnosis. It would also allow timely access to services for those individuals awaiting ADHD diagnostic assessments.

- **Communication strategy for families about myth busting:** The development and implementation of a communication strategy for families and stakeholders is focusing on sharing and signposting to resources and approaches which exist within services / communities. The communications / marketing campaign will support the shift in ethos

recognising neurodiversity as an important feature of inclusive communities and details what neurodivergent people should expect in terms of support and explains how to access it. It will include explaining to families and stakeholders that diagnosis is not critical to receive appropriate support at the right time. Key elements of the project include:

- Support families and stakeholders to understand and access pre diagnosis support and service with a particular focus on the education offer.
- Provision of information, advice and support for those families and individuals who do not reach diagnostic thresholds or who are either on waiting lists or waiting to be referred.
- Provide accessible information and resources pre diagnosis so families, children and young people feel listened to and have developed strategies to manage the challenges they experience in a timely manner regardless of diagnosis.

An awareness raising video campaign is also being produced, which includes animation videos in English and Welsh language, developing testimonial representing different cohorts of people, telling their stories.

- **Qualified behavioural advice and guidance:** Within statutory Social Services we have seen an increase 'year on year' in referrals that outline behaviours that challenge and often carers who are at crisis point. A large percentage of these referrals are in relation to young people who have a Neuro developmental condition such as ASD and ADHD, with there often being a co-morbidity of diagnoses. An increase is also seen in those being referred that do not have any assessed learning disability. Parents are often asking for guidance around the management of these behaviours and how they can develop both their understanding of the condition and why these behaviours occur.

Additional resource for a trained behavioural specialist to be based within each of the local Child Disability Teams. This practitioner would work alongside assessing social workers to understand the behaviour and to help formulate a Positive Behaviour Support (PBS) plan for families. This would include an educative element for parents who may struggle to understand the diagnosis and how this may impact on the child's world and mentoring for LA staff who undertake the PSB training.

Outcomes include parent/carers will have a better understanding of why their child may challenge them and help them understand how to create a better environment around their child that will support them to be able to reach their full potential. It will also support the child/young person at the earliest point to understand why they use behaviours that challenge. The intention would then be to reduce the impact that this is having on the child/young person at the earliest point. This may in turn lead to greater social opportunities, a more stable home life and greater engagement with education.

Outputs include:

Timely assessment and intervention for children and young who have a Neuro developmental condition such as ASD and ADHD but do not have any assessed learning disability.

Educative element for parents who may struggle to understand the diagnosis and how this may impact on the child's world.

Mentoring for LA staff who undertake the PSB training to increase capacity and develop resilience across the service.

- **Summer Camp for children with complex needs and ND diagnosis:** Delivery of deliver a two week 'summer camp' for complex disabled children who struggle to manage

the disruption to their routine during the school summer holidays. **30 children to access the project and 10 parents engage in family support sessions.**

Qualitative Indicators

In this section you'll need to consider the key headings outlined below and utilise the prompts / questions to aid completion. It's important that you illustrate how individuals felt about what has been delivered, providing clear examples of changes made and innovative practices that have improved people's lives.

What we did and why (Input and Outputs in the last 6 months)

Dynamic Divergent Project:

100% of individuals reported they are feeling less Isolated; **100%** of individuals reported they have maintained or improved their emotional health & wellbeing and **100%** of individuals reported their independence has improved or remained the same. (These figures were based on a statistical sample of service users).

The project has built a small community and safe place for the **24 young people** who attends the groups which has encouraged independence and seen friendships develop, particularly with the shy young people who struggles to make friends.

They have seen a rise in self-confidence and young people disclosing their personal struggles enabling us to support them and signpost them to get the help they need. Often, they have never discussed these issues with anyone.

Parents and caregivers, as well as the young people, rely on this service for respite. The groups are kept small given it is less overwhelming for the young people, so they enjoy coming.

Gwaith Da Project:

100% of individuals reported they have maintained or improved their emotional health & wellbeing and **100%** of individuals reported their independence has improved or remained the same as a result of this project. **100%** of individuals report achieving their personal outcomes. (These figures were based on a statistical sample of service users).

3 participants applied for long term Access to Work Funding to maintain their positions in work. Successful applications made for benefits to support those who are unable to work.

The support from the job coaches is crucial to this project. ASDES job coaches have a wealth of experience behind them. One job coach has been working in the supported employment industry for over 20-years.

Due to the positive development of participants in the other projects ASDES has running, job coaches are training participants to become administrators of social activities, which will help sustain the social activities going forward. This also releases up time of job coaches to support the new referrals coming into ASDES.

