

# CHALLENGING BEHAVIOUR: ASSESSING RISK FACTORS IN PEOPLE WITH LEARNING DISABILITY

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## ABSTRACT

Challenging behaviour is common amongst people with learning disability and represents one of the greatest challenges to clinicians and service providers. This behaviour can be costly to manage and frequently leads to a significant burden of care, social exclusion, high health and social care costs. The main aim of this article is to highlight the important risk factors that need to be considered by clinicians whilst assessing people with challenging behaviour, to help formulate holistic and robust care plans tailored towards identified needs of an individual. Literature at Psych info, Medline and Cinahl (1980-2010) is reviewed for risk factors associated with challenging behaviour in people with learning disability. Various risk factors associated with challenging behaviour include male gender, adulthood, living at residential services, severe learning disability, underlying mental health disorders, and physical health problems etc. This article also aims to guide recommendations based on highlighted risk factors, for future planning of services and support by commissioners and service providers for this client group.

**Key words:** Learning disability, challenging behaviour.

## INTRODUCTION

People with learning disability may display aberrant or maladaptive behaviour collectively termed as challenging behaviour. Although the term 'challenging behaviour' had been used in the US, the King's Fund is accredited with its introduction in the UK. The intention was to focus on those, who challenge services and to bring into use the term that aimed to be less stigmatizing than labels such as aberrant or maladaptive behaviours<sup>1</sup>.

The most commonly cited definition of challenging behaviour in the literature is 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities'<sup>2</sup>. Common types of challenging behaviour with examples are listed in Table 1.

### Epidemiology of Challenging Behaviour

Current available evidence highlights wide variations in reported prevalence of challenging behaviour within the learning disability population. Deb et al<sup>3</sup> found the prevalence of challenging behaviour amongst com-

**Table 1**

**Examples of challenging Behaviour**

Aggressive behaviour to others	Screaming, shouting, spitting, kicking
Self Injurious behaviour	Hitting, head butting, biting, nail pulling.
Behaviour directed at property	Throwing objects, Stealing.
Inappropriate sexualized behaviour	Public masturbation or groping
Stereotyped Behaviour	Repetitive rocking, hand wringing.

munity based population of adults with learning disability aged between 16-64years to be 60.4%. Where as prevalence of challenging behaviour found by Jones et al<sup>4</sup> in (population based cohort n=1023) adults with learning disability was 22.5%. Emerson et al<sup>5</sup> found that 10-15% of people with learning disability known to local education, social and health care services showed challenging behaviour.

In a study by Lowe et al<sup>6</sup>, all services providing for people with learning disability across seven unitary authorities in South Wales, with total population of 1.2 million, were screened to determine prevalence of challenging behaviour. In total 4.5 people per 10 000 population were found to have challenging behaviour representing 10 % of total population. It was also found that the most prevalent general form of challenging behaviour was aggressive behaviour.

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In the UK Kiernan and Moss<sup>7</sup> found prevalence of challenging behaviour in a hospital population of people with learning disability to be 40%, whereas estimated prevalence of challenging behaviour in a hospital population of people with learning disabilities by Qureshi and Alborz<sup>8</sup> was 30%.

Wide variation in reported prevalence is due to difference in inclusion and exclusion criteria used to define challenging behaviour by various investigators at different settings.

### **Risk factors associated with Challenging behaviour:**

It is important to identify risk factors of challenging behaviour and why it may be displayed by people with learning disability for two fundamental reasons. The first is that identification of these risk factors can lead to introduction of constructive interventions to alleviate behavioural problems. Second, identification of risk factors can guide recommendations for future planning of care and support for this client group.

Evidence from many studies indicates that behavioural disorders amongst people with learning disability are related to a range of psychological, demographic, neurobiological and social factors which are as follows:

### **Challenging Behaviour and Age**

Age is one of the important risk factor associated with challenging behaviour in adults with learning disability. Challenging Behaviour in people with learning disability is reported to occur more in childhood, reaches a peak in the age range 15-34 years and then declines after 34years of age<sup>9</sup>.

Lowe *et al*<sup>6</sup> screened all services in South Wales providing for people with learning disability across seven unitary authorities, it was found that greatest proportion (40%) of learning disabled individuals displaying challenging behaviour were young adults aged 16-39 years, 34% aged 40-59 years, 17% were children below 16 years and only 9% were aged above 60 years.

In a study by Joyce *et al*<sup>23</sup> examining prevalence of challenging behaviour amongst adults with learning disability in community services also found that out of a total sample of 448 individuals identified to have challenging behaviour, 63% were between 19- 34years of age, after which there was a marked decline. Approximately 36 % of the subjects were aged between 34-54years with only 6% being over the age of 54 years.

Richard *et al*<sup>10</sup> also found a higher prevalence of self injurious behaviour (one form of challenging behaviour) in young adults with learning disability in a population based sample of 2277 adults (with overall prevalence of 17.4% for self injurious behaviour in the sample) known to Leicestershire Learning Disabilities register.

### **Challenging Behaviour and Gender**

Most studies have found higher prevalence of challenging behaviour amongst male service users with learning disability.

A survey conducted on aggressive behaviour within a population of 2412 people with learning disability in Queensland, Australia by Sigafoos *et al*<sup>11</sup>, found that in a sample of two hundred and sixty one individuals who were identified to have aggressive (challenging) behaviour, there was a higher percentage (64%) of males.

The results also correspond to the results of a study conducted by Lowe *et al*<sup>6</sup> to determine administrative prevalence of challenging behaviour in people with learning disability in South Wales with total population of 1.2 million. He also found that 1770 individuals with learning disability were identified to have challenging behaviour; out of those 63% were males.

