



North East Lincolnshire

Report on Equality and Diversity work 2012/13



Contents

Introduction.....	3
Section 1: Strategy.....	4
Authorisation requirements.....	4
Public Sector Equality Duties (Equality Act 2010)	4
Equality Delivery System	4
Equality objectives for the CCG	5
Mechanisms for consultation.....	5
Local engagement in North East Lincolnshire	5
Mechanisms for governance and assurance	6
Ongoing monitoring.....	7
Conclusion.....	7
Section 2: Action Plan for Equality and Diversity in NELCCG Update April 2013	8
Appendix 1: Equality and Diversity Engagement report 2013-14.....	12
Appendix 2: Report on Specific Equality Objectives regards Dementia.....	20

Introduction

North East Lincolnshire Clinical Commissioning Group (NELCCG) is committed to the promotion of equality and diversity and the prevention of any form of discrimination in the planning, development or commissioning of services.

NELCCG is also committed to commissioning the best possible quality of service for all service users within its area of operation and seeks to ensure that all services are being commissioned so that they are provided in an equally accessible way and do not discriminate against any member of, or group within, the community.

Within the planning process the following information is considered to ensure equality:

- Demographic data and other statistics, including information from the JSNA
- Recent research findings, including studies of deprivation
- The results of consultations or recent surveys
- The results of equality monitoring data.
- Information from groups and agencies directly in touch with particular groups in the communities we serve, for example qualitative studies by trade unions and voluntary and community organisations
- Analysis of records of public enquiries about services or policies, or complaints/praise about them
- Analysis of complaints of racial discrimination in employment or service delivery
- Recommendations of inspection and audit reports and reviews, such as 'best value', Care Quality Commission, Audit Reports etc.
- Recommendations from consultations carried out with local groups with protected characteristics

NELCCG recognises that there will be some areas of targeted work to address disadvantage in order to further work to address the gap in inequalities within areas of social deprivation.

This document sets out the progress made against the Equality and Diversity strategy and action plan for North East Lincolnshire CCG undertaken on behalf of North East Lincolnshire Care Trust Plus and the Humber Cluster during 2012/13

Section 1: Strategy

Authorisation requirements

The NHS Institute for Improvement and Innovation in their Preparing for Authorisation Workbook (2012) states that CCGs 'must have meaningful engagement with patients, carers and their communities'¹, this requirement clearly links to the 3 aims of the Equality Duty as set out in the Equality Act 2010 (EA2010).

Meeting the Equality duties as set out in the EA2010 is a statutory requirement for CCG's as they take over the reins of commissioning local health and wellbeing services ground

Equality and Diversity was a particular focus for the Authorisation visit in September 2012 and all key lines of enquiry were successfully addressed.

All Authorisation requirements were successfully met, enabling North East Lincolnshire CCG to come into being on 1st April 2013

Public Sector Equality Duties (Equality Act 2010)

NELCCG will ensure that all the policies and practices carried out in the area or on behalf of the CCG are informed by decisions based on equality analysis and assessment of impact that has identified if there are any effects on people; specifically with protected characteristics; within our community who may use our services or on the people we employ in line with the EA2010.

Equality Delivery System

The Equality Delivery System (EDS) was designed to support NHS commissioners and providers to deliver better outcomes for patients and communities and a better working environment for staff.

The EDS is a tool for both current and emerging NHS organisations in partnership with patients ,the public, staff and staff side organisations to use to review their equality performance and identify future priorities and actions .It offers local and national reporting and accountability mechanisms.

The EDS is a set of 18 outcomes grouped into four goals. These outcomes focus on the issues of most concern to the patients, carers and communities, staff and Boards .It is against these outcomes that performance is analysed, graded and action determined.

The NHS EDS has an underpinning principle to undertake meaningful engagement with patients, carers and their communities.

The EDS has four clear goals aimed at enabling local people to grade their NHS organisations in relation to their performance against these four goals.