What is being done differently?

Through the ND funding a communication strategy for families about myth busting has been developed. ~~The development and implementation of a communication strategy for families and stakeholders is focusing on sharing and signposting to resources and approaches which exist within services / communities.~~

The communications / marketing campaign will support the shift in ethos recognising neurodiversity as an important feature of inclusive communities and details what neurodivergent people should expect in terms of support and explains how to access it. It will include explaining to families and stakeholders that diagnosis is not critical to receive appropriate support at the right time. Key elements of the project include:

- Support families and stakeholders to understand and access pre diagnosis support and service with a particular focus on the education offer.
- Provision of information, advice and support for those families and individuals who do not reach diagnostic thresholds or who are either on waiting lists or waiting to be referred.
- Provide accessible information and resources pre diagnosis so families, children and young people feel listened to and have developed strategies to manage the challenges they experience in a timely manner regardless of diagnosis.

Gwaith Da Project: This project was set up as there was clear demand for support for individuals and this is evident through the ongoing referrals that ASDES receives.

Not all individuals are able to access the Government's ATW scheme. In some cases, support needs fall outside the workplace remit; others might not have formal identification of needs, such as an autism diagnosis, to enable them to be eligible. The current waiting time from application to assessment for ATW is roughly 6-months. There is also a long waiting period for others who are looking for an assessment leading to a formal diagnosis of autism or associated conditions. In addition, ASDES receives regular request from individuals who are off sick from their workplace. They are not eligible for ATW funding to enable them to get back to work.

Reach: Who we worked with (priority population groups – older people including people with dementia, children and young people with complex needs, people with learning difficulties and neurodevelopmental conditions, unpaid carers, people with emotional and mental health wellbeing needs).

The population group supported by this programme are neurodivergent children and adults across the region. There are also links to the other following programmes although specific actions around these cohorts may be delivered via the specific programmes:

- Wellbeing & Learning Disabilities Programme, given there are people with ND and LD.
- West Glamorgan Carers Partnership Programme, supporting carers and families for people with ND
- Emotional Wellbeing and Mental Health Programme, in relation to MH services for people with ND.
- Children and Young People Programme, for children with complex needs and ND including the transition process for children with ND.

The following primary models of care will be developed for people with ND through the development of the programme:

- Community Based Care – Prevention and Community Coordination
- Community Based Care – Complex Care Closer to Home
- Promoting Good Health and Wellbeing

There are links to accommodation solutions model of care and the capital plan given there are people with LD and/or complex needs who have a ND diagnosis who require housing as they are unable to live alone in the community or with their family.

How have people felt about what has been delivered
This will be updated in quarter 4
What have we learned about things that went well? What have we learned from any challenges that occurred?
<p>The transformational funding for the ND proposals were only funded for 9 months, given the funding was only for a year and approval was granted in June. Recruitment for posts in some proposals have been challenging, given the extent of the skilled workforce shortages and the short-term nature of the funding.</p> <p>Creating digital stories for a project such as Gwaith Da is challenging given it supports people with autism in the workplace and often those people do not want to be filmed or photographed when they are getting support in the workplace. The majority of the work therefore cannot be filmed or photographed due to the sensitivity of the support being put in place at a crucial time in an individual's life.</p>

Changes to System
System Outcomes/Benefits
To be reported in quarter 4
Programme Progress
To be reported in quarter 4
Lessons Learned
<p>The cross-cutting nature of the various population programmes need to be managed carefully in order to address any overlaps with other programmes. In the LD strategy there are a number of priority themes that could end up overlapping with the ND priorities once defined. The following are examples of the LD themes:</p> <p>'People have told us they want to be part of their local community and feel safe'</p> <p>'People have told us they want more opportunities and support in learning and training opportunities'</p> <p>Partners have agreed that any overlapping workstreams will need to be amalgamated in order to avoid duplication and to maximise resources.</p>
System Constraints
Financial Climate

The challenging financial climate is putting pressure on individual partners to deliver statutory services which makes it difficult to have the time and space required to develop transformational pieces of work. It continues to be a priority to develop and deliver preventative support to address increasing demands on services and reducing the long-term financial impact that this poses, however space is required to enable this work to be undertaken.

Financial issues in relation to inflation and the cost-of-living crisis are impacting on those voluntary organisations that support the most vulnerable in society. Even if RIF funding is maintained, partners who need to make difficult decisions in order to balance the budgets, could result in local funding being cut which will impact on the overall service offer across the region. This will then impact on those service users who rely on these essential community services, which could result in escalating needs, which in turn impacts on the statutory services. At the same time some of these voluntary organisations are seeing record high service demand together with escalating complexity of service user needs.

