

# AddictionsUK

A knowledge base on neurodiversity coupled with addictions

## Towards better and more joined up policy & practice for people with addictions & neurodiversity conditions

Our journey so far...

### Abstract

Report of early investigations into the complexities of addictions when they are coupled with neurodivergent conditions

Dr Louise Harvey-Golding, Dr Sue Robson, James King and Simon Stephens,  
September 2020

## **Preamble**

Addictions North East have been closely involved in AUK's action research work and have supported it through sharing our own records, consultations, and developments. We are committed to further investment in this vital work. Unless there is more multi-agency co-operation, our respective service users will once again be failed by administrative incompetence.

Addictions UK have been concerned about the complexities of addictions when they are coupled with neurodivergent conditions for several years. We noticed that a high proportion of our service users were presenting with neurodivergent conditions and this was resulting in complex barriers towards accessing services. Feeling strongly that this was something that we could no longer ignore, we brought together a small team of researchers and experts and began our investigations.

Early on in our investigations, we identified that both commissioned substance misuse services, and conversely those specifically designed for those with neurodivergent conditions, may not be equipped to meet the needs of those affected by these conditions combined. We found this situation to be compounded by limited research in the field and thus little knowledge to influence policy and practice.

We began to think about the possibilities for joined up policy and practice for people with addictions and neurodiversity conditions, and what might need to be done to achieve those. This report documents our journey so far.

Addictions UK is now positioning itself as a catalyst towards bringing together the two domains of addiction and neurodiversity. Our intention is to work collaboratively towards promoting and disseminating good practice and building a robust knowledge base to influence social policy. Ultimately, so that those with addictions coupled with neurodivergent conditions have better outcomes and become self-empowered and have more promising futures.

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# 1. Executive Summary

## 1.1 Introduction

The purpose of this report is to highlight and disseminate findings from early investigations into the complexities of addictions when they are coupled with neurodivergent conditions. It documents what we have learned from our journey so far and outlines several projects that we are in the initial stages of developing in response to the gaps and needs identified, namely:

- a) A welfare rights and legal service for people with addictions coupled with neurodivergent conditions
- b) A participatory action research project to expand and disseminate our knowledge about the correlations between neurodiversity and addictions
- c) An online resource for an addictions / neurodiversity community
- d) Training in issues surrounding neurodiversity and addictions

## 1.2 Background and scope

Through our housing support and welfare benefits work in the North East of England, Addictions UK became aware that a high proportion of our service users were presenting with neurodivergent conditions. The combination of addictions with neurodivergent conditions were resulting in complex barriers for our clients towards accessing supported housing and welfare benefits. We felt strongly that this was something that we could no longer ignore, so we brought together a small team of researchers and experts and began our investigations, involving:

- literature surrounding neurodiversity and pathological dependency
- an initial strategy scoping meeting with the Chief Executive of North East Autism Society
- consultations with community groups led-by-and-for people with neurodivergent conditions
- Initial partnership discussions regarding the development of an online resource
- Participation in the Association of Child and Mental Health (ACAMH) Neurodevelopmental Disorders Conference, in Malta

## 1.3 Early investigation findings

Our early investigations corroborated our original proposition that statutory commissioned substance misuse treatment, supported housing and welfare benefits services may not be equipped to meet the needs of those with neurodivergent conditions; and conversely that services designed specifically for those with neurodivergent conditions may also not be equipped to meet the needs of those with addictions. The situation is compounded by research in the field being severely limited, so there is very little knowledge to influence policy and practice around addressing neurodiversity coupled with addictions.

Our initial focus for the and we found research in this field was limited. Research studies predominantly focus on individuals within the criminal justice system and male participants, and there is a lack of research with adults who have not been in contact with the criminal justice system and females. Research findings are mixed and inconclusive.

We then extended our literature review to research into the links between neurodiversity and pathological dependency, i.e. addictions and misuse of substances and behavioural addictions/compulsions, which we also found to be limited.

Table 1: Findings into early investigations into addictions coupled with neurodivergent conditions

Inferences from research into Autism Spectrum Disorder (ASD) and substance misuse
<ul style="list-style-type: none"> <li>• Although substance misuse is lower for those with ASD than the general population</li> <li>• The risks of alcohol and substance misuse when ASD is combined with other co-morbid conditions such as ADHD, psychotic disorders and personality disorders</li> </ul>
Inferences from research into neurodiversity and pathological dependency <sup>1</sup>
<ul style="list-style-type: none"> <li>• Repetitive behaviours, such as substance use and behavioural addictions may be used as coping strategies for dealing with symptoms of ND conditions</li> <li>• Symptoms of ND conditions such as impulsivity, compulsions, and repetitive and obsessive thoughts and behaviours, may contribute to substance misuse and behavioural addictions</li> <li>• Deficits in executive functioning such as ability for self-control may increase the risk of substance misuse and behavioural addictions</li> <li>• The habitual and repetitive symptoms of ASDs may lend themselves to addictive behaviours</li> <li>• Use of alcohol and substances to cope with symptoms of ND conditions and to aid socialisation (typically alcohol in adults and cannabis in young people)</li> <li>• Use of alcohol and substances to reduce or enhance sensations from symptoms of ND conditions</li> <li>• Drug culture may be more accepting of 'difference'</li> </ul>
Findings from community consultation event
<ul style="list-style-type: none"> <li>• Substance misuse and addiction is not just about 'self-medication' for those with neurodivergent condition, individuals may be driven towards addiction and risky behaviours due to the symptoms of their conditions</li> <li>• Isolation compounds and exacerbates conditions and compulsions/addictions:</li> <li>• There may be a correlation between environments and backgrounds and developing addiction/substance misuse problems for individuals with ASD (i.e. low socio-economic backgrounds)</li> <li>• Tension between social and medical models of diagnosis and treatment where diagnosis can be key to understanding and addressing addictions</li> <li>• Individuals are passed between mental health (MH) and substance misuse (SM) services:</li> <li>• Early intervention and support are key</li> <li>• Recognition needed that those with neurodivergent conditions may be susceptible to addiction/substance misuse</li> </ul>
Findings from ACAMH conference
<ul style="list-style-type: none"> <li>• Substance misuse can co-exist of neurological conditions such as Tourette's and ADHD</li> <li>• Links between anxiety and sleep problems affecting those with Tourette's coupled with substance misuse issues</li> <li>• Suggestion that sobriety from alcohol misuse issues can result in worsening tics</li> <li>• Parents paralleling ASD child's internet addiction with alcoholism</li> <li>• Male bias associated with later and slower diagnosis of ASD in females [which could potentially be linked to self-medication]</li> </ul>

<sup>1</sup> Arnevik & Helverschou, 2016; Buchman, Illes, & Reiner, 2011; Butwicka et al., 2017; Copoeru, 2014; Szalavitz, 2017

## Findings from Autism in Mind (AIM) conference

- “Self-harm” by using of alcohol, drugs and prescription pain killers is was linked to “wanting to feel normal”, “stopping overthinking” and to “gain confidence”.
- Users found that drugs and alcohol “increased anxiety and escalated problems” so was a “vicious circle.”
- Somewhat conversely, in relation to gaming, one of the speakers said that this is used as a strategy for “self-soothing” often to ease the discomfort of masking and being sensory overloaded all day at school or work.

### 1.4 Conclusions from early investigations

Our early investigations combined with our experiences also suggest that statutory commissioned substance misuse treatment, supported housing and welfare benefits services may not be equipped to meet the needs of those with neurodivergent conditions; and conversely that services designed specifically for those with neurodivergent conditions may also not be equipped to meet the needs of those with addictions. The situation is compounded by a dearth in academic research surrounding neurodiversity and addictions, with what exists narrowly focusing upon males in the criminal justice system.

Neurodiversity encompasses a range of neurological, developmental, intellectual, genetic, psychiatric and mental health conditions and disorders. The purpose of the neurodiversity movement was to promote disability-rights, inclusion, diversity and societal change, through proper support, care, validation and appreciation of difference and opposing discrimination and exclusion. However, since the movement began in the 1990’s provision for those with neurodivergent conditions remains segregated and disconnected according to specialism i.e. Special Educational Needs (SEN) and Disability support and provision, mental health (MH) services, and psychiatric support and care, and variable according to location and severity of condition(s). Moreover, there is a lack of collaboration between the statutory sector and specialist services. In addition, the links between the extensive range of neurodivergent conditions and pathological dependency, i.e. addiction/misuse of substances/addictive and compulsive behaviours, is under researched and thus there are huge gaps in knowledge, provision and practice. This lack of understanding, provision and support for those with comorbid neurodivergent and pathological dependency conditions is compounded by the disconnection between SEN provision, MH services, psychiatric care, and addiction/substance misuse services. Furthermore, whilst there are clear associations between the characteristics of pathological dependency and neurodivergent conditions, such as impulsivity, repetitive and obsessive thoughts and behaviours, deficits in executive functioning such as ability for self-control there is a lack of research exploring and examining these associations. It is vital that we increase knowledge in this under researched area and improve the provision, care and support to better meet the needs of these populations. It is also important that a network of collaboration is developed between support services for those with pathological dependency and neurodivergent conditions, and for the statutory sector to work more closely with specialist services, in order to develop a holistic model of care.

### 1.5 Our intentions and project proposals

In response to the findings of our early investigations, Addictions UK are now positioning themselves as a catalyst towards bringing together the two domains of addiction and neurodiversity. Our intention is to work collaboratively towards promoting and disseminating good practice and building a robust knowledge base to influence social policy. Ultimately, so that those with addictions coupled with neurodivergent conditions have better outcomes, become self-

empowered and have more promising futures. To this end we are seeking partnership interest and investment of funding and resources into the development of four specific projects

#### [A welfare rights and legal service for people with addictions coupled with neurodivergent conditions](#)

To assist service users in achieving and sustaining recovery, through the provision of a more integrated and holistic approach, which will include practical assistance and support in legal advice / welfare rights matters including: welfare benefits, debt advice, educational legal entitlements, legal issues relating to social and economic exclusion, and signposting to more specialist services such as employment and housing law. In addition, the service will provide clients with specialist recovery support, including techniques and coping mechanisms to deal with life challenges, triggers for relapse and to maintain recovery, and barriers to recovery and sustaining recovery will also be addressed from a civil legal advice perspective.

#### [A participatory action research project to expand and disseminate our knowledge about the correlations between neurodiversity and addictions](#)

Undertaking a mixed methods study that will examine the prevalence of comorbid neurodivergent conditions amongst substance misusers and explore potential associations between neurodiversity and addictions (substance misuse and pathological dependency). The research project will consist of three main stages, including a scoping review, prevalence mapping and participatory action research to pursue practical solutions to issues of pressing concern to people affected by neurodiversity and addictions

#### [An online resource for an addictions / neurodiversity community](#)

A 'Wiki' style website or database developed collaboratively by a community of users, allowing any user to add and edit content. This will provide a platform for asynchronous communication, collaboration, composition and repository for knowledge and information about neurodiversity and addictions.

#### [Training in neurodiversity and addictions](#)

Addictions UK have developed and are continuing to develop a range of high-quality training modules in addictions and associated topics. Led by evidence-based theory and practice, this bespoke training is designed and developed by a range of experts. The training is suitable for professionals, practitioners and anyone who is interested in the field of addiction. These comprehensive training modules cover all aspects of addiction and recovery and we are in the process of developing a module focussing upon addictions and neurodivergent conditions.

These four projects will combine to build a comprehensive and widely accessible knowledge base about neurodiversity coupled with addictions to influence social policy and practice.



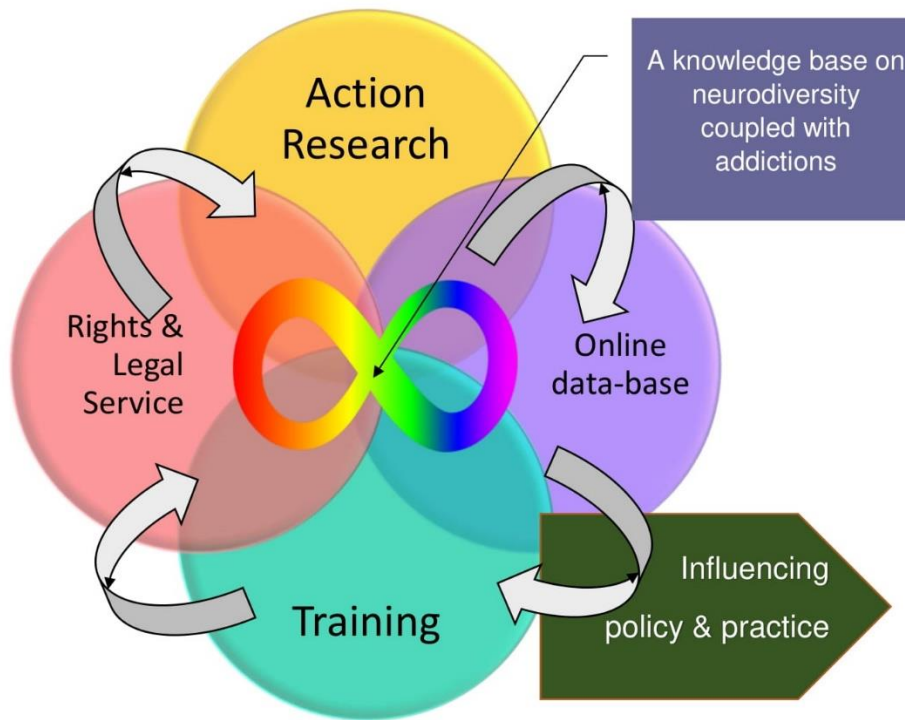


Figure 1: Developing knowledge base on neurodiversity coupled with addictions

## 2. Introduction

The purpose of this report is to highlight and disseminate findings from early investigations into the complexities of addictions when they are coupled with neurodivergent conditions. It documents what we have learned from our journey so far and outlines several projects that we are in the initial stages of developing in response to the gaps and needs identified:

- a) A welfare rights and legal service for people with addictions coupled with neurodivergent conditions
- b) A participatory action research project to expand and disseminate our knowledge about the correlations between neurodiversity and addictions, alongside pursuing practical solutions to issues of pressing concern to people affected
- c) An online resource for an addictions / neurodiversity community
- d) Training in issues surrounding neurodiversity and addictions

Addictions UK are now in the process of expanding our partner base so that we can cultivate an inter-agency approach to developing and delivering these projects. Our intention is to work collaboratively towards promoting and disseminating good practice and building a robust evidence base to influence social policy. Ultimately, so that those with addictions coupled with neurodivergent conditions have better outcomes, become self-empowered and have more promising futures.

## 3. Background

Through our housing support and welfare benefits work in the North East of England, Addictions UK became aware that a high proportion of our service users were presenting with neurodivergent conditions. The combination of addictions with neurodivergent conditions has resulted in complex barriers towards accessing supported housing and welfare benefits. We felt strongly that this was something that we could no longer ignore. Addictions UK became interested in being part of a collaborative network to identify and address gaps in support for those addictions coupled with neurodivergent conditions and potentially to develop better signposting and pathways.



We brought together a small team of researchers and experts and began our investigations.

- James King – is a founder and Director of Addictions UK and Addictions North East. Jim also has a background in welfare rights advice and campaigning
- Dr Louise Harvey-Golding BA (Hons) MA PgCE PgDip PhD is a research, evaluation and training consultant. Louise has a PhD in psychology and a master's in special needs and education
- Dr Sue Robson – is a freelance community development practitioner and researcher and specialises in participatory action research approaches. Sue PhD is in Applied Social Science
- Simon Stephens - is recovery from addiction (Pathological Dependence). He is a Senior Accredited Counsellor and a Graduate Psychologist and Director of case Work for Addictions UK

Our expert team are close to the experience of neurodiversity and addictions and all have experience of working with a wide range of diverse marginalised groups, such as: women and girls; those with learning, sensory and physical disabilities; lesbian, gay and bisexual groups; Black and minority ethnic groups, including asylum seekers and those with English as a second language, people from different faith groups, children and young people and older people.

Our investigations so far have involved:

- an initial outline review of academic literature on ASD and substance misuse
- a wider review of the literature surrounding neurodiversity and pathological dependency
- an initial strategy scoping meeting with the Chief Executive of North East Autism Society (1<sup>st</sup> March 2019)
- consultations with community groups led-by-and-for people with neurodivergent conditions in Northumberland, involving: SPLinter Group (Northumberland), Action on Impulse and Calmer Therapy, Borders Tourette's Support Group, Tourette's Action (15<sup>th</sup> March 2019)
- Initial discussions with Open University Psychological Society regarding the development of an online resource
- Participation in the Association of Child and Mental Health (ACAMH) Neurodevelopmental Disorders Conference, in Malta (4<sup>th</sup> and 5<sup>th</sup> April 2019) for the purpose of expanding our potential partnership base by networking and promoting our project ideas

Through this process we have held regular team meetings to reflect upon our learning and devise action plans for our next steps.

## 4. What we know so far about neurodiversity and addictions

### 4.1 Neurodiversity overview

Neurodiversity (ND) is a compound word for 'neurological' and 'diversity' that was coined in 1990s as part of a civil disability rights movement. This movement was led by an international autism rights campaign, which promoted inclusion, diversity and societal change, and advocated a social model for understanding disability in favour of medical, deficit and disease models (Waltz, 2013). The fundamental philosophy of this model is that neurodivergent conditions are the result of normal variations in neurology and genetics (Jaarsma & Welin, 2012). The model rejected 'cure' approaches, instead respecting human diversity and variation, by addressing the environmental and social barriers to inclusion and providing autonomy to individuals over their lives, care and treatment (Fenton & Krahn, 2007; Griffin & Pollak, 2009; Ortega, 2009).

However, the concept of neurodiversity is controversial (Jaarsma & Welin, 2012) and the ND model and approach have been criticised by those in support of the medical model of understanding and treating neurodivergent conditions. A primary criticism is that whilst the ND approach may be beneficial to those individuals who are high-functioning, the rejection of medical modes of care and treatment is not beneficial to low-functioning individuals and those with profound neurodivergent conditions and disabilities. Critics argue that the ND approach trivialises the complex difficulties and suffering experienced by these individuals and their carers and families (Osborne, 2002).

Whilst the movement was initially associated with autism, over the last three decades, the neurodiversity umbrella has grown to encompass a wider range of neurological, developmental, genetic, psychiatric and even medical conditions (Armstrong, 2015; Bumiller, 2009; Mackenzie & Watts, 2011). The conditions can be crudely classified into developmental/genetic, psychiatric/mental health, and medical, although the symptoms of one disorder may overlap into another classification, i.e. ADHD is classified as a mental health condition, but has developmental and genetic associations. The table below provides a list of the conditions and disorders encompassed by the ND umbrella – however, this list may not be exhaustive.

Table 2: List of Developmental, Psychiatric/Mental Health, and Medical Neurodivergent Conditions

Classification	Condition/Disorder
Developmental and/or Genetic	<ul style="list-style-type: none"> <li>• Autistic Spectrum Disorder (ASD) and Asperger's</li> <li>• Dyspraxia, Dyslexia and Dyscalculia</li> <li>• Developmental Speech Disorders</li> <li>• Anomia</li> <li>• Nystagmus</li> <li>• Foetal Alcohol Syndrome (FAS)</li> <li>• Attachment Disorder</li> <li>• Intellectual Disability or General Learning Disability (GAD) ('Syndromic' i.e. Fragile X Syndrome and Down's Syndrome, and 'non-syndromic' (i.e. intellectual disabilities without other conditions) (Mild, Moderate and Severe/Profound)</li> <li>• Tourette Syndrome</li> </ul>
Psychiatric and/or Mental Health	<ul style="list-style-type: none"> <li>• Attention Deficit Hyperactivity Disorder (ADHD)</li> <li>• Bipolar disorder</li> <li>• Schizophrenia</li> <li>• Schizoaffective Disorder</li> <li>• Obsessive Compulsive Disorder (OCD)</li> <li>• Personality Disorders               <ul style="list-style-type: none"> <li>- Paranoid</li> <li>- Schizoid</li> <li>- Schizotypal</li> <li>- Antisocial</li> <li>- Borderline</li> <li>- Histrionic</li> <li>- Narcissistic</li> <li>- Dependent</li> <li>- Avoidant</li> <li>- Obsessive-compulsive</li> </ul> </li> </ul>
Medical	<ul style="list-style-type: none"> <li>• Parkinson's Disease</li> </ul>

#### 4.2 Findings from initial literature review ASD and substance misuse

Having identified the problem, our first step was to look at formal research into potential associations between neurodiversity and addictions. Our focus for the initial literature review was specifically ASD and substance misuse and we found research in this field was limited. Research studies predominantly focus on individuals within the criminal justice system and male participants, and there is a lack of research with adults who have not been in contact with the criminal justice system and females.

Research findings are mixed and inconclusive, but the following can be inferred:

- a Substance misuse is lower for those with ASD than the general population. Where substance use is reported, alcohol is the most frequently used substance followed by cannabis then cocaine.
- b Male gender is a main predictor of substance use amongst those with ASD.
- c Risk increases when ASD is combined with other co-morbid conditions. For example, autistic traits and ADHD symptoms are associated with elevated levels of smoking and cannabis use, and nicotine, alcohol, and cannabis use disorders. Moreover, autistic traits and ADHD elevate risk for developing alcohol dependence. The now widespread belief that

ASDs are un-associated with substance abuse may be true for those who have only ASD, but not for those with ASD who have comorbid ADHD.

- d Regarding associations with criminality, the crimes committed by individuals with ASD, are less likely to involve alcohol, illegal drugs or substance misuse. However, mental disorder, substance abuse, unemployment, being young, male gender and socioeconomic status, are factors that increase the likelihood of offending in individuals with ASD.
- e Risk factors for violent offending in ASD are the same as in the general population, i.e. male gender, comorbid psychosis and substance misuse. However, offences by offenders with Asperger's in high secure units are in most cases have taken place in the context of substance misuse, and the majority are detained under the mental health category of mental impairment.
- f Psychotic disorder, any substance use, and personality disorder are significantly associated with violent convictions in individuals with ASD. Co-morbid psychosis and illicit substance misuse may be particularly problematic for increasing vulnerability towards interpersonal violence for those with ASD.

Summaries of literature on ASD and substance misuse are in Appendix 1.

### 4.3 Findings from review of literature on neurodiversity and pathological dependency

Research into the links between neurodiversity and pathological dependency, i.e. addictions and misuse of substances and behavioural addictions/compulsions, is limited. However, the following can be inferred from the available research literature (Arnevik & Helverschou, 2016; Buchman, Illes, & Reiner, 2011; Butwicka et al., 2017; Copoeru, 2014; Szalavitz, 2017):

- Repetitive behaviours, such as substance use and behavioural addictions may be used as coping strategies for dealing with symptoms of ND conditions
- Symptoms of ND conditions such as impulsivity, compulsions, and repetitive and obsessive thoughts and behaviours, may contribute to substance misuse and behavioural addictions
- Deficits in executive functioning such as ability for self-control may increase the risk of substance misuse and behavioural addictions
- The habitual and repetitive symptoms of ASDs may lend themselves to addictive behaviours
- Use of alcohol and substances to cope with symptoms of ND conditions and to aid socialisation (typically alcohol in adults and cannabis in young people)
- Use of alcohol and substances to reduce or enhance sensations from symptoms of ND conditions
- Drug culture may be more accepting of 'difference'

This lack of understanding of the associations between ND and pathological dependency is further compounded by fragmented care, support and treatment provision for those with ND and pathological dependency; disjointed service provision between specialisms (i.e. SEN and Disability, Psychiatric and Mental health, and Addiction/Substance Misuse services); and lack of collaboration between statutory sector, third sector and specialist services. Therefore, getting help for pathological dependency can be challenging for those with ND conditions. For example, addiction treatment programmes may be unsuitable due to strict rules, group participation, and difficulties in articulating problems and emotions for those with ND (i.e. anxiety and frustration may be misinterpreted as defiance). There is a vital need for research and radical change in policy, provision and practice in care, support and treatment for those with comorbid ND conditions and pathological dependency.

#### 4.4 Findings from community consultation event

Reflecting upon an initial strategy scoping meeting with the Chief Executive of North East Autism Society (1<sup>st</sup> March 2019), a sense emerged that addiction issues encompass the different behavioural characteristics that form the neurodiversity agenda. This conjecture widened our initially narrow focus upon ASD and substance misuse, and it was highlighted that we need to examine the links between addiction, in terms of substance misuse and pathological dependence (e.g. gambling, gaming, excessive Internet use and compulsive shopping etc.), and comorbid neurodiversity in all of its forms (e.g. Attention Deficit Hyperactivity Disorders, Tourette's Syndrome, Foetal Alcohol Spectrum Disorders and/or Attachment Disorders etc.)

On 15<sup>th</sup> March 2019, Addictions UK brought together a small but diverse group of individuals involved in four grassroots organisations that were established by those with neurodivergent conditions and/or those caring for them. There were 10 participants in total, including 4 of us from Addictions UK. The event took the form of a facilitated conversation around the question

**Is there an issue with neurodivergent conditions and addictions/ substance misuse?**

The following is a summary of the findings (conversation points are in Appendix 2):

- Substance misuse and addiction is not just about 'self-medication' for those with neurodivergent conditions:
  - Individuals may be driven towards addiction and risky behaviours due to the symptoms of their conditions, i.e. impulsive, compulsive
  - Individuals may be drawn into the community due to their character, i.e. different, 'odd-ball,' funny etc
- Isolation compounds and exasperates conditions and compulsions/addictions:
  - Parents and carers may increase isolation through restrictions, controlling etc.
  - Where is the line between controlling and supporting a young person with neurodivergent conditions?
- Environments and backgrounds:
  - Is there a correlation between environments and backgrounds and developing addiction/substance misuse problems for individuals with ASD?
  - Are those from low socioeconomic backgrounds/living in deprived communities more likely to develop problems with addiction and substance misuse?
- Tension between social and medical models of diagnosis and treatment:
  - Diagnosis can be key to understanding and addressing addictions
  - Problems persist through generations if not diagnosed and addressed
  - Diagnostic labels are linked to our identities – what are the problems with this? What are the advantages?
- Individuals are passed between mental health (MH) and substance misuse (SM) services:
  - MH creates barriers to accessing SM services and SM problems create barriers to accessing MH services
  - Consequence – neither service take responsibility for supporting the individual until the point of crisis
- Early intervention and support are key:
  - Understanding, recognition and support
  - Formal and informal support
  - Education programmes
  - Mentoring and peer support

- Recognition that those with neurodivergent conditions may be susceptible to addiction/substance misuse:
  - Breaking the taboo that those with ASD are less likely to encounter difficulties with SM
  - Impacts of peer pressure for those with neurodivergent conditions in using/misusing substances – can this be countered through mentoring and peer support?
  - Risks may increase during adolescence – developmental changes, i.e. puberty, increased symptomatic difficulties, peer pressure

From the community consultation event we identified that the following were needed.

- Strategic/good practice
- Advice, representation and advocacy
- Research to influence social policy
- Training (Public/ Third Sector/ Private)
- Publications - research and internet
- Inter-agency – key person support – including availability for reports
- Service user empowerment

#### 4.5 Learning points from ACAMH Neurodevelopmental Disorders Conference

In the course of our early investigations, for the purpose of expanding our potential partnership base by networking and promoting our project ideas, Dr Sue Robson participated in ACAMH Annual Conference on “Neurodevelopmental Disorders” in Malta on 4th & 5th April 2019.

The aim of the conference was to delve deeper into the most recent research literature on neurodevelopmental disorders, whilst providing the platform for networking and sharing of knowledge with regards to the recognition and assessment of neurodevelopmental disorders and practical management and evidence based therapeutic interventions.

The following learning points relating to neurodiversity and addictions were noted (extended notes and references are in Appendix 3):

- Substance misuse can be a co-existing symptom Tourette’s and links between substance misuse and ADHD
- Linking anxiety and sleep problems affecting those with Tourette’s coupled with substance misuse issues
- Case study of young man with Tourette’s suggests that sobriety from alcohol misuse issues can result in tics becoming dramatically worse
- Parent in a study of benefits of sport in ASD parallels child’s internet addiction with alcoholism
- Male bias in clinical impressions, diagnostics criteria and tools associated with later and slower diagnosis of ASD in females [which could potentially be linked with self-medication]

#### 4.6 Learning points from AIM (Autism in Mind) Conference

James King and Dr Sue Robson were delegates at the Autism in Mind “Understanding Autism” conference at the Stadium of Light in Sunderland on 21<sup>st</sup> June 2019.<sup>2</sup>

At the conference, it was said that among the 100 service users at AIM, the use of alcohol to mask social differences is very common among the 100 or so adult service users of AIM. “Self-harm” by

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<sup>2</sup> Autism In Mind are based in Sunderland and provide low level preventative support for adults with high functioning autism - <https://www.autisminmind.com/>



the use of alcohol, drugs and prescription pain killers is linked to “wanting to feel normal”, “stopping overthinking” and to “gain confidence”. However, users found that drugs and alcohol “increased anxiety and escalated problems” so was a “vicious circle.” Somewhat conversely, in relation to gaming, one of the speakers said that this is used as a strategy for “self-soothing” often to ease the discomfort of masking and being sensory overloaded all day at school or work.

The question this raised for us was:

“If coping strategies such as gaming are a substitute for unmet support needs/ or the absence of reasonable adjustments (i.e. at school or in the workplace), then what is the likelihood of them becoming unmanageable and leading to pathological dependency (i.e. addiction)?”

We will be following up the conference with meetings to discuss our tentative research proposals around neurodiversity and pathological dependency, the potential for collaboration with around our respective training offers using a social enterprise model.

- Kieran Rose, Autism Advocate and Infinite Autism (6<sup>th</sup> September 2019) Among other roles, Kieron leads steering group within the North East Autism Society, comprised of other autistic adults, helping to shape future services and projects offered by the Society.
- The Directors of Autism in Mind (10<sup>th</sup> September 2019).

## 5. Conclusion from findings

Our early investigations combined with our experiences also suggest that statutory commissioned substance misuse treatment, supported housing and welfare benefits services may not be equipped to meet the needs of those with neurodivergent conditions; and conversely that services designed specifically for those with neurodivergent conditions may also not be equipped to meet the needs of those with addictions. The situation is compounded by a dearth in academic research surrounding neurodiversity and addictions, with what exists narrowly focusing upon males in the criminal justice system.

Neurodiversity encompasses a range of neurological, developmental, intellectual, genetic, psychiatric and mental health conditions and disorders. The purpose of the neurodiversity movement was to promote disability-rights, inclusion, diversity and societal change, through proper support, care, validation and appreciation of difference and opposing discrimination and exclusion. However, since the movement began in the 1990’s provision for those with neurodivergent conditions remains segregated and disconnected according to specialism i.e. Special Educational Needs (SEN) and Disability support and provision, mental health (MH) services, and psychiatric support and care, and variable according to location and severity of condition(s). Moreover, there is a lack of collaboration between the statutory sector and specialist services. In addition, the links between the extensive range of neurodivergent conditions and pathological dependency, i.e. addiction/misuse of substances/addictive and compulsive behaviours, is under researched and thus there are huge gaps in knowledge, provision and practice.

This lack of understanding, provision and support for those with comorbid neurodivergent and pathological dependency conditions is compounded by the disconnection between SEN provision, MH services, psychiatric care, and addiction/substance misuse services. Furthermore, whilst there are clear associations between the characteristics of pathological dependency and neurodivergent conditions, such as impulsivity, repetitive and obsessive thoughts and behaviours, deficits in executive functioning such as ability for self-control there is a lack of research exploring and

examining these associations. It is vital that we increase knowledge in this under researched area and improve the provision, care and support to better meet the needs of these populations. It is also important that a network of collaboration is developed between support services for those with pathological dependency and neurodivergent conditions, and for the statutory sector to work more closely with specialist services, in order to develop a holistic model of care.

## 6. Our intentions and project proposals

Based upon the conclusion from our initial findings, and a growing sense that there are significant gaps between the two domains of addiction and neurodiversity, in terms of research, policy and practice, Addictions UK are now positioning themselves as a catalyst towards bringing together these two domains. We intend to achieve this by continuing to expand and share our experience, expertise and knowledge, and identifying multidisciplinary and holistic solutions to address the barriers identified and improve social policy and practice. To this end we are seeking partnership interest and investment of funding and resources into the development of four specific projects that combined will build a comprehensive and widely accessible knowledge base about neurodiversity coupled with addictions.

### 6.1 Welfare rights and legal service

Proposal for civil legal advice / welfare rights service for people with neurodivergent and mental health conditions. Incorporating a Legal Advice component within a multi-disciplinary community-based health and neurodiversity agencies, including addictions agencies.

#### 6.1.2 Benefits to Service Provider(s)

The purpose of the service would be to assist service users in achieving and sustaining recovery, through the provision of a more integrated and holistic approach, which will include practical assistance and support in legal advice / welfare rights matters including: welfare benefits, debt advice, educational legal entitlements, legal issues relating to social and economic exclusion, and signposting to more specialist services such as employment and housing law. In addition, the service will provide clients with specialist recovery support, including techniques and coping mechanisms to deal with life challenges, triggers for relapse and to maintain recovery, and barriers to recovery and sustaining recovery will also be addressed from a civil legal advice perspective.

Moreover, the specialist service we propose would provide opportunities for up-skilling of professionals and workers to improve their knowledge and understanding of the needs of service users with neurodivergent and mental health conditions, including addictions, substance misuse and pathological dependency. In addition, scoping and mapping will be undertaken to develop a network of knowledge on specialist services and the specialities of colleagues working in the field, to improve and facilitate collaboration and cross referrals. Beyond up-skilling there will be opportunities to train existing third sector support workers to deliver some of the specialist advice services, with the aim of the third sector offering a more integrated and multi-disciplinary service, that is more effective from a social health and cost perspective.

Accessibility and engagement issues are more easily addressed where there are already established points of contact. Greater flexibility can be built in, and advice can be delivered in a more tailored way organised by the recovery service and its professional support workers who are already engaging with their service users. Advice and services will be delivered via drop in sessions, alongside group meetings, appointments in familiar surroundings, telephone and webchat via existing and familiar links.

Whilst we are aware of agencies providing some of these services, resources and support services are often limited and/or short-term project based. Despite considerable opportunities for the development of social enterprise practices and policies, few services specialise in working with the ever-increasing number of people with Neurodivergent and/or mental health issues. It is safe to assume that this will be having long-term detrimental impacts on health and socioeconomic outcomes for this population. Therefore, an innovative service, within or closely allied to a specialist health / learning needs agency, has the potential to address this gap in essential service provision and improve outcomes for those with neurodivergent and mental health conditions.

Furthermore, this would provide opportunities to identify and monitor social policy issues from individual, and extended network perspectives i.e. families, communities etc. This would provide vital information to influence social policy campaigns in collaboration with other agencies.

#### 6.1.2 Advantages for the Individual Service User

The service will aim to maximise client incomes by assisting them to deal with welfare and debt issues. Thereby, removing stressors, obstacles and distractions, improving lives of individuals and extended families and carers, and creating space for the service user to focus on their recovery. Clients will be helped to obtain additional funds, such as Personal Independence Payments (PIP) to support additional health and welfare needs. In many cases individuals are incorrectly / inadequately assessed for PIP leading to ineligibility or are unaware of their eligibility. An improved and well managed income may allow the service-user to undertake and afford activities that contribute to their general wellbeing and continuing recovery.

Moreover, an accessible advice service will be provided, which will be informed by an understanding of the difficulties in initiating and maintaining engagement for those individuals with neurodivergent, mental ill health and addictions/substance misuse disorders. The service will provide opportunities to see an advice worker in familiar surroundings, and in quieter and less stressful environments, with options for digital and telephone advice. Digital and telephone advice is already offered via Addictions UK websites, along with advice pages on common topics have (operational since 2006). This methodology could be replicated in part by a new integrated service.

An inter-disciplinary methodology will underpin the service and levels of advice support will consider the service users' needs and ability, with the aim of not only dealing with the advice issue, but by improving self-esteem and confidence in achieving tasks and positive outcomes. In addition to advice on practical matters, the service will also provide opportunities to improve life skills, solve problems and other key skills that are transferable to other areas of the service users' life. For those who have become socially and economically excluded, i.e. experienced homelessness, the service will deliver financial capability over the longer-term on a one-to-one to prepare for living more independently back within the community.

#### 6.1.3 Advantages for the Immediate and Wider Community

##### Family, close friends and carers:

Advice services will be made available to family and carers, with the purpose of relieving pressure on families and carers and improving their health and wellbeing. Families and carers of client users may experience difficulties as direct and indirect consequences of their family members/loved one's addictions. This may include the loss of trust, damage to relationships, damage to personal property, financial risks such as loss of home/employment/income etc, and fears, anger, frustration and despair for loved ones. It is envisaged that resolution of some of these issues, from a practical support perspective, will foster the rebuilding of the lives of individuals and the families, reduce pressure and conflict, improve communication and relationships, and aid clients' recovery.

## Community/ social impact

Pathological Dependence, linked to neurodivergent and mental health issues, has adverse impacts in society, such as an increase levels of anti-social behaviour, and crimes including theft, violence, prostitution, drug-dealing, child abuse/neglect and domestic abuse. Moreover, addictive and substance misuse often inevitably leads to relationship and family breakdowns and potentially removal of children, loss of employment and homeless. These issues and situations can have devastating physical and psychological impacts on the individual and those close to them, which lead to longer-term generational and societal impacts. For example, children involved in the lives of addicts may have taken on carer roles and/or suffered abuse, which potentially increases their own risk of addictive, substance misuse and other mental health disorders.

## Impact upon public spending

All the aforementioned issues impact public spending and place a strain on public services such as the NHS, police, courts, prison and probation services, local authorities, homelessness services, children's and adult social services and the welfare state. A well-managed partnership between the advice sector and health and neurodivergent needs related services is urgently required to assist and support some of the most vulnerable members of society, with the most complex needs. It is envisaged that this partnership would confer benefits to this client group and their families, carers and loved ones, which will cumulate in wider positive outcomes for families, communities and society and create economic savings in terms of reducing pressure on public services.

### 6.1.4 The Next Steps

Addictions UK already offer an established and defined advice and representation service to their clients. Fees are charged for this service on a limited basis and whilst the service operates at a small loss, client have benefitted from health-related support alongside an advocacy service. Effectively, Addictions UK have replicated the model operated by the Department of Works and Pensions (DWP), in separating health related services from the legal decision-making process relating to the payment of benefits. This model works well for a small number of clients and there is scope for testing whether the multi-disciplinary model works with a larger number of diverse clients based in a defined geographical area.

It is recommended that an action research model is implemented, over a five-year project, which establishes a multi-agency service that offers advice, support and representation to a defined number of clients in the North East of England, who present neurodivergent, pathological dependence, mild mental health issues. The service would require charitable income and possible contract resources through public sector agencies. It would operate as a social enterprise and would additionally attract income through training services and case work. It is anticipated that partner agencies involved in the project would permit the use of their resources to promote services such as seconded staff and free use of premises.

Initially a strategic development plan would be prepared, and a small working group established. A combination of funds from the public sector, third sector and related private sector legal services would be requested. The need for such a service is considerable and the need for such a service is recognised by both commissioners and service providers. Other agencies such as some social housing providers have an interest in these client groups and promote their own advice and welfare rights services and are full members of Advice UK. It is thought that some of these agencies may also wish to discuss their involvement in such a pilot scheme.

## 6.2 Participatory action research project

A review of the literature into ASD and substance misuse highlighted a lack of research, including a limited number of studies focused on males within the criminal justice system (CJS). We aim to expand on the research in this field, by undertaking a mixed methods study that will examine the prevalence of comorbid neurodivergent conditions amongst substance misusers and explore potential associations between neurodiversity and addictions (substance misuse and pathological dependency). The research project will consist of three main stages, including a scoping review, prevalence mapping and participatory action research to pursue practical solutions to issues of pressing concern to people affected by neurodiversity and addictions.

As the topics concerning comorbid neurodivergence and substance misuse/addictive/pathological dependency have not yet been extensively reviewed, the first phase of our research project will involve an in-depth scoping review of the literature. The purpose of the review will be to map the body of literature onto the topics under investigation. The scoping review will aim to examine the extent and range of research activity in the area, the emerging evidence and identify gaps in knowledge. Findings will be presented as a descriptive overview and definition of the topics under investigation. The findings will also be used to make inferences about the potential associations between neurodiversity and substance misuse/addictive disorders.

The second phase of the research project will aim to map the prevalence of comorbid neurodivergent conditions amongst substance misusers. Existing client health monitoring data from Addictions UK and Addictions North East will be analysed to gain information of the proportion of clients with comorbid neurodivergent conditions, the types of neurodivergent conditions present, and the demographics i.e. sex and age. Further desktop research will identify additional suitable existing data sources, including government, health and social care databases. A comparative analysis will examine for similarities and differences across the data sets and aim to determine the prevalence and nature of comorbid neurodivergent conditions for individuals with substance misuse/addictive disorders.

The final phase of the research project will be underpinned by a participatory action research methodology, which will explore the gaps in the research identified from the scoping review and the key factors discovered during the mapping analysis.

Action research is a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities

Reason & Bradbury, 2001



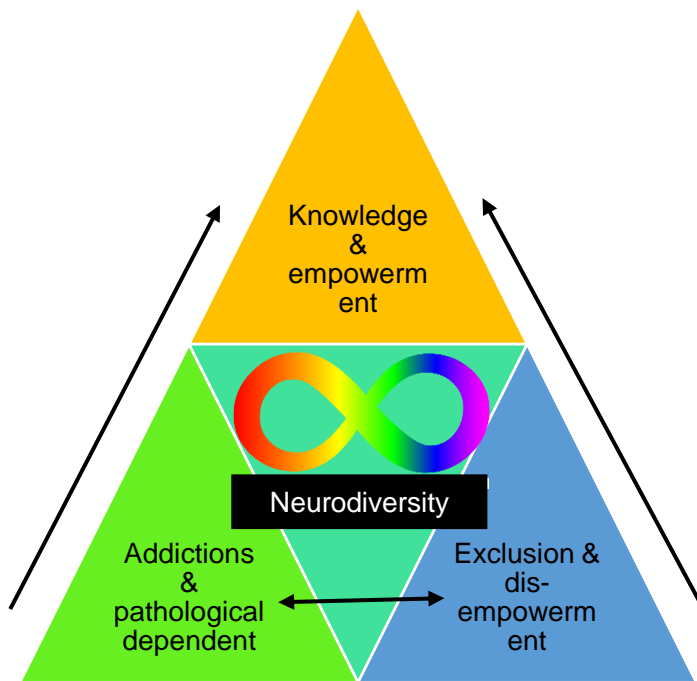


Figure 2 Emerging model for Action Research into Neurodiversity and addictions/ pathological dependency

Mixed methods, including both qualitative and quantitative methods, will be utilised to enable a more complete and synergistic investigation. Methods will include surveys, semi-structured interviews, focus groups and/or observations, with individuals with experiences of comorbid neurodivergent conditions alongside substance misuse/addictive disorders/pathological dependency and those working with/supporting/caring for them, and other stakeholders influencing policy and practice. Purposive and theoretical sampling will be employed to recruit participants based on their relevance to the key research topics and subsequently, to recruit participants based on their potential contribution to the development of themes that emerge from the data. As part of the action research framework, analysis of initial data will drive subsequent data collection and sampling. Data collection and analysis will conclude once the key themes have been saturated.

Using the evidence gathered from the scoping review, mapping research and action research, a model will be developed to illustrate the prevalence of comorbid neurodivergent conditions amongst substance misusers/addicts and the potential associations. It is envisaged that the evidence postulated in this model will increase knowledge and understanding around the comorbidity of neurodivergent conditions amongst substance misusers/addicts, thus providing an original contribution to an emerging field of research. We will use these findings to influence further research, policy and practice across the disciplines of substance misuse, addiction, pathological dependency, mental health and neurodiversity. Moreover, we intend to publish these findings in a peer-reviewed academic journal in collaboration with our academic partners.



### 6.3 An online resource for an addictions / neurodiversity community

As part of our strategy to promote the goals of influencing public and professional understanding of addictions and the links to neurodiversity, we plan to develop a 'wiki' style website. A 'Wiki' is a website or database developed collaboratively by a community of users, allowing any user to add and edit content. The most famous of these is Wikipedia, the online encyclopaedia. A 'wiki' is a platform for asynchronous communication, collaboration, composition and repository for knowledge and information. What makes 'wikis' different to any other website or database is collaborative editing by the users without the requirement of coding knowledge. The wiki format is easy to administer and maintain, and content can be uploaded and managed easily. The format and function of 'wiki' sites are broadly recognised and understood, and they are considered benign, trustworthy and non-commercial.

Our 'wiki' [[neurodiversitywiki.co.uk/com](http://neurodiversitywiki.co.uk/com)] will provide us with a resource that will become a central repository for information, research, news and debate concerning the neurodiversity agenda. This will enable us to collaboratively build an encyclopaedia of current knowledge and emerging research regarding neurodiversity. Content will be supplied by an invited community of academics, medical professionals, support groups, third sector charities and community interest groups. It is hoped that the website will co-operate with partners such as The Open University Psychological Society, third sector agencies working with neurodivergent client groups of people, advice and support agencies, public and private sector agencies with an interest in self-help and social inclusion issues, the friends and relatives and service users with neurodiversity issues, educational organisations, and a range of other interest groups.

This body of knowledge on neurodiversity will be organised and clearly indexed to allow ease of access to topics, disciplines, information and research in the fields of neurodiversity and addictions. Entries will include references and hyperlinks to further information, resources, and research. The body of knowledge and information will take the form of broadly accepted definitions, learned articles, case histories, journalism and peer group created content. The website will be fully optimised for search, helping interested parties to find and access the website and its contents by keywords and key phrases. In addition to the repository of knowledge and information, the website home page will include a live news and digest area where the very latest information, debate and campaigning are displayed and updated in real time.

Access to the site will be completely open, but contributions will only be made by invited individuals who will be provided with login and password details by a central administrator. Users will be provided with accessible guidelines on how they can contribute to the site. Moreover, users will be invited to register to receive email communication from [neurodiversitywiki.co.uk](http://neurodiversitywiki.co.uk), allowing us to engage with our community. The website will serve to bring together those people working in a multi-disciplinary style and will promote much needed changes within this field of interest. We wish to create a "conversation" which is respectful of stakeholders and which will lead to positive exploration and action.

In sum, we know that the links between pathological dependency and addictions with neurodivergent and mental health conditions are not fully understood due to a lack of research in the field. Our initial review of the literature has shown a lack of studies into the associations between substance misuse and addictions, and comorbid neurodivergent conditions, with a limited number of studies focusing on male adults in the criminal justice system. We anticipate that this 'wiki' page will provide a platform for our own emerging knowledge and to collaborate with others from various disciplines to build knowledge in this under researched field, which we envisage will positively influence research, policy and practice.

## 6.4 Training in neurodiversity and addictions

In collaboration with Dr Louise Harvey-Golding and Hope Trust, Addictions UK have developed and are continuing to develop a range of high-quality training models in addictions and associated topics. Led by evidence-based theory and practice, this bespoke training is designed and developed by a range of experts including psychologists, psychiatrists, counsellors, therapists, and other professionals. The training is suitable for professionals and those working with or supporting people experiencing addiction, students, or anyone who is interested in the field of addiction.

We have developed five comprehensive training modules covering all aspects of addiction and recovery and other relevant topics including comorbid neurodivergent and mental health conditions, carers of loved ones/family members with addictive and other mental health disorders, and recovery and treatment programmes, i.e. 12-steps and CBT. We are developing further modules in areas including self-esteem, confidence and anger management, and welfare benefits and support systems for those living with addictions and neurodivergent conditions. We will be developing the training further in as we expand our knowledge base through our research and practice.

Training can be delivered face-to-face as short and long courses and is also available online using innovative software and platforms. We currently offer training in the following subjects and topics:

- Addiction: Definitions and Theories
- Addiction: Withdrawal, Abstinence, Relapse and Recovery
- 12 Steps Recovery from Addiction Programme
- Co-occurrence of Substance Misuse and Mental Health Disorders
- 12 Steps and Cognitive Behavioural Therapy (CBT) Approaches in Treatment for Addiction
- Neurodiversity and pathological dependency (under development)

We have developed several innovative bitesize online training sessions using Storyline software, which we will deliver via a learning management system to monitor learner progress and achievement. The online training is user friendly, interactive and the content is provided in a range of formats to suit different learning styles. Learners can access a suite of materials including training and additional resources, and can complete the training at their own pace, with each bitesize session providing core knowledge and assessment. Accompanying each bitesize session there are numerous resources providing the tools for learners to tailor their experience and explore areas further.

Face-to-face training will be provided as short half-day workshops and longer one-to-three-day courses. Delegates will be invited to take part in a range of interactive activities, discussions and demonstrations, focused on addiction and a range of other relevant topics and listen to the experiences of others. Moreover, bespoke training can be developed for specific organisations and purposes.

### 6.4.2 Next steps - Piloting the training

An application has been submitted to Awards for All (August 2019) by Addictions North East for around £10K to pilot the training package. If successful, this project will provide a platform for us to share our learning for the benefit of others, particularly those groups considered “hard to reach.” It will enable us to make the training available to grassroots community-based groups who would otherwise not be able to access it, due to lack of resources and/or funding. Our intention is to reach individuals, organisations, consortiums or networks wanting to increase their understanding of addiction and related issues, those working with and/or supporting people experiencing addiction or those wishing to embark on a career in addiction. It is expected that this project will

enable people affected by addictions to fulfil their potential and create a firm platform for individuals and community groups to address addictions and associated issues. The evaluation and learning from this pilot will be used to develop the training package, in advance to it being rolled out to mainstream service providers and practitioners. Thus, once the training is formally launched, it will have been informed and shaped from grassroots community groups.

## 7. Development and delivery funding and resource requirements

Table 3 Development and delivery funding and resource requirements

	<b>Action research project</b>	<b>Welfare rights and legal service</b>	<b>Training in neurodiversity and addictions</b>	<b>Online resource for addictions / neurodiversity</b>
<b>Addictions UK offer</b>	<p>Research experience, in both academic scientific and action participatory approaches</p> <p>Wide experience of engaging “hard to reach groups” as research participants</p> <p>Expertise in addictions and intelligence in neurodiversity and addictions</p> <p>Potential research participants</p> <p>Potential contribution to Universities Research Excellence Framework 2021</p>	<p>Long standing expertise and experience in delivering welfare rights advice services and conducting legal case work with a high success rate</p> <p>National connections through Advice UK</p>	<p>Five comprehensives and accessible training modules covering all aspects of addiction and recovery and other relevant topics</p> <p>Modules in areas including self-esteem, confidence and anger management, and welfare benefits and support systems for those living with addictions and neurodivergent conditions under development.</p>	<p>A unique space for exploring neurodiversity and addictions and expanding knowledge and influence</p> <p>Technical expertise</p> <p>Potential partnership with The Open University Psychological Society</p>
<b>What Addictions UK are seeking to develop the project proposals</b>	<p>Funding to develop and deliver action research</p> <p>A research partner with expertise in neurodiversity</p> <p>National connections to field of neurodiversity</p> <p>University partner for critical supervision and to bring academic rigour</p> <p>Wider access to research participants</p>	<p>Funding to develop, deliver and market the service</p> <p>Agencies buying into welfare rights advice and legal service to maximise benefits for service users</p> <p>Access to politicians and policy makers to influence investment the service</p> <p>Knowledge about Direct Payments systems</p>	<p>Funding to develop, deliver and market neurodiversity and addictions training module</p> <p>Agencies buying into full package of Addictions UK training</p> <p>Support with marketing and promoting training to wider audiences</p>	<p>Funding to develop, launch and administer the online resource</p> <p>Agencies and individuals contributing to the online resource</p> <p>Agencies and individuals promoting the online resource to wider audiences</p>

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## Appendix 1: Summaries of literature on Autism Spectrum Disorder (ASD) and substance misuse

Author, Title, Year	Type of Study	Key Findings
A selective review of offending behaviour in individuals with autism spectrum disorders (2010, de la Cuesta, Journal of Learning Disabilities and Offending Behaviour)	Review of studies	<ul style="list-style-type: none"> <li>• Crimes committed by those with ASD are unlikely to involve alcohol, drug abuse or substance misuse</li> <li>• Nature of crimes committed by individuals with ASD, are less likely to involve alcohol, illegal drugs or substance misuse</li> <li>• Those with AS Broadmoor high security psychiatric hospital were less likely to have a history of alcohol or substance abuse</li> <li>• Male offenders referred for psychiatric assessment in Sweden with diagnoses of ASD or antisocial personality disorder were less likely to be intoxicated at the time of the crime</li> </ul>
ADHD Symptoms, Autistic Traits, and Substance Use and Misuse in Adult Australian Twins (2014) DUNEESHA DE ALWIS et al.	Cross-sectional interview and self-report questionnaire largescale study data	<ul style="list-style-type: none"> <li>• Greater ADHD symptoms and autistic traits scores were associated with elevated levels of regular smoking; cannabis use; and nicotine, alcohol, and cannabis use disorders</li> <li>• In contrast, for alcohol use, those with high autistic traits scores were less likely to report drinking to intoxication</li> <li>• However, ADHD and AT elevate risk for developing alcohol dependence</li> </ul>
Asperger syndrome and criminal behaviour (2010) Dein & Woodbury-Smith, Advances in psychiatric treatment	Overview of the empirical evidence relating to criminality within the context of Asperger syndrome	<ul style="list-style-type: none"> <li>• Both alcohol and drug misuse (Schwartz-Watts 2005) and drug offences (Allen 2007) have been reported in this population</li> <li>• Although substance use is rare (Murphy 2003; Woodbury-Smith 2006; Mouridsen 2008)</li> <li>• Regarding offenders with Asperger's in high secure units, in most cases the offences have taken place in the context of substance misuse, and the majority are detained under the mental e health category of mental impairment</li> </ul>
Recreational substance use patterns and co-morbid psychopathology	Study on clinical and socio-demographic information, and substance use patterns for adults with ID	<ul style="list-style-type: none"> <li>• Alcohol was the most frequently used substance (80%) followed by cannabis (28%) and cocaine (12%)</li> <li>• Substance use was significantly more likely among male patients, those with a mild level of ID</li> </ul>

Author, Title, Year	Type of Study	Key Findings
in adults with intellectual disability (2011), Chaplin Gilvarry, Tsakanikos, Research in Developmental Disabilities		<ul style="list-style-type: none"> <li>• Substance use was less likely among patients with autism and more likely among those with schizophrenia spectrum disorders</li> <li>• Patients with autism disorder were less likely to have current substance use, either recreational/occasional or continuous/heavy</li> <li>• Male gender was the only predictor for legal substance (alcohol) use</li> </ul>
Autism spectrum conditions and offending: An introduction to the special Edition (2013) Article in Journal of Intellectual Disabilities and Offending Behaviour, Chaplin, McCarthy & Underwood	Review of studies	<ul style="list-style-type: none"> <li>• People on the autistic spectrum may not fully understand the consequences of their actions and the impact they have on others. There are a number of factors that are believed to independently increase the likelihood of offending in individuals such as that mental disorder, substance abuse, unemployment, being young, male gender and socioeconomic status</li> </ul>
Characteristics of male autistic spectrum patients in low security: are they different from non-autistic low secure patients? (2013), Haw, Radley & Cooke, (2013), Journal of Intellectual Disabilities and Offending Behaviour	Case-control study of admissions to two ASD units and one non-ASD unit at a tertiary referral centre. Subjects were compared on demographic, personal, clinical and offending behaviour variables	<ul style="list-style-type: none"> <li>• Compared to controls, the ASD group were less likely to have a diagnosis of alcohol or substance misuse or dependence</li> </ul>
Risk factors for violent offending in autism spectrum disorder, (2009) Langstrom et al. Journal of Interpersonal Violence	Study uses data from Swedish longitudinal registers for all 422 individuals hospitalized with autistic disorder or Asperger syndrome during 1988-2000 and compares those committing violent or sexual offenses with those who did not	<ul style="list-style-type: none"> <li>• Risk factors for violent offending in ASD appear to be the same as in non-ASD subjects, namely male gender, comorbid psychosis and substance misuse</li> <li>• Violent offending has been found to be more common in Asperger's syndrome than in autism</li> <li>• Psychotic disorder, any substance use, and personality disorder were significantly associated with violent convictions in individuals with ASD</li> </ul>

Author, Title, Year	Type of Study	Key Findings
		<ul style="list-style-type: none"> <li>• When diagnoses of autistic disorder and Asperger syndrome were considered separately, only 3.2% (n = 10) had been convicted of a violent crime in the autistic disorder group, compared with 20.0% (n = 21) in the Asperger group</li> <li>• Risk factors for violent offending among individuals with ASD were male gender, older age, comorbid psychosis (identified at any time during the study period), substance use disorder, and personality disorder, respectively</li> <li>• Co-morbid psychosis and illicit substance misuse may be particularly problematic for increasing an individual with an ASD vulnerability towards interpersonal violence</li> </ul>
Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome, (2010), Lugnega et al. Research in Developmental Disabilities	Investigate psychiatric comorbidity in young adults with Asperger syndrome. Psychiatric comorbidity was assessed by the Structured Clinical Interview for DSM-IV Axis I Disorders. IQ was measured using the Wechsler Adult Intelligence Scale, Third Edition. Autism spectrum diagnoses were confirmed using the Diagnostic Interview for Social and Communication Disorders	<ul style="list-style-type: none"> <li>• Psychotic disorders and substance-induced disorders were uncommon</li> <li>• Six participants (11%) had had a previous substance dependence disorder (one woman and one man with a combination of alcohol and drug dependence, two men with alcohol dependence and two men with drug dependence)</li> <li>• Even though the rate of substance abuse was relatively small in the group as a whole, most of the variance was accounted for by individuals with AS who also had a diagnosis of ADHD. This is clinically important given the now widespread belief that ASDs are unassociated with substance abuse. This may be true for those who have “only” ASD, but clearly is not for those with ASD who have comorbid ADHD</li> </ul>
Practice Guideline on Attention Deficit Hyperactivity Disorder Article in Archives of Disease in Childhood, (2010), Collis, Education and Practice	Guide for practitioners	<ul style="list-style-type: none"> <li>• The management of ADHD in the presence of co-morbid conditions in children, young people and adults including conduct problems, anxiety, autism spectrum disorder (ASD), learning disability, neurological disorders and substance misuse</li> </ul>
Staff Perspectives of Substance Use and Misuse	Study explored the perspectives of staff with respect to the	<ul style="list-style-type: none"> <li>• Alcohol was reported to be used most often but at lower rates than reported in the general population</li> </ul>

Author, Title, Year	Type of Study	Key Findings
<p>Among Adults With Intellectual Disabilities Enrolled in Dutch Disability Services, (2011) VanDerNagel et al. Journal of Policy and Practice in Intellectual Disabilities</p>	<p>occurrence of substance use and abuse, as well as users' profiles, and service organization policies regarding substance use. A semi-structured questionnaire asked staff to comment on lifetime, current, and problematic substance use among their clients, provide illustrative case reports, and describe policies within their service regarding substance-related problems. Data from 39 IDS were included</p>	<ul style="list-style-type: none"> <li>• Cannabis and other drugs were reported to be used relatively often when compared with the rates noted in the general population</li> </ul> <p>Psychiatric comorbidity and lack of daytime activities were highly prevalent among users</p> <ul style="list-style-type: none"> <li>• Comorbidities and use of prescribed drugs - Developmental disabilities (such as attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder) and psychiatric comorbidities, mainly personality disorders and challenging behaviors, were present in almost half of the cases. Some 44.7% (n = 38) of the adults were reported to use prescribed medications, predominantly psychoactive drugs. The use of anticonvulsant and other somatic medications was very low. Substance-related medications reported to be used included opiate replacement therapy with methadone (n = 2), an aversive drug (n = 1), and acamprosate (n = 1)</li> </ul>

## Appendix 2: Conversation points from community consultation events

- ‘Learning Difference’ is another term for ‘Neurodiversity’
- Individuals with ASD may be less likely to seek/ask for help for additional needs and comorbid conditions
- What is the difference between ‘compulsion’ and ‘addiction?’ – compulsive behaviours and compulsions have a high prevalence amongst those with ASD, i.e. is gaming a compulsion or an addiction?
- Difficulties in gaining employment (although holds a first-class BA hon in computing) due to ASD and perceptions of people with ASD in the work environment and amongst employers
- Working on developing an online game that examines the issues in working environments and the difficulties faced by those with neurodiversity conditions in seeking, gaining and maintaining employment
- A representative of the SPLinter Group is involved in developing ‘Safe Places,’ a national network scheme: <https://www.safeplaces.org.uk/>
- “Feeling normal was not an option.” – Engaged in substance misuse and high-risk behaviours (escapism) in an attempt to silence the negative thought patterns. Eventually led to family and psychological breakdowns, and homelessness. Finally received a diagnosis, which started the journey towards recovery. The diagnosis provided an understanding of ‘why?’ and provided empowerment
- Does the ‘social model’ detract from the benefits of a medical diagnosis?
- Problems associated with ASD symptoms, compulsions and addictions, i.e. ‘gaming’ exasperated by ‘social isolation.’ This is worse for those who live in rural areas
- Gaming is a hidden addiction
- Lack of support for those with Tourette’s in the North East
- More children who have experienced trauma are developing Tourette’s However, there is a reluctance and resistance to examine the darker side of the Tourette’s condition in terms of associates with past trauma
- Tourette’s is overrepresented in prisons
- Combinations of neurodivergent conditions, i.e. ADHD and Tourette’s increases risk of engaging in high-risk behaviours, compulsions and substance misuse

Comments made in advance of the day by email:

- A high vulnerability to addiction with ASD and related conditions (that combination of impulsivity, obsessiveness and social difficulties), that often leads to horrific abuse/exploitation in the community.
- The lack of awareness within the statutory agencies is astonishing – although individual clinicians have a great deal of insight and may have quite an evidence base to draw upon.

## Appendix 3: Notes from ACAMH Conference Malta - Neurodevelopmental Disorders

### Joseph Kilgariff - Assessment, diagnosis and treatment of tic disorders in CAMHS

Joseph Kilgariff works as an Advanced Nurse and non-medical prescriber for neurodevelopmental psychiatry. His role includes assessing, diagnosing and treating neurodevelopmental conditions such as ADHD and tic disorders. Department of Child and Adolescent Psychiatry, Queen's Medical Centre, Nottingham.

- replace “naughty, intolerance and exclusion” with “illness, empathy and modification”
- Linking anxiety and sleep problems affecting those with Tourette’s coupled with substance misuse issues
- Young man with Tourette’s and alcohol misuse issues says his tics are dramatically worse in 6 months since he’s been sober



Figure 3 - Relaxation and distraction are key to reducing tics

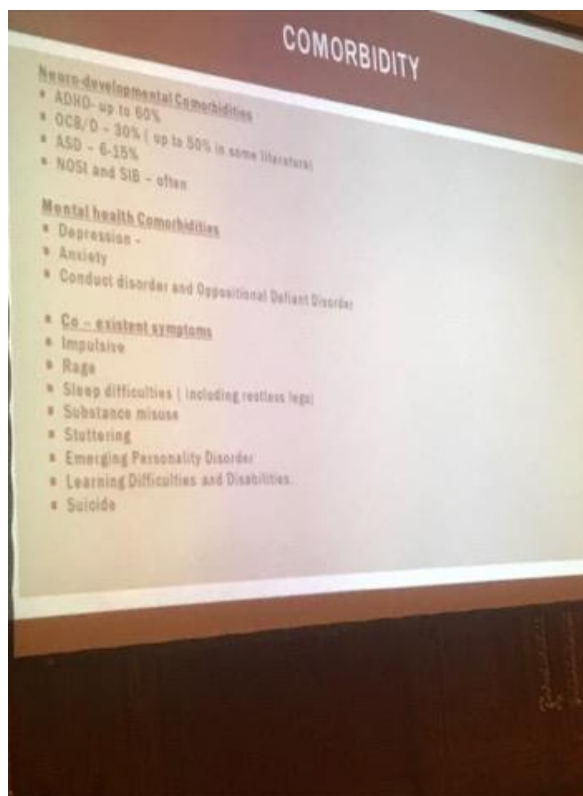


Figure 4 - On co-morbidity and Tourette’s showing substance misuse as a co-existing symptom



## Dr Mark Lovell - How to identify a Learning Disability - A to H approach (linked to ACAMH topic guide and resources)

Dr Mark Lovell (MBChB(hons), BSc(hons), PGDipMedSc(merit), MRCPsych) is a Consultant Child and Adolescent Intellectual Disability Psychiatrist and Chief Clinical Informatics Officer at Tees, Esk and Wear Valleys NHS Foundation Trust. He is the lead for CPD and training on ACAMH's board and the Vice chair of ACAMH's neurodevelopmental conditions special interest group.

8. Distinguishing between ASD and attachment issues where they can present in identical ways

## Max Davie - Physical aspects of neurodevelopmental disorders

Max is a consultant community paediatrician (Guys and St Thomas Hospital), who has a special interest in the assessment and diagnosis of neurodevelopmental conditions in school age children and, more generally, in the mental health of paediatric patients.

9. We need to move away from single condition diagnostic tools, an accessible neurodevelopmental toolkit to follow
10. holistic assessments needed for those with neurological disorders

## Dr Nigel Camilleri- Consultant Child & Adolescent Psychiatrist - Latest updates on the treatment of ADHD

11. clinical trials show amphetamines most effective in ADHD symptoms, side effects can be poor appetite and weight-loss
12. links between substance misuse and ADHD
13. links between child deprivation, attachment issues and ADHD symptoms

## Daniel Vella Fondacaro, A qualitative study assessing parents' perspective on young people with autism spectrum disorder in relation to the benefits of sport; comparing individual to group sport

14. Parent in a study of benefits of sport in ASD parallels child's internet addiction with alcoholism

## Stephanie Hunter - Helping children with complex needs make successful transitions

15. Some of those who are rejected and traumatised self-medicate to manage pain (Rohner, 2012)

## Dr Ann Ozsivadjian - Mental health problems in ASD – prevalence, presentation and pathways

Ann is a Principal Clinical Psychologist with 15 years' experience in a specialist complex neurodevelopmental disorders team, which provides assessments and treatments for a wide range of neurodevelopmental difficulties and co-occurring conditions  
<https://www.drannozsivadjian.co.uk/>

- Lack of research into eating disorders with the ASD community

### Michelle Mifsud - Girls with Autism Spectrum Disorder: Missed diagnosis or misdiagnosis

- Suggests male bias in ASD clinical impressions, diagnostics criteria and tools
- Mother's experience guilt and poor mental health when their daughters have extended waits for ASD diagnosis
- Every mother in study mentioned dismissal of maternal concerns a factor in girls going undiagnosed with ASD

### Jessica Borg - Evaluating the readiness of Maltese Speech and Language Pathologists in identifying the subtle clinical presentation of autism in females on spectrum

- If you listen to girls' stories, they are really struggling with ASD, they need diagnosis to get support - we need to bridge the knowledge gap
- "Camouflaging" in females with ASD obscuring identifications and diagnosis and featuring the campaigner Laura James