- 1. Better health outcomes for all**
- 2. Improved patient access and experience**

3. Empowered engaged and included staff
4. Inclusive leadership at all levels

The EDS is currently being reviewed nationally in light of NHS infrastructure changes and outcome of this review is expected in June 2013. Consequently NELCCG is holding full implementation of the toolkit in abeyance subject to further guidance.

Equality objectives for the CCG

The current Equality objectives have been developed in line with the Local Implementation Plan and approved by the CCG

Our Equality Objective

To improve dementia care to people with protected characteristics whilst recognising and respecting a person's individual history, in particular:

- **The experience of dementia for an older person may be very different to the experience of a younger person.**
- **The experience of dementia may be different for individuals who are approaching the end of their life:**
 - **Who have a learning disability**
 - **Who are from a black or minority ethnic background**
 - **Who are lesbian, gay, bisexual or transgender**
 - **Gender**

This objective is in line with our Dementia Strategy which demonstrates that the operation of service will affect the over 65 years group of the population in North East Lincolnshire. This is expected to increase by 38% from 2008 to 2025 with an increase of 52% in the incidence of dementia. There are around 800 individuals currently registered with their GP as having dementia compared with the expected total of around 2000, based on national incidences.

Full consideration has been given the human rights of people considering the equality, dignity, respect, autonomy and fairness through equality impact analysis.

A full report on progress against this objective is included at Appendix 2

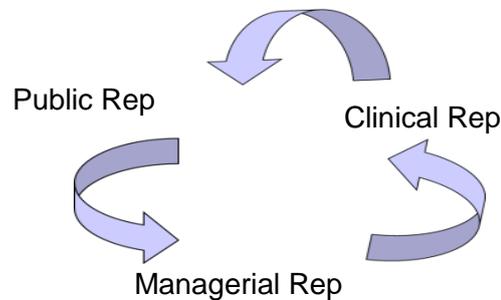
Mechanisms for consultation

Local engagement in North East Lincolnshire

Within NEL a community engagement model is in place which utilises a community membership (Accord) of over 2500 citizens that focuses specifically on

ideas/proposals for service change. This ensures public involvement at each stage of the commissioning cycle.

To lead reviews into service change we use a triangle basis of approach that consists of a lead commissioning clinical representative, a managerial representative and a public representative



The public representatives' responsibilities are to ensure that there has been public involvement in each stage of the commissioning cycle and to challenge any proposals that do not appear to fulfill that requirement. This also applies to equality and diversity considerations where the public representative will ensure that the protected groups are considered. There is a lay member that leads on Equality and Diversity and offers support and advice to community members and clinicians.

There is a list of representative groups including those with protected characteristics throughout the community and service plans and changes are tested through these groups as appropriate.

Representatives from the Accord community membership have been involved in setting priorities for both health and social care for the forthcoming financial year. A process was developed to involve clinicians and public representatives to judge health and social care priorities. The result was that access to services for dementia, together with treatment, are a real issue for those with learning disabilities. It is anticipated the same groups will be involved in grading the CCG and providers against the EDS goals and outcomes.

A full report on our engagement activities is included at Appendix 1

Mechanisms for governance and assurance

Governance

NELCCG has created proper constitutional and governance arrangements with the capacity to deliver on all its duties and responsibilities.

Governance structure for NEL

Action	Oversight group
Strategy development and EQIA review	Equality and Diversity Strategy Group
Strategy approval	CMM, CCG Governing body and

	Council of Members
Ongoing monitoring	Equality and Diversity Group, Delivery and Assurance Committee
Strategic Review	CCG Governing body receives periodic summary reports on progress of delivery

Ongoing monitoring

NELCCG Delivery and Assurance Committee will receive progress reports every 2 months and progress will be published annually in May as part of Year End Reporting.

Monitoring will include:

- Standing item including performance of CCGs against equality objectives and progress of EDS (evidence collected , EIA completed and complaints and SI)
- Exception reports on providers performance CSS, Public Health and Governance committee
- Involving Accord members to scrutinise CCGs provider performance
- Clear process on how goals were determined

Conclusion

The Equality and Diversity Core Group has undertaken a range of activities during 2012/13 which have provided a sound basis for progress on this agenda into the future. Further planning work is currently underway to set out a clear and robust revision to the strategy and action plan which will underpin enhancements in quality of commissioning and procurement practice and quality development in service delivery.

Key activities will be:

- Finalising baseline data for groups with protected characteristics in North East Lincolnshire
- Developing additional specific objectives as informed by the baseline data
- Collaborative working with other Public Sector providers to optimise impact of the specific objectives
- Review of translation and interpreting services available to our staff and service users

Equality and Diversity is currently and will continue to be a key priority underpinning all the work undertaken and commissioned by North East Lincolnshire CCG.

Section 2: Action Plan for Equality and Diversity in NELCCG Update April 2013

Action	Responsible person	Target date	Update April 2013
General Duty			
Aim 1: Eliminate unlawful discrimination, harassment and victimisation			
NELCCG will develop a Governance structure for Equality, Diversity and Human Rights	Lisa Hilder	July 31 st 2012	Core Group established from June 2012. CCG leads now operating in accordance with agreed governance structure
CCG leads should be informed and involved to assure equality, diversity and human resource practices			
NELCCG will ensure all staff undertake equality and diversity training at a level pertinent to supporting them to carry out their role effectively	Zena Robertson	March 31 st 2013	Equality and Diversity Impact assessment training has been undertaken by all service leads. Governing Body training workshop took place September 2012
Equal opportunity policies are in place and reviewed in accordance with the organisation's policy guidance and amended as new legislation and guidance requires	Lisa Hilder	July 31 st 2012, then ongoing	Policies have been reviewed and updated in relation to commissioning. Work is currently being undertaken with CSU HR reps on HR policies
Human Resources (HR) recruitment policies (and exit interviews) are fair and transparent	Helen Lambert	November 2012	
Staff record any 'Serious Untoward Incidents' relating to the identified equality strands	Zena Robertson	March 31 st 2013	Processes are in place to interrogate the Datix reporting system by Equality Strand
Customer Care Monitoring based on complaints, comments, compliments and concerns is carried out			The Complaints team monitor issues and concerns by Equality strand
Organisations carry out access audits to ensure services are accessible.			Further work is required to ensure this is mandated within tendering, procurement and contracting processes
Aim 2: Advance equality of opportunity between different groups			
NELCCG will have in place an Equality Analysis and Assessment of Impact Toolkit which allows the CCG to identify potential risks to the outcomes of patients as part of its decision making process	Lisa Hilder	July 31 st 2012	EQIA Toolkit in place and available via CCG intranet
The commissioning process will include the need to undertake	Strategic Leads for	October 31 st 2012	Requirement included in service redesign and business case

Action	Responsible person	Target date	Update April 2013
Equality Analysis and Assessment of Impact	Service Redesign		processes
NELCCG will have an Engagement Strategy which aims to ensure that people of protected groups are engaged effectively	Janet Gaiger	July 31 st 2012	Engagement strategy agreed and in place
NELCCG will demonstrate how it is committed to promoting Staff Side activities and will work with partner agencies from the public and voluntary sector	Helen Lambert	November 2012	Work currently being undertaken with CSU/HR staff – revised target date of March 2013
Aim 3: Foster good relations between different groups			
NELCCG will aim to carry out: Engagement with the workforce, partners and statutory partners Engagement with service users and carers	Janet Gaiger	March 31 st 2013	See Appendix 1, Engagement report
Specific Duty			
NELCCG will meet the requirements of the Specific Duties of the Equality Act by publishing equality information	Lisa Hilder	Ongoing	All data publication requirements for the CCG have been met and information is available via the internet
Actions to support CCG Authorisation			
Publish annual equality data information JSNA, Equality Impact Assessments, Staff Profile	Lisa Hilder	July 31 st 2012, then ongoing	Annual Equality data relevant to the size of the organisation will be published in September 2013. Links to the JSNA are published on the CCG website and the data repository for Equality Impact Assessments is in development to enable access via the CCG website Implementation of the EDS is currently under review nationally with guidance expected by the end of Quarter 1 2013/14 A robust process for Equality Impact Assessment has been implemented Governing Body engagement has taken place with a workshop
Publish equality objectives annual report on the outcomes as a result of objectives			
Implement EDS showing year on year improvement			
Robust assessment of impact of EIA which have been carried out as part of the decision making process from the beginning and enables the CCG to have full understanding of the equality risks to patients of decisions they have made			
NELCCG should undertake Equality and Diversity development to embed an Equality and diversity approach to decision making as part of their authorisation and beyond			

Action	Responsible person	Target date	Update April 2013
			delivered in September 2012 on responsibilities and recommended actions. Further workshops are planned, the first of which will be in June 2013. Report on progress against our specific objectives is included at Appendix 2
Performance of Priorities			
Equality and Diversity outcomes including EDS are written in to all provider contracts including SLA and MOU with Commissioning Support Services	Eddie McCabe	Ongoing	KPIs have been agreed for inclusion in 13/14 contracts. Assurance measures are currently in development
Develop assurance measures in Quality and contract reports			
Protected groups are engaged in the decision making including those communities which are seldom heard or marginalised			
CCG needs a clear understanding of the demographics of the people they will be serving including protected groups	Janet Gaiger	Ongoing	EDS implementation review will be undertaken during 2013/14. See Appendix 1 for Engagement report
Local interest groups across protected groups are engaged and involved in grading the CCG and its providers against the 4 goals in the EDS			
HR requirements			
The CCG undertakes robust equality analysis on transition plans	Emma Kirkwood	November 2012	Cluster and CSU have delivered the HR transition process. Reasonable Adjustment policy and process is in place
The CCG has JDs and selection criteria appropriate to delivery of expectations within available resources	Emma Kirkwood	November 2012	
When recruiting and advertising the CCG considers ED requirements. The CCG can demonstrate reasonable adjustments	Emma Kirkwood	November 2012	
All the Human resource policies have been assessed for their impact on protected groups.	Emma Kirkwood	September 2013	Work is ongoing to review all CCG policies
Equality Delivery System Implementation			
All groups with protected characteristics will be considered whenever any service changes are planned, to identify unfair	Strategic Leads for	Ongoing	Training has been rolled out for relevant staff to ensure consideration

Action	Responsible person	Target date	Update April 2013
disadvantages for any group whilst fostering good relations between groups.	Service Redesign		of protected groups. The business case process mandates an EQUIA for all new service proposals
Equality Impact Assessment training to be undertaken by Service Leads (managers / Clinicians)			
A ratification group will be set up and will be representative of the protected groups and of the local demographics. Any gaps will be identified.	Lisa Hilder	October 31 st 2012	Group has been established and EQIAs are reviewed as part of the sign off for service proposals EDS implementation is being reviewed nationally in light of NHS restructures. Once the outcomes of the review are published NELCCG will determine if and how it continues to implement the EDS.
The ratification group will set the EDS gradings, and any differences of opinion will be logged together with the grading to be reviewed as per the action plan			
The outcomes of the grading process will be published on the internet and website and will be embedded into the mainstream NHS objectives			
Accountability for fulfilling the EDS requirements rests with the CCG governing body, therefore EDS information will be reported to the governing body as required	Lisa Hilder	Ongoing	Reports are submitted to the Delivery and Assurance Committee receive bi-annual reports on Equality and Diversity issues

Appendix 1: Equality and Diversity Engagement report 2013-14

Public engagement: Effective engagement in health and social care means listening and speaking to the people who receive the services as they are the ones who can tell us what is working well and suggest how things could be done better.

Our aim is for more effective engagement

Accord is a health and social care community membership scheme that is open to people who live in, or are registered with a GP in North East Lincolnshire. The North East Lincolnshire CCG needs the help of local people to help improve health and adult social care services.

The engagement process used is inclusive to groups with protected characteristics and supports the Equality Act 2010 and the Equality Delivery System.

Resources to support effective engagement

The Accord database is the tool used to provide accurate data used in the monitoring of equality, this includes;

- Age
- Disability
- Ethnicity
- Gender
- Socio-economic status
- Health Acorn data

Equal Opportunities Monitoring Forms are completed by attendees at events and this tool identifies the following categories:

- Age
- Disability (physical, mental, learning)
- Ethnicity
- Gender
- Sexual orientation

Equality impact assessments guide the requirements for reaching potentially groups which might be disadvantaged. Each specific activity is assessed to ensure that the engagement reaches the groups most affected.

Equality and Diversity Stakeholder list enables more effective engagement to the wider community and seldom heard groups plus people who are not Accord members. There is a comprehensive list which is constantly updated and includes local organisations, groups and individuals with protected characteristics.

Out of pocket expenses policy. This has removed some barriers to public involvement, such as transport and child care.

Communication methods used:

- Face to face
- Email

- Postal
- Telephone
- Website
- Newsletter
- Social media

Special communications requirements of Accord members can be identified from the Accord database, such as large print.

An overview of engagement and consultation in NEL 2012-13

There has been significant service user and public engagement in shaping our priorities and our plans for services in 2012-13

The examples shown below are some of the engagement activities of 2012-13 and the equality data shown is taken from the equal opportunities forms completed by the attendees.

Commissioning intentions 2013-14

Planning for the future – moving forward together 4th July 2012

21 completed forms out of 24 attendees

Ethnicity

White British	90%
Indian	5%
No response	5%

Gender

Male	52%
Female	43%
No response	5%

Age

30 to 39	5%
40 to 49	5%
50 to 59	19%
60 or over	57%
No response	14%

Sexual Orientation

Heterosexual/straight	72%
Other	5%
No response	23%

Disability and special needs

Do you consider yourself to have a disability?

Yes	23%
-----	-----

No	67%
No response	10%

Type of disability

Physical	23%
----------	-----

Dragon's Den event 18th October 2012

19 completed forms out of 34 attendees

Ethnicity

White British	95%
Indian	
No response	5%

Gender

Male	42%
Female	58%
No response	

Age

30 to 39	10%
40 to 49	32%
50 to 59	26%
60 or over	32%
No response	

Sexual Orientation

Heterosexual/straight	85%
Other	5%
No response to this question	10%

Disability and special needs

Do you consider yourself to have a disability?

Yes	16%
No	74%
No response	10%

Type of disability

Physical	16%
----------	-----

Improving Local Health Services 16th May

Responses 25 out of 25 attendees

Ethnicity

White British	76%
Black Caribbean	4%
Uncompleted forms	20%

Gender

Male	32%
Female	48%
Uncompleted forms	20%

Date of Birth

30 to 39	8%
40 to 49	4%
50 to 59	20%
60 or over	48%
Uncompleted forms	20%

Sexual Orientation

Heterosexual/straight	60%
No response to this question	20%
Uncompleted forms	20%

Disability and special needs

Do you consider yourself to have a disability?

Yes	32%
No	40%

Type of disability

Physical	28%
Mental	12%
Sensory	4%
No response to this question	8%
Uncompleted forms	20%

Pain Management Focus Group

4 out of 4 attendees

Ethnicity

White British	75%
Unclear forms	25%

Gender

Male	50%
Female	50%
Uncompleted forms	

Date of Birth

30 to 39	25%
40 to 49	
50 to 59	50%
60 or over	25%
Uncompleted forms	

Sexual Orientation

Heterosexual/straight	50%
No response to this question	50%
Uncompleted forms	

Disability and special needs

Do you consider yourself to have a disability?

Yes	50%
No	50%

Type of disability

Physical	50%
Mental	50%
Learning	25%

Review of Neurology Services 18th June 2013

16 responses

Ethnicity

White British	94%
No response	6%

Gender

Male	31%
Female	69%

Date of Birth

30 to 39	6%
40 to 49	25%
50 to 59	38%
60 or over	31%

Sexual Orientation

Heterosexual/straight	88%
No response to this question	12%

Disability and special needs

Do you consider yourself to have a disability?

Yes	63%
No	31%
Uncompleted forms	6%

Type of disability

Physical	44%
Mental	6%
Sensory	12%
Other	6%

OVERALL % from these 5 events (85 responses)

Ethnicity

White British	86%
Indian	5%
Black Caribbean	5%
No response	14%

Gender

Male	41%
Female	54%
No response	5%

Date of Birth

30 to 39	11%
40 to 49	13%
50 to 59	31%
60 or over	39%
No response	7%

Sexual Orientation

Heterosexual/straight	71%
Other	18%
No response to this question	11%

Disability and special needs

Yes	37%
No	52%
No response to this question	3%

Summary

The gaps in these engagement events are in ethnicity, young people, gay/lesbian/bisexual.

Other engagement activities

Proposed relocation of Diagnostic Services questionnaire Sept 2013

Over 1,000 Accord members were offered the opportunity to complete a questionnaire. Using the Equality and Diversity Stakeholder list, representatives from 25 local groups and organisations were sent information and a copy of the questionnaire which helped to reach the wider community and seldom heard groups plus people who are not Accord members.

Communities Together posted the questionnaire on their website which resulted in direct access to ethnic minority groups. Total responses were 84.

Safeguarding Vulnerable Adults – ongoing engagement

Community Voice is a community group of approximately twenty five members who feel passionate about community issues and protecting those who are vulnerable. The members are a challenging and active group of local people who are keen to have their say and to be heard. They hold monthly meetings to provide an engagement opportunity for the local population.

The makeup of the core group encompasses many of the groups with protected characteristics, such as:

- Carers
- Disabled people – physically / mentally
- Older people/younger people
- Socially isolated
- Different gender
- Gay
- Single people / married / civil partnership

The members openly welcome any individual to join them and actively seek out new members by speaking to the public at local events and meetings and by regular refreshes of the Accord database search and by working in partnership with local organisations.

The group have worked with partner organisations to hold events and support events in local areas and their main aim is to make local people feel safe in their homes and out in the community.

The engagement process used is inclusive to groups with protected characteristics and supports the Equality Act 2010, the Equality Delivery System and the NHS Constitution.

What could we do better?

Although we try to use the networks we have built up to reach the wider community in terms of groups with protected characteristics, there are still gaps in some areas which need to improve, such as transgender, sexual orientation and ethnicity.

Some BME groups require a more direct engagement than the usual invitation to an event. It might be more effective if we go into the community and engage with some people on their own ground where they feel more comfortable. The Communities Together Forum would be a good example.

Appendix 2: Report on Specific Equality Objectives regards Dementia

Background and context

A Dementia Strategy Group and Dementia Forum (with representation from a broad spectrum of stakeholders) were established locally to take forward the development and implementation of a local dementia strategy. A three year strategy and associated action plan was developed and this has been updated regularly. The latest version (currently in draft form) includes four key areas for improving the quality of life for people with dementia.

1. Ensuring better knowledge about dementia and removing the stigma.
2. Ensuring early diagnosis, support and treatment for people with dementia and their family and carers.
3. Developing services of good quality to meet local and changing needs to provide better quality care.
4. Committing to reduce the use of antipsychotic medication for people with dementia.

The strategy sets out to update our local plans to work towards improving standards of care for all people with dementia and their carers as set out in the National dementia strategy and within our commissioning framework. We know how important it is for people to stay independent for longer, as well as to actively reduce any admissions to hospital and care homes and to work in an integrated way to transform health and social care for people with dementia. We are investing in early diagnosis, better information and developing the support to improve the quality of care delivered by all care providers. This will be reinforced through the vast training and development that has been provided to all involved with dementia care including the Dementia Champions Programme and we recognise the importance of a good knowledge base and skill set. This will support continual improvements to the care people receive in North East Lincolnshire (NEL). We recognise that it is important to ensure that people are given the right prescriptions and we have signed up to be part of a national programme to help us to reduce the use of anti-psychotic medication.

The revised dementia strategy “Living well with dementia in North East Lincolnshire” sets our intention to ensure equality is embedded in the provision of dementia care, as per the guidance set out by NICE and SCIE recommended and is interpreted as :

- Always treat people with dementia and their carers with respect;
- Check out and ensure that plans are in place for people if there is a language barrier by the offer of providing written information in the preferred language and/or in a format that can be easily accessed; or to provide independent interpreters;
- Provision of Psychological interventions in the preferred language.

It also identifies specific needs arising from:

- Diversity (such as sex, ethnicity, age, religion and personal care);
- Ill health, physical and learning disabilities, sensory impairment, communication difficulties, problems with nutrition and poor oral health;
- Identify and, wherever possible, accommodate preferences (such as diet, sexuality and religion) particularly in residential care.

The increasing incidence of dementia as a result of the ageing population means practitioners need to develop and improve communication skills in caring for people with this condition. The dementia awareness and dementia champions training has contributed to ensuring that communication is being improved and is having a positive effect on patients' quality of life and well-being.

We recognise that dementia has a big effect on our society and that, whilst most people with dementia are over 65 years old, there are many people under 65 who have the illness. Dementia can affect anyone whatever their gender, ethnic group or class. People with learning disabilities are at particular risk, especially those diagnosed with downs syndrome. The strategy recognises that dementia makes the lives of people who have it, and the lives of their families and carers, very difficult. Family carers are often old and frail themselves. The strain of caring for someone with dementia can cause physical or mental illness in the carer.

Within the strategy we have set out to include improvements in dementia care to people with protected characteristics whilst recognising and respecting a person's individual history, in particular:

- The experience of dementia for an older person may be very different to the experience of a younger person
- The experience of dementia may be different for individuals who are approaching the end of their life
- Who have a learning disability
- Who are from a black or minority ethnic background
- Who are lesbian, gay, bisexual or transgender

Person Centred Support Planning for People with Dementia

Fundamental to a person centred approach are the concepts of equality, diversity and inclusion. It is important to understand that each person's experience of dementia is unique. It is essential to recognise and respect a person's individual history. For People diagnosed with Dementia it is essential the care & support they receive is focused around them enabling them to be as independent as possible and remain in control of decisions that affect their life.

The NEL Dementia Forum together with partner agencies and families have joined together to develop "my life" Person Centred Support Planning for People with Dementia in NEL.

My life is a series of planning tools that can be used to develop meaningful plans that outline the person and family's wishes.

My life will help people find out things like: Who they are, their personality, how they interact: what they bring to the World.

And identify:

What is essential to them, what must be in place, and ensure what everyone needs to do in order to support and enable them to live their life, the way they choose?

The plan will support and enable uniform / individualised care, by all care providers.

Progress against our Specific Objective

North East Lincolnshire's specific objective related to Dementia is articulated as;

To improve dementia care to people with protected characteristics whilst recognising and respecting a person's individual history, in particular:

- The experience of dementia for an older person may be very different to the experience of a younger person.
- The experience of dementia may be different for individuals who are approaching the end of their life:
 - Who have a learning disability
 - Who are from a black or minority ethnic background
 - Who are lesbian, gay, bisexual or transgender
 - Gender

Younger people with dementia

The local strategy sets out that people diagnosed with dementia aged under 65, benefit from a specialist Younger Dementia support as part of the memory support service provided by NAVIGO. It has been acknowledged that getting an accurate diagnosis of dementia can take a long time due to a lack of awareness that dementia can happen in younger people. The dementia pathway sets out that if a GP decides that specialist assessment is required, they can refer into the Specialists in dementia memory support service. They may then be referred to a neurologist. It is recognized that the route to diagnosis can be complicated, and younger people with dementia can receive very different levels of support from different doctors and professionals. Specialist diagnostic services for younger people with dementia tend to be run by neurologists with a special interest in cognitive problems and dementia – however, these are few and far between, due to lack of resources. Consultants appointed to be responsible for younger people with dementia also tend to be neurologists.

Later stages and end of life

Joint working with the end of life team is taking place to assist people with dementia in North East Lincolnshire, especially during the late stages of the disease where it may be a struggle to communicate feelings and symptoms, or to understand and co-operate with. For example the usual methods for administration of medication and the incidence of physical symptoms and needs in the late stages of the condition means that the majority of people will be in a care home or in hospital. Support is being offered to support the choice of the person and family, and is entirely appropriate e.g. when a care home has been the person's home for some time.

