



Northern Ireland  
Assembly

# Research and Information Service Briefing Paper

Paper No. 36/20

28th May 2020

NIAR 132-2020

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## Autism: (i) Programmes of Care and (ii) Use of Language

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## 1. Context

This briefing paper has been prepared to support the development of a potential Private Member's Bill concerning Autism. The paper focuses on two separate topics (i) Programmes of Care within the NI Health and Social Care (HSC) System (current and the potential for a new one specific to 'social and communication disabilities') and (ii) an introduction to the best practice around the use of language in the UK for the diagnosis of autism and to describe autism.

## 2. Programmes of Care

### 2.1 Current Programmes of Care in the HSC in NI

Programmes of Care within the Northern Ireland (NI) HSC are divisions of healthcare, into which activity and finance data are assigned, to provide a common management framework. They are used to plan and monitor the health service, by allowing performance to be measured, targets set and services managed on a comparative basis.<sup>1</sup> In total, there are nine Programmes of Care (PoC):<sup>2</sup>

- PoC1 – Acute Services;
- PoC2 – Maternity and Child Health;
- PoC3 – Family and Child Care;
- PoC4 – Elderly Care;
- PoC5 – Mental Health;
- PoC6 – Learning Disability;
- PoC7 – Physical and Sensory Disability;
- PoC8 – Health Promotion & Disease Prevention;
- PoC9 – Primary Health and Adult Community.

The Northern Ireland Capitation Formula is used by the Health and Social Care Board (HSCB) to determine the 'target fair shares' of the available resources for hospital and community services, which should be used to serve the population of each Local Commissioning Group (LCG). These services are then commissioned from the Health

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<sup>1</sup> Hospital Activity, Outpatient Statistics, Statistics 2018/19, Department of Health, Information Analysis Directorate, Appendix 5, Appendix 5: Hospital Specialties by Programme of Care, <https://www.health-ni.gov.uk/sites/default/files/publications/health/hs-outpatient-stats-18-19.pdf>

<sup>2</sup> Factsheet – Northern Ireland Capitation Formula, Department of Health NI (July 2014) <https://www.health-ni.gov.uk/publications/capitation-formula-factsheet>

and Social Care Trusts (HSCT) by the HSCB. The current capitation formula is based on the Programme of Care (PoC) approach.

Each PoC listed above has its own formula to determine its shares of resources; however, PoCs 1 and 2 each have two formulae to determine how their shares should be allocated. Each of the PoC formulae comprises of three elements; the Relevant Population, the Age/Gender Weightings and the Additional Needs Weighting.<sup>3</sup>

It is likely that presently funding for services for Autism fall under at least three PoC - PoC 5, PoC 6 and PoC 7. The Member is proposing that this may not be suitable and that a new separate PoC be considered for Social and Communication Disability.

## 2.2 Potential for a New PoC in NI

In terms of understanding the origins of the current PoC and the potential to instigate a new PoC, RalSe posed a number of questions via email to the Department of Health as follows:

- When and how were the current nine PoC established?
- Are the PoC set out in legislation anywhere or are they an administrative construct? and
- If there were to be a new PoC – what would the process be for its establishment?

The response from the DoH can be found in follow-up RalSe briefing NIAR-208-2020.

As stated above, the HSCB in NI commissions services from the HSC Trusts and the current capitation formula for allocation of resources is based on the Programme of Care (PoC) approach. The following paragraphs take a brief look at the commissioning systems in England, Scotland and Wales.

**For England**, NHS England and its partners set the overall commissioning strategy and clinical priorities for the NHS. NHS England commissions: primary medical services (for GPs this is mostly devolved to Clinical Commissioning Groups (CCGs)); 'specialised' services (such as treatments for rare conditions and secure mental health care); military and veteran health services; health care in prisons and also some public health services.<sup>4</sup>

The 'specialised' services are grouped into six National Programmes of Care (NPoC). Each has an NPoC Board, which coordinates and prioritises work across the

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<sup>3</sup> Factsheet – Northern Ireland Capitation Formula, Department of Health NI (July 2014) <https://www.health-ni.gov.uk/publications/capitation-formula-factsheet>

<sup>4</sup> NHS Commissioning, <https://www.england.nhs.uk/commissioning/who-commissions-nhs-services/nhs-england/>

services in that programme of care. The six NPOC's are – Internal Medicine; Cancer; Mental Health; Trauma; Women and Children; and Blood and Infection.<sup>5</sup>

The CCGs are groups of general practices (GPs) in each area to commission services for their patients and population. CCGs commission most secondary care services, and play a part in the commissioning of GP services. CCGs commission: planned hospital care; rehabilitative care; urgent and emergency care; community health services; learning disability and/or autism services; and mental health services.<sup>6</sup>

**In Scotland**, the Scottish Government sets national objectives and priorities for the NHS and signs delivery plans with each NHS Board and Special NHS Board. There are 14 NHS Boards and seven national or 'special' NHS Boards providing national services. NHS Boards in Scotland are all-purpose organisations: they plan, commission and deliver hospital and community NHS services. At local level, there are committees of the NHS Boards called community health partnerships or community health and social care partnerships. NHS Boards work together regionally and nationally to plan and commission specialist services such as heart and lung surgery and neurosurgery<sup>7</sup>

The Scottish Resource Allocation Formula is used in the allocation of around 70% of the total NHS Budget between the 14 NHS Boards in Scotland. The Formula calculates target shares (percentages) for each NHS Board based on a weighted capitation approach that starts with the number of people resident in each NHS Board area. The formula then makes adjustments for the age/sex profile of the NHS Board population, additional needs based on morbidity and life circumstances (including deprivation) and the excess costs of providing services in different geographical areas.<sup>8,9</sup>

**In Wales**, health services are managed and delivered by seven local health boards (LHBs). These Boards are both commissioners and providers of services in their areas, with responsibility for the health of their local population. This means that they deliver or commission the full range of health services. Unlike the other six, the Powys Health Board commissions many of its hospital services from across the border in England, and is much less involved in directly providing secondary hospital care.<sup>10</sup>

A RalSe initial literature research revealed **little reference to the use of PoC outside of the NI HSC** (apart from NHS England's NPOC). To gain more certainty about the

<sup>5</sup> National Programmes of Care and Clinical Reference Groups, NHS England,

<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/>

<sup>6</sup> NHS England, CCGs, <https://www.england.nhs.uk/commissioning/who-commissions-nhs-services/ccgs/>

<sup>7</sup> NHS Scotland, How it Works? <http://www.ournhsscotland.com/our-nhs/nhsscotland-how-it-works>

<sup>8</sup> The final shares actually allocated to the Boards are different from the target shares calculated by the formula. The policy of the Scottish Government Health Directorate is to phase in the Formula by way of 'differential growth' whereby all Boards would continue to enjoy real-terms growth in their allocations year-on-year, with those above parity (i.e. above their formula target share) receiving less growth than those below parity until the new distribution was achieved.

<sup>9</sup> Resource Allocation Formula, Public Health Scotland, <https://www.isdscotland.org/Health-Topics/Finance/Resource-Allocation-Formula/>

<sup>10</sup> Worthington, Dr P. (2019), Is healthcare in Wales really that different? Wales Centre for Public Policy, 21st October, 2019, <https://www.wcppp.org.uk/commentary/is-healthcare-in-wales-really-that-different/>

use or otherwise of PoC in neighbouring jurisdictions (to assign resources or manage services) RalSe then posed a number of questions via email to NHS England, NHS Scotland, NHS Wales and also to the HSE in the Republic of Ireland as follows and referring to the PoC in NI:

- Is there a similar system in use within NHS England/Scotland/Wales or in the HSE?
- If not, what is the system used to assign finance to areas of healthcare?
- If there are such PoC in use – in which one does Autism Services sit or belong?

The responses from the DoH can be found in follow-up RalSe update briefing NIAR-208-2020.

### 3. Autism and Use of Language

#### 3.1 Introduction

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people. Autism is a spectrum condition and often people feel being autistic is a fundamental aspect of their identity. All autistic people share certain difficulties, but being autistic will affect them in different ways.<sup>11</sup>

The NHS states that autism is not an illness or disease but means a person's brain works in a different way from other people. Some people with autism will also have learning disabilities, mental health issues (such as anxiety or depression) or other conditions such as attention deficit hyperactivity disorder (ADHD), dyslexia, and epilepsy, meaning people need different levels of support.<sup>12</sup>

Qualitative differences in social interaction are arguably the core defining features of the autism spectrum. Such differences can result in social isolation and exclusion and can potentially pervade all aspects of ordinary living such as relationships, employment and access to leisure and consumer experiences.<sup>13</sup>

Some people with autism are able to live relatively independent lives but others may face more challenges. Areas of life that can be challenging include - socialising and social interactions; interpreting both spoken language and body language; differences in social imagination and difficulty in understanding abstract concepts, which can make

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<sup>11</sup> What is Autism? National Autistic Society, <https://www.autism.org.uk/about/what-is/asd.aspx>

<sup>12</sup> What is Autism? NHS, <https://www.nhs.uk/conditions/autism/what-is-autism/>

<sup>13</sup> What is Asperger's Syndrome? Scottish Autism, <https://www.scottishautism.org/about-autism/about-autism/what-aspergers-syndrome>

it harder for people with autism to cope with new, unfamiliar or unexpected situations; and 'under' or 'over' sensitivity in any of the senses (sight, hearing and balance).<sup>14</sup>

## 3.2 Language used in Diagnosis of Autism

### 3.2.1 Profiles

The following information is directly extracted from the website of the National Autistic Society.<sup>15</sup>

All autistic people share certain difficulties, but being autistic will affect them in different ways. These differences, along with differences in diagnostic approach, have resulted in a variety of terms/language being used to diagnose autistic people including autism, autism spectrum disorder (ASD), autism spectrum condition (ASC), atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and pathological demand avoidance (PDA).

Because of recent changes to the main diagnostic manuals, 'autism spectrum disorder' (ASD) is now likely to become the most commonly given diagnostic term. However, clinicians will still often use additional terms to help to describe the particular autism profile presented by an individual.

#### **Asperger syndrome profile:**

A clinician might describe someone as having an Asperger syndrome profile if there has been no clinically significant delay in language or cognitive development but they still have social communication difficulties. They may also have specific delays in motor development as well as motor 'clumsiness'.

#### **Demand-avoidant profile:**

A clinician might describe a person as having a demand-avoidant profile, or pathological demand avoidance (PDA), if they are driven to excessively avoid demands and expectations. Underpinning this avoidance is an extremely high level of anxiety about conforming to social demands and of not being in control of the situation.

#### **Misdiagnosis:**

Clinicians lacking autism experience may miss the fact that autism is underlying the obvious difficulties seen on the surface and make clinical observations that do not take the issues related to autism into account. For example, they may observe issues such as a person's clumsiness (possible dyspraxia), reading difficulty (possible dyslexia),

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<sup>14</sup> What is autism? Ambitious about Autism, <https://www.ambitiousaboutautism.org.uk/information-about-autism/understanding-autism/what-is-autism>

<sup>15</sup> Autism profiles and diagnostic criteria, National Autistic Society, <https://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>

poor attention span (possible Attention Deficit Disorder), difficulty with social communication (semantic pragmatic disorder or social communication disorder), mental health issues, or behavioural issues and diagnose that as the main condition instead.

### 3.2.2 International Classification of Diseases (ICD-11)

The ICD-11 is the most recent version of the most commonly used diagnostic manual in the UK. The information in this section is summarised from the website of Research Autism.<sup>16</sup>

**In ICD-11 Autism Spectrum Disorder** is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests.

The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not fully manifest until later, when social demands exceed limited capacities.

The deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.

ICD-11 also lists several sub-types of Autism Spectrum Disorder:

**6A02.0** - Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.

**6A02.1** - Autism spectrum disorder with disorder of intellectual development and with mild or no impairment of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.

<sup>16</sup> Autism (Autism Spectrum Disorder), Diagnostic Criteria, ICD-11, Research Autism, [http://www.researchautism.net/conditions/7/autism-\(autism-spectrum-disorder\)/Diagnosis](http://www.researchautism.net/conditions/7/autism-(autism-spectrum-disorder)/Diagnosis)

**6A02.2** - Autism spectrum disorder without disorder of intellectual development and with impaired functional language. All definitional requirements for autism spectrum disorder are met. Intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is marked impairment in functional language (spoken or signed) relative to the individual's age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.

**6A02.3** - Autism spectrum disorder with disorder of intellectual development and with impaired functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is marked impairment in functional language (spoken or signed) relative to the individual's age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.

**6A02.4** - Autism spectrum disorder without disorder of intellectual development and with absence of functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.

**6A02.5** - Autism spectrum disorder with disorder of intellectual development and with absence of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.

## 3.3 Language used to Describe Autism

### 3.3.1 Key Research Study

The complex nature of the autism spectrum gives rise to a range of personal and professional perspectives. It can therefore be a challenge to find a common language that reflects the values and principles of the various groups who are invested in advancing the understanding and support of people of all ages.

A key study published in 2016 sought to elicit the views and preferences of the UK autism community – autistic people, parents and their broader support network – about the terms they preferred to use to describe autism. The findings demonstrated that there is no single way of describing autism that was universally accepted and preferred by the UK's autism community and that some disagreements appeared deeply entrenched. The study found that the term 'autistic' is preferred by adult individuals



(and their families) whilst professionals tend to prefer terms such as ‘individual with autism’<sup>17</sup>

In all, 3470 UK residents responded to the online survey. The results showed that the most highly endorsed terms were ‘autism’ and ‘on the autism spectrum’, and to a lesser extent, ‘autism spectrum disorder’, for which there was consensus across community groups. The groups disagreed, however, on the use of several terms. The term ‘autistic’ was endorsed by a large percentage of autistic adults, family members/friends and parents who responded to the survey but by considerably fewer professionals. ‘Person with autism’ was endorsed by almost half of professionals but by fewer autistic adults and parents.

### 3.3.2 NHS England Learning Disability and Autism Advisory Group (2017)

In 2017, the NHS England Learning Disability and Autism Advisory Group published the results of focus group work with autistic people. The advisory group helps NHS England with work that affects people with a learning disability, autism or both and their families. The group is made up of 15 experts by experience, which includes people with a learning disability, autism or both and their families. Its members are used to speaking out and have good connections with local and national learning disability and autism groups.

Part of the discussions were around the ‘Dos, Don’ts and Maybes’ of good language about autism using the research referred to in Section 3.2 above as a starting point. The results included<sup>18</sup>:

#### **When talking with people DO:**

- Talk about autistic people rather than people with autism;
- Talk to people as humans - as you would talk to someone in your family;
- Use clear, precise, concise, everyday language;
- Consider alternative communication;
- NHS communications need to be clear and concise for everyone; and
- Think of us as individuals, not as labels.

#### **In news or campaigns DO:**

- Use social model of disability in language;
- If you run a campaign, launch it positively and actively - communicate about positives of autism not just negatives;

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<sup>17</sup> Kenny L. et. al. (2016), Which terms should be used to describe autism? Perspectives from the UK autism community, *Autism*, 20(4):442-62, <https://pubmed.ncbi.nlm.nih.gov/26134030/>

<sup>18</sup> Autism focus 2 ‘You Said, We Did’, NHS England Learning Disability and Autism Advisory Group, Learning Disability and Autism Engagement Team, December 2017, <https://www.england.nhs.uk/wp-content/uploads/2018/03/focus-on-autism-2-plain-english.pdf>

- Talk about difference not different;
- Promote communication by and from autistic people and their parents; and
- Talk about how to talk to people in a way that includes autistic people.

**DO NOT:**

- Use the medical model of disability;
- Use the labels 'high' or 'low' functioning as they can mask the need for support. People who are described as 'high functioning' can become suicidal;
- Confuse autism with learning disability - 75% of autistic people do not have a learning disability;
- Be paternalistic- talk to people as equals;
- Limit people, for example by talking about the kind of jobs autistic people would do (they can do all sorts of jobs);
- Say 'challenging behaviour' or 'behaviour that challenges' - could talk about 'potentially violent behaviour';
- Do not talk about 'how to talk to autistic people' as this implies a huge difference;
- Do not talk about treatment – it is the National Health Service not the National Treatment Service;
- Do not assume if someone does not talk that they do not understand or that they cannot be involved.

There was discussion around the need for better language on 'challenging behaviour'. Some autistic people preferred the term 'a risk to self or others', but others preferred 'potentially violent behaviour'. In the absence of a clear preference, the group concluded that the term 'behaviour that challenges services' was to be used in the interim.

### 3.3.4 Getting the Language Right about Autism

Based on the work of the NHS England Learning Disability and Autism Advisory Group, NHS England have published five top tips and a table offering best practice on the language to use when talking about autism:<sup>19</sup>

1. Talk about autism positively. Many autistic people see autism as part of who they are, rather than something separate, and prefer to be described as 'autistic' or 'on the autism spectrum' – rather than as 'someone with autism'.
2. Do not use negative language like 'suffering from autism', 'symptoms' and 'treat'. Instead, talk about characteristics, support and reasonable adjustments.
3. Every autistic person is different. Try to make sure people know this in all communications.
4. Autism is not a learning disability or a mental illness. However, some autistic people also have a learning disability and many people have a mental health problem.
5. Some people on the autism spectrum understand language very literally. Avoid phrases that do not say what they mean. Like "it's raining cats and dogs". Use clear, everyday language.

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<sup>19</sup> Making information and the words we use accessible, NHS England, <https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/#autism>

## Table - Getting the Words Right about Autism

The information in the table below is taken from a table on the website of NHS England: 'Getting words right about autism'.<sup>20</sup>

Words to Use	Words to Avoid	The Reasons
<p><b>Autism or</b></p> <p><b>The autism spectrum</b></p>	<p>ASD, Autism Spectrum Disorder</p>	<p>Autism Spectrum Disorder is the official way of describing autism but many autistic people and families feel that the term 'disorder' is too negative for everyday discussions. Autism is a difference rather than a disorder.</p> <p>The words autism and autism spectrum are widely accepted by autistic people and their families.</p>
<p><b>Autistic adult/people</b></p> <p><b>or</b></p> <p><b>People on the autism spectrum</b></p>	<p>Adult/person with autism</p>	<p>This is a sensitive issue in the autism community, as many autistic people see autism as a part of who they are – rather than something separate.</p> <p>Research shows that there is not one way accepted by everyone. However, autistic and on the autism spectrum were the preferred terms among most autistic adults and families.</p>
<p><b>Children on the autism spectrum</b></p>	<p>Children with autism</p>	<p>There is less agreement about how to describe children. Many autism organisations, particularly those focused on children and young people, use the terms 'with autism' or 'on the autism spectrum'. Research shows that families are divided on which term they like best.</p>

<sup>20</sup> Making information and the words we use accessible, NHS England, <https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/#autism>

Words to Use	Words to Avoid	The Reasons
<b>Characteristics</b>  <b>or traits</b>	Symptoms	Symptoms make it sound as though autism is a disease.  It also does not recognise that there are many positive things associated with autism, like working hard to achieve things and seeing things in a different way, which can be great for problem solving.
<b>Support</b>  <b>or</b> <b>adjustments</b>	Treat	Words like 'treat' mean that people may think that autism is a disease that can be removed or cured. This upsets many autistic people and families. With support and/or reasonable adjustments, many autistic people live independent lives.
<b>Behaviour that challenges,</b>  <b>behaviour that challenges services or</b>  <b>behaviour that communicates distress</b>	Challenging behaviour	This phrase is very unpopular with many autistic people and families.  There is not an accepted alternative. However, it is sometimes necessary to talk about this issue and 'behaviour that challenges services' is better to use.  The term 'challenging behaviour' makes people think that the behaviour itself is the problem, when often it is actually a sign that a person's needs are not being met. The term 'behaviour that challenges' is better because it does not make people think that this behaviour is necessarily meant to challenge. This kind of behaviour is often communicating distress and is sometimes described as behaviour that communicates distress.
<b>Learning disability, autism or both</b>	Learning disability and/or autism	This makes it clear that learning disability and autism are two different things.