Data and information sharing

Work is required on how the region can increase data sharing opportunities and processes to allow for this to happen safely. Without being able to access all the data available it makes it difficult to measure impact of the work.

National Models of Care (NMoC)

Depending on regional structure, include reporting NMoC relevant to the programme (maybe single NMoC Contribution or multiple) For each NMoC section you complete you must consider:

- *How is the project meeting the outcomes of the Model of Care to which it is aligned?*
- *The activities you have delivered which you think could be important 'ingredients' (e.g., specific activities/components) of a national Model of Care, and explain why you think this is so*
- *What have been the gains / advantages for people brought about by those activities or components?*
- *If you were looking to help another team provide a service similar to yours, what would be the important things that you would want them to include?*
- *What advice would you give them about this? What might they avoid?*

NMOC: Prevention & Community Co-ordination NMOC – Outcome Statements:

1. People's well-being is improved through accessing co-ordinated community-based solutions
2. Local prevention and early intervention solutions support people to avoid escalation and crisis interventions

Programme Contribution

It is key that we have third sector organisations working together supporting the prevention and community coordination model of care through signposting to other opportunities in communities.

An example is ASDES who are able to signpost autistic participants to social based activities that it has running funded by other grants, these include weekly social groups around walking, board games, art based activities and gardening.

ASDES is also able to support autistic participants into volunteering sessions in their local community that allow them to engage with others and develop an important routine to their week.

NMOC: Complex Care

1. People are more involved in deciding where they live while receiving care and support
2. Complex care and support packages are better at meeting the needs of people and delivered at home or close to home

Programme Contribution

To be updated in quarter 4

NMOC: Emotional Health and Wellbeing

1. People are better supported to take control over their own lives and well-being
2. People have improved skills, knowledge and confidence to be independent in recognising their own well-being needs

Programme Contribution

Ensuring that people with ND look after their health is key to promoting good emotional health, however some people with ND struggle to manage to keep on top of health appointments.

ASDES supports autistic participants to access appointments that are important to their wellbeing, these include doctors and other welfare support organisations, without this support participants are too overwhelmed to attend appointments.

Ensuring people with ND have a purposeful life is important and therefore have a reason to get out of bed in the morning. Work opportunities and work experience are a key element of ensuring someone has purpose in their lives as well as providing stability in terms of an income. This will be a key element in the promoting good emotional health model of care.

ASDES cites some of the opportunities and challenges around this.

Autistic participants facing hurdles in their employment are able to get immediate support to help them identify, with their team and managers, reasonable adjustments that can be put in place to enable them to maintain their employment. As part of this process participants are supported to apply for long term Access to Work funding that continues the support that they need in employment

Autistic participants who are unable to continue in their employment are supported to have a positive exit strategy with their managers that enables them to move onto financial benefits that prevent them from hitting financial crisis.

Autistic participants who are off sick from work due to overwhelming anxiety are able to receive support from this grant to return to work or move onto a more positive outcome. Support workers in this instance work with managers to identify a working pattern that enable the individual to return to work positively. Alongside this support the grant enables allows support workers to spend time completing benefit applications such as Personal Independence Payments with participants to provide financial stability for the increased costs they face as a person with a hidden impairment.

Building safe communities for people with ND will support people's emotional wellbeing.

Dynamic Divergent Project allowed young people to build a small community of young people who understood the struggles they faced. The project gave a voice to them allowing them to choose activities they wanted ; this improved their confidence and wellbeing and built a small community.

Families to stay together

1. Families get better support to help them stay together
2. Therapeutic support improves and enhances the well-being of care experienced children

Not Applicable

NMOC: Home from Hospital

1. People go home from hospital in a more timely manner with the necessary support in place at discharge
2. People have a better understanding of the discharge process and are more involved in pre and post discharge planning

Not Applicable

NMOC: Accommodation

1. People are more involved in the design of accommodation to meet their needs
2. People have more choice about where they live and with whom

There are links to the capital programme given there are some HCF funded schemes for people with LD who also have a ND diagnosis.

Financial and Economic Data

There are currently only 2 RIF funded projects which exclusively support people with ND.

There will however be other projects for people with MH, LD and CYP that also support people with ND. Further analysis is needed around these projects.

Further work is required around the return on investment for the more preventative type schemes in order to calculate any cost avoidance figures attributable to schemes.

Programme Case Studies

There is a digital story available below for the Dynamic Divergent Project which is run by Anxiety Support Wales:

Digital Story [Anxiety Support Wales Final on Vimeo](#)