However, unplanned admissions very near to end of life are not ideal, and can often be prevented and more work needs to be done to prevent this occurring with support developed by community services who are now working on a shared understanding that the person is approaching end-of-life. There has been the opportunity to agree with the patient (if possible) and family that the focus of care should be aimed around good symptom management and maintaining quality of life and dignity, not attempts at prolonging life at all costs.

Developments are needed to make this information available via a GP palliative care register to all professionals involved so mechanisms can be put in place, including the availability of medications, to ensure patients can be cared for and die in the usual place of residence.

People who have a learning disability and dementia

The needs of people with a diagnosis of dementia who have a learning disability continue to be provided in an effort to support a holistic approach, that incorporates the mainstream abilities and provides services that are individualised to meet the needs of the person using them, ensuring that they have choice and control over the services offered, by utilising the pathways set out from the learning disability support teams. Early diagnosis and recognition of the risk of developing dementia has been the key to providing good follow up support and the learning disability support team have good knowledge to enable forward planning. This supports the maintenance of independence and friendships for as long as possible and to assist people to remain in their accommodation, if appropriate. A joint decision is taken to only move someone to a dementia specific care provider if needs became too complex to continue with their usual support.

A training programme providing practice development guides, called “supporting Derek” has been purchased and incorporated into practice to help to understand the needs and learn how best to support people with this dual diagnosis.

The needs of people who are black or minority ethnic background.

Black and minority ethnic (BME) people are generally under-represented in dementia services and within North East Lincolnshire. Therefore it is important not to forget the development of appropriate health and social care services to meet their needs. This has started in a small way and some of the ideas for addressing this have been to :

- Develop a multi-purpose leaflet instead of individual leaflets from each separate service. Such a leaflet would include information about memory problems and about what sort of help is available.
- Holding ‘roadshows’ at religious establishments and community centres.
- Providing DVDs and videos about dementia which can be particularly useful where members of a community are neither literate in English or their mother tongue.
- Creating links with local communities – for instance, at places of worship.

Services for those who are lesbian, gay, bisexual or transgender

We have recognised that the discrimination and prejudice suffered by many LGBT people with dementia means that a true estimate of the numbers affected is difficult to judge. Many LGBT people are reluctant to identify their sexuality and access local services because of the discrimination they have suffered, or fear they may suffer. There is a belief that between 5 and 10 per cent of the population is thought to be homosexual. This translates to significant numbers of LGBT people with dementia and their caregivers whose needs may not be fully recognised or met. Whilst the numbers in North East Lincolnshire may not be huge, as this is dependent on the area in which they live. Unlike most big cities that have significant numbers of LGBT people who are active in local community politics, or social and medical services, and who often provide specialist voluntary services and advocate on behalf of their members but in North East Lincolnshire the town and in rural communities, there are many people who are isolated by their sexuality. In order to offer the right support we intend to:

- Review the publicity material and policy documents produced to show policies relating to confidentiality or zero-tolerance to homophobic language.
- Make sure that the language used is inclusive of people who are not in heterosexual partnerships and acknowledges that not all carers are heterosexual and/or blood relatives of the person with dementia.
- If pictures or photographs are used, think about including some images of people in same-sex relationships.
- Ensure that appropriate understanding and awareness of the different needs of people who are LGBT by all staff and professionals who may come into contact and provide support.
- If the person with dementia is lesbian or gay, they may have difficulties with the kind of support offered therefore consider the importance of setting up provision of contact with other gay people to support their identity and confidence at a time of loss and change.

While the majority of issues faced by people with dementia and their families and carers may be similar, everyone's experience of dementia is different. Some people may face additional challenges, and we intend to ensure that they are able to access specialised services or support groups to assist with these challenges as set out in the revised dementia strategy for North East Lincolnshire.

Gender

Specific work to address the differing needs of men and women will be a focus of work during 2013/14

Jeanette Logan

April 2013