Similarly Turner and Sloper<sup>12</sup> found greater prevalence and frequencies of challenging behaviour among boys in his study investigating behaviour problem pattern over 5 years in 55 boys and 36 girls (aged 11-17years) with Down's syndrome and learning disability. Behaviour problem patterns were investigated by using Behaviour Problems Questionnaires together with maternal appraisal of seriousness of the problem.

### **Challenging Behaviour and degree of Learning Disabilities**

In general, challenging behaviour is associated with degree of learning disability and lack of skills, particularly communication. Restless and overactive behaviour is very common in people with moderate or severe learning disability, often compounded by excitability and/ or aggression<sup>13</sup>. The only exception to this close association is among people with profound learning disability, as many are so disabled that apathetic and listless behaviour dominate the presentation<sup>13</sup>.

It has been found that people with profound or severe learning disability display the highest rate of self injurious behaviour and less outwardly directed behaviour because of their restricted mobility and poorly developed communication. It is suggested that up to 90 % of those who self injure have profound learning disability<sup>14</sup>.

### **Challenging Behaviour and Other Mental Disorders**

Learning disabled individuals can experience the full range of mental disorders, and prevalence of other mental disorders is at least three to four times greater than in general population<sup>15</sup>.

Reported prevalence of mental health disorders among people with learning disability referred to psychiatrists is 30 – 40%<sup>16</sup>.

There are two possible forms of relationship of challenging behaviour and co morbid mental disorders. Firstly mental health problems may cause or exacerbate chal-

lenging behaviour among people with learning disability. Secondly challenging behaviour may be the atypical presentation of psychiatric disorders in people with learning disability<sup>17</sup>.

Two sources of circumstantial evidence suggested that some forms of challenging behaviour (self injurious) may constitute the atypical presentation of obsessive – compulsive disorder among people with severe learning disability. First, there are clear topographical similarities between obsessive- compulsive disorder and self injurious behaviour in that both categories of challenging behaviour are repetitive, stereotyped, ritualistic, apparently unrelated to the immediate demands of the person's situation and are extremely resistant to change<sup>18</sup>. Second there is a growing evidence to suggest that serotonergic agonists or reuptake inhibitors (e.g. fluoxetine, clomipramine) can reduce obsessive compulsive disorders in people without developmental disabilities and self injurious behaviour in people with severe developmental disabilities<sup>19</sup>.

Moss *et al*<sup>20</sup> in a case control study of a total sample of 320 learning disabled adults presenting with challenging behaviour (cases= 234) and (controls= 86) without challenging behaviour, conducted in the North West of England reported that increased prevalence of psychiatric symptoms was significantly associated ( $p < 0.001$ ) with challenging behaviour, depression showing the most marked association. It was also found that anxiety symptoms were associated with the presence of self injurious behaviour in that population. A potential limitation of that study was that data on psychiatric symptoms were collected by using Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS- ADD) checklist by support staff, rather than diagnosis made by psychiatrists with expertise in learning disability based on ICD -10 criteria.

A study conducted by Deb *et al*<sup>3</sup> to explore possible risk factors that are associated with overall rate as well as different types of behaviour disorder involving one hundred and one randomly selected adults with challenging behaviour and learning disability. Strong association was found between the use of psychotropic medication, including antipsychotics, antidepressants, and antiepileptic medication and the rate of behaviour disorders. One may argue that the association was a reflection of association of psychiatric illness and behaviour disorders.

Jacobson<sup>21</sup> conducted a survey on over 30,000 clients receiving services for developmental disabilities from New York State. He reported that behaviour problems were consistently more common in persons with dual diagnosis (with learning disability and co morbid psychiatric illness) as compared with controls sample without evidence of mental health problems. Aggression was reported to occur in 19.5% of the individuals with dual diagnosis versus 10.6% in the control group; destructive behaviour occurred in 6.6% and 4.2%, and self injurious behaviour in 12.2% and 8.9%, respectively.

Similarly Nihira *et al*<sup>22</sup> surveyed behavioural problems in learning disabled individuals receiving services from the California State Department of Developmental Services. They drew clinical files of almost 4,000 individuals with dual diagnosis (learning disability and psychiatric disorders) and an equal number of matched controls with learning disability but without diagnosis of psychiatric disorders. They found that behavioural problems were more common in people with psychiatric diagnosis than the control subjects. In addition it was found that certain forms of psychiatric disorders, particularly pervasive developmental disorders in children and schizophrenic disorders in adults, showed distinct pattern of behavioural problems.

### **Challenging Behaviour and Residential Status**

Joyce *et al*<sup>23</sup> examined the prevalence of challenging behaviour amongst adults with learning disability residing in three London Boroughs. Four hundred and forty eight (448) individuals were identified with challenging behaviour and learning disability from a total borough population of 670,000. The study reported that 24 % of the sample was still living at home with their families and 50% were in staff supported community residential services and 20% were living in out of borough residential services.

Sigafoos *et al*<sup>11</sup> also found that the relative prevalence of aggressive behaviour was higher among institutionalized persons (35%) when compared to those living in group homes (17%) or other community-based facilities (3%), in his survey involving 261 individuals with learning disability displaying aggressive behaviour (as mentioned above in challenging behaviour and gender section)

Evidence suggests that people with learning disability who live in staff supported community residential services are more likely to display challenging behaviour than those living at home with their families.

However the extent to which people with challenging behaviour are present in community and the extent to which community services can support them still requires significant research.

### **Challenging behaviour and Physical illnesses/ Genetic Disorