



North West
Learning Disability and Autism
Operational Delivery Network

The ODN Children and young people s' models of care work stream

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The Children and young people s models of care work stream

- A model of care for Mental Health services for Children and Young People with an Intellectual Disability and Autistic young people for North west England.
- Main themes from the NW England ODN baseline Audit
- Survey of intensive support pilots in NWE
- The Dynamic Needs Assessment Tool – SEN
- The Getting Help offer for NW England
- Clinical practice example : The Intensive support model
- ISF outcomes framework
- Northwest CYP-ISF Best Practice Peer Support Network
- Summary and next steps

Children and young people with neurodevelopmental conditions such as Autism, ADHD, Tics or Intellectual disability may present with emotional and behavioural issues due to multiple factors.

The factors could include developmental, educational, social, physical, and mental health needs.

They may easily fall between services and agencies.

11 years since the Winterbourne View abuse scandal



#HumanToo
#StrippedofHumanRights

The latest data shows there are

at least 1,990

people with a learning disability and/or autism in inpatient units.

NHS Digital Assuring Transformation data, July 2022

Shocking levels of restrictive practices

5,355

Within May 2022

reported uses of restrictive interventions in one month e.g. **physical, chemical, mechanical restraint** and being **kept in isolation**.



Of these,

840

were against **Children** (under 18s)

NHS Digital MINDS Data, May 2022, published August 2022

Delayed discharge

205

 people had their discharge delayed.

Main reasons: **lack of social care** and **lack of suitable housing** in the community.



NHS Digital Assuring Transformation data, July 2022

Shut away for too long

The average length of stay for people with a learning disability and/or autism who are currently in inpatient units is

5.5 years



NHS Digital Assuring Transformation data, July 2022

Children in units

Under 18s

The number of children with a learning disability and/or autism in inpatient units has **increased** since the start of the Transforming Care programme.



July 2022

205

March 2015

110

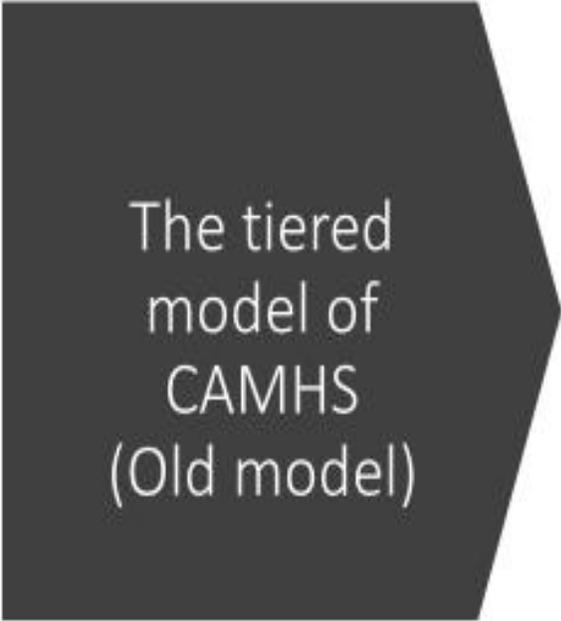


NHS Digital Assuring Transformation data, July 2022

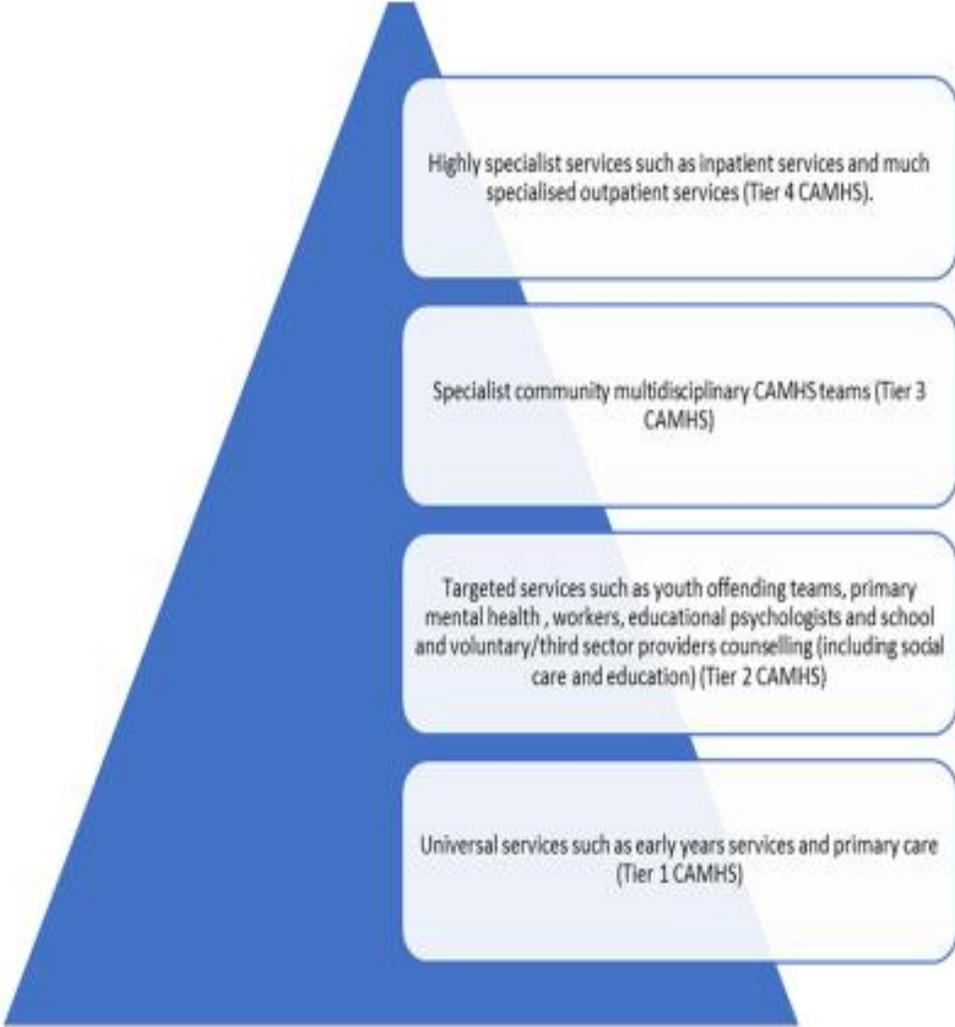


August 2022

Registered charity number 222377
(England and Wales); SC041079
(Scotland) 2022.014



The tiered
model of
CAMHS
(Old model)



Highly specialist services such as inpatient services and much specialised outpatient services (Tier 4 CAMHS).

Specialist community multidisciplinary CAMHS teams (Tier 3 CAMHS)

Targeted services such as youth offending teams, primary mental health workers, educational psychologists and school and voluntary/third sector providers counselling (including social care and education) (Tier 2 CAMHS)

Universal services such as early years services and primary care (Tier 1 CAMHS)

A Model of Care for Mental Health services for Children and Young People with an Intellectual Disability and Autistic young people for the NW.

A pathway for general services for CYP with learning disability with emotional or behavioural needs set within the national THRIVE multi agency framework for CAMHS.

The model should be aimed at children and young people between 0 to 25 years, reflecting the SEND agenda (Children and Families Act 2014):
Brings to together the provision that s already provided by LAs and their partner agencies for children and young people with SEND and a disability.

Including early help, a neurodevelopmental pathway with pre and post assessment support, an intensive support model (ISF) to prevent placement breakdown which should also link into specialist ASD/LD beds in order to facilitate a better return to the community
Uses the Dynamic Support Database for predicting increased risk of placement breakdown with a key worker

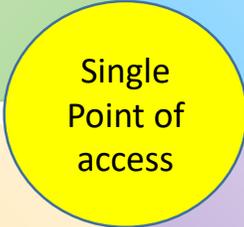
The ODN - Thrive Offer for the North West

ODN - Thrive model describes mental health support from multi agency services for autistic young people and those with learning disability from 0-25

- Led by education
- Early recognition and advice in educational settings led by education with support of CAMHS and social care
- Reasonable adjustments by staff skilled in all settings
- Access to early help

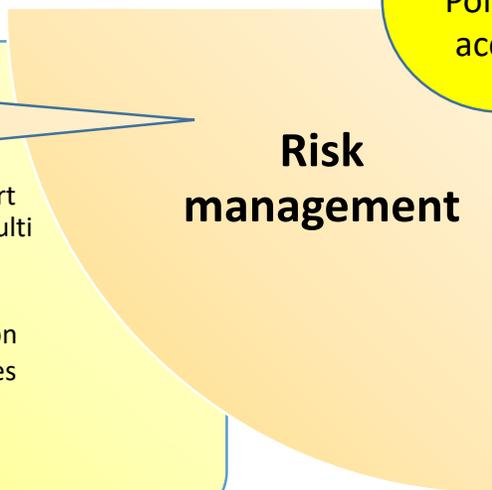


- Led by CAMHS
- Emotional and behavioural issues lead to a holistic multi agency response to the causes
- Mild to moderate mental health issues
- A single neurodevelopmental (NDC) waiting list
- Pre and post assess support on NDC pathway
- Seamless access to more specialist pathways



Tools to help target support for children and young people at risk of admission or being placed away from home Such as the Dynamic Support Database.

- Risk management support led by social care with multi agency support
- Key workers
- intensive support function
- Respite short break places
- residential placements
- Educational placement
- Hospital admission



- Led by CAMHS with multi agency response
- More specialist mental health pathways
- Eating disorders specialist service
- Avoidant , restrictive food intake disorder service
- Short breaks respite placements
- Neurodevelopmental assessment of Autism, ADHD , tics , Tourette's, Foetal alcohol syndrome

Needs led person centred .Equity of access and outcomes. Staff skilled /autism informed. Reasonable adjustments to environments. Adapted interventions. Seamless transitions experienced .All agencies work together around the child

ODN Base line audit of services in the North West using the Thrive model 2019-20 : Main themes

Aspects of model not in place at the time

- Single Point of Access
- Key worker
- Dynamic Support Database
- Annual health checks

Training gaps

- Including mandatory training
- Early recognition of MH
- Reasonable adjustments

Gaps/inconsistent access to services for certain population groups

- Including access to full Multi-disciplinary service/intervention

Lack of joined up multi agency working and understanding

Survey of Intensive support pilots in North West England 2021



Common challenges

Resources
Referral pathways
Multi agency working
Skills and training
Lack of access to support at an earlier stage

Variation
Baseline measures
Model
Population

Common approaches

Joint working or multi-agency working
Multi-disciplinary team
Person centred and working with the family
Flexible and responsive
Not just PBS but draws on different therapeutic frameworks as needed
Evidence based approach
Clear eligibility criteria, referral pathway and Standard Operating Procedure
Clear step up/step down process
Clear baseline assessments, and outcome measures

The Dynamic Needs Assessment Tool - SEN

ODN Audit and Surveys of ISF highlight a need for more joined up working and earlier intervention

The DNAT-SEN will be a needs stratification tool, to objectively identify multi-agency support needs of children and young people and their families

Used in the educational/community setting to identify children who are not receiving a service but may have multi agency needs – including unidentified neurodevelopmental / mental health / special educational needs / social care needs.

It would support early recognition of multi agency needs and early interventions and transition planning and enable fragmented information to be brought together about a child to produce a holistic measure of needs.

Development will use the same methodology as the DST-PH , focus groups experts in the relevant fields from education, social care , neurodevelopmental clinicians and CAMHS as well as groups with young people and carers to coproduce the tool.

The Getting Help Offer for the North West

Thrive describes mental health support from multi agency services for young people from 0-25

- Early signs of mental health, learning needs, neurodevelopmental conditions are picked up
- Emotional and behavioural support for children with SEN needs that lead to further support and pathways where needed.
- Special education needs
- Local authority Early Help
- Short break activities

The Dynamic needs assessment tool – for children and young people with special educational needs

Getting Advice

Single Point of access

Getting Help

- Emotional and behavioural issues lead to a holistic multi agency response to the causes
- Mild to moderate mental health issues
- Comprehensive assessment
- A single neurodevelopmental (NDC) waiting list
- Pre and post assess support on NDC pathway
- Seamless access to more specialist pathways
- Pathways that fall across agencies such as Selective mutism, Sensory needs, encopresis, enuresis
- Clear communication of offer

The Getting Help offer for Autistic children and young people, or those with other Neurodevelopmental Conditions or Intellectual Disability. and for Children & Young people at risk of eating disorders

Tools to help target support for children and young people at risk of admission or being placed away from home.

- Key workers
- Intensive support function
- Respite short break places
- residential placements
- Educational placement
- Hospital admission

Risk management

Getting more help

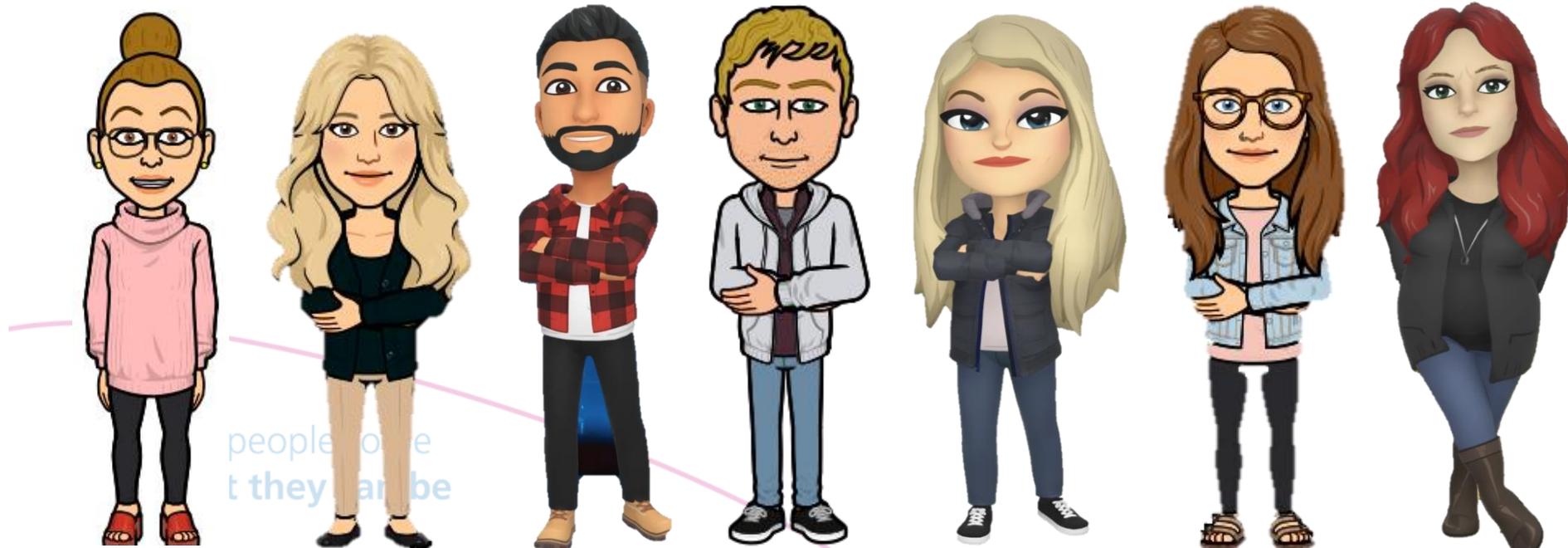
- More specialist mental health pathways
- Eating disorders specialist service
- Avoidant , restrictive food intake disorder service
- Short breaks respite placements
- CAMHS tier 3
- Neurodevelopmental assessment of Autism, ADHD , tics , Tourette's, Foetal alcohol syndrome

Step down for children and young people leaving Eating disorder services in the community

Needs led person centred .Equity of access and outcomes. Staff skilled /autism informed. Reasonable adjustments to environments. Adapted interventions. Seamless transitions experienced .All agencies work together around the child

CYP ISF Wirral

- Clinical Psychologist
- Specialist Nurse
- 2 Assistant Psychologists
- 1 Additional Assistant Psychologist for 12 months
- 1 Family Support Workers



CYP ISF Cheshire's

- 1 Clinical Psychologist
- 1 Specialist Partitioner
- 1 Mental Health Nurse
- 1 PBS Practitioner
- 2 Assistant Psychologists
- 2 Associate Practitioners
- 2 Clinical Support Workers
- 1 Admin



Background

- CYP ISF was based on the Ealing ITSBS (Intensive Therapeutic and Short Breaks Services)
- Transforming care aimed to end over-reliance on hospital admissions for people with LD/Autism
- Research found that individuals with LD/ASD admitted in inpatient units were there for an average of 5.6 years.
- There is a need for an alternative to inpatient care which adopts to the needs of the family and YP.

Criteria for CYP ISF

YP with
Autism
and/or LD

Open to
Tier 3
CAMHS

Tier 3 formulation
available and
Intervention tried



At risk of out of
area placement
or Tier 4 admission

Rating on
amber/red on
Dynamic Support
Database



Strengths



- **Enhances current provision-** to work intensively with families and system– The ISF consult about & hold case information for some of the most complex cases open to CAMHS.
- **Flexible & adaptable** – Our intensive & holistic approach allows us to provide services in locations and mediums not available to mainstream services.
- **Removing blocks** – The ISF team has capacity to work as a central point of contact for agencies to reduce misunderstanding & clarify the network or consider alternative pieces of work not in scope for mainstream teams.
- **A whole family approach-** CYP-ISF work with parents and siblings to create a consistent approach in being able to effectively manage the young person's behaviours of concern as well as support the family members with their own wellbeing.
- **Cost benefit analysis-** the average length of stay in an inpatient ward is 62 days and this approximately costs £219K per annum/733 per day. With CYP-ISF's input, inpatient placements are prevented which saves considerable amount.

ISF Process- Intervention

Assessment

- Comprehensive case formulation and identifying any gaps in understanding
- Completing standardised questionnaires and behavioural chart to retrieve a baseline score
- Complete a developmental history to gather a summary on the family's history.

Formulation

- Creating a 5P's formulation which will then be shared with the family and system
- This follows a person-centred and a collaborative approach with the family.

Goals

- Create SMART goals with the CYP and careers
- Gather a rating for each goal every week to track progress
- These ratings will be supported by evidence such as standardised questionnaires and behavioural charts

Multi-agency approach

- Identifying any gaps in support
- Providing training and resources to families and agencies as needs
- Liaising and supporting multiple systems such as social care and education re focus of intervention and strategies to help.
- Supporting ward staff- de-escalation techniques and debriefing
- Managing multiple risks and working with agencies about managing risk

3 Month Review

- Carry out ROMs to measure the effectiveness of the ISF intervention and identify areas of improvement.
- Carry out a 3 month review meeting to review progress with the team which will determine whether ongoing work is need or if the family need to be discharged from the team

“the relationship is totally different; they get on great now!”

“The holistic approach for us as a family has been brilliant”

“without the team’s involvement, I think we would have gone beyond breaking point”

“this was the best most constructive support we have received.”

“encouragement from the team helped me believe in myself”



“grown our confidence and strengthened our relationship with our son”

“Integrating their expertise with our experience and enabling us to be part of the improvement.”

“Putting the right things in place has made an unbelievable difference to his life.”

“My family will always be grateful for the support and understanding the team have shown.”

Helping people to be
the best they can be

ISF Outcomes Framework

Acknowledging our challenges:

- ❑ New service, cross national variability in commissioning, team structures, interventions offered. ISF teams having greater similarity in eligibility criteria.
- ❑ Different outcomes used across the CYP care group (e.g. inpatient to community)
- ❑ Small but intensive caseload within ISFs – harder to build a ‘data pool’ to evaluate effectiveness
- ❑ Heterogeneity of population – capturing meaningful outcomes for all
- ❑ Growth of model of ISF nationally, regionally and locally
- ❑ IT systems challenges for data collection



Both Wirral and Cheshire ISF teams currently bring their clinical experience with CYP&F and carers to the ODN.
The aim is to develop a co-produced outcomes framework for ISF-CYP.

Demonstrating meaningful and effective outcomes

Our ODN work will include

- Consistency with key national NHSE outcomes frameworks domains. The aims are to drive transparency, improve quality and measure outcomes consistently within our regional ISF services.
- Co-production is key – outcomes need to be meaningful to CYP&F
- A clear and collaborative approach to outcomes setting will be strived for (e.g. to use common language across settings)
- The outcomes will support and improve the delivery of our ISF services
- On-going cycle of service improvement planning – contributing towards demonstrating the longevity of ISF services

NHSE outcomes framework (2014):

Domain 1	Domain 2	Domain 3	Domain 4	Domain 5
Preventing people from dying prematurely	Enhancing quality of life for people with long-term conditions	Helping people recover from episodes of ill health or injury	Ensuring that people have a positive experience of care	Care in a safe environment and protecting them from avoidable harm



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Northwest CYP-ISF Best Practice Peer Support Network



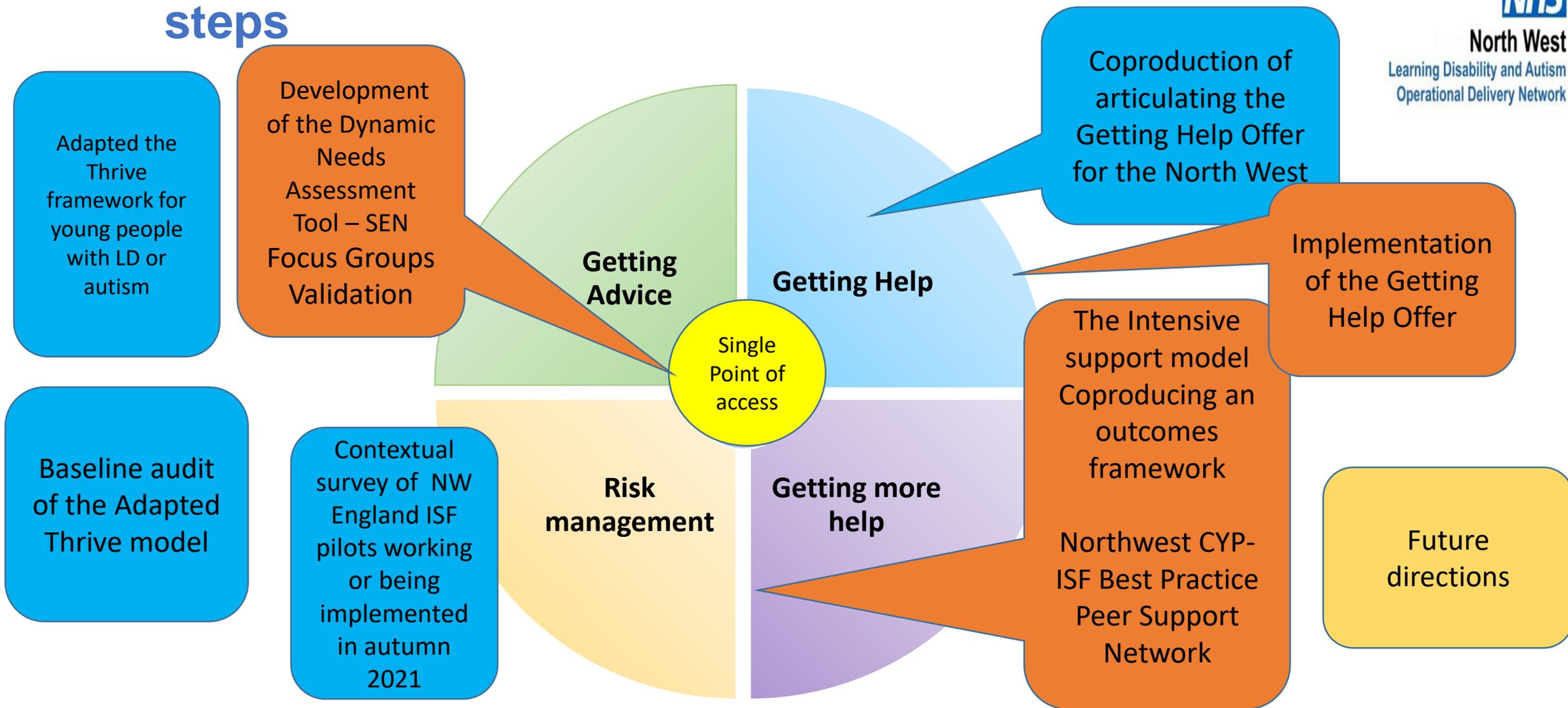


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The ODN CYP work stream –Summary and next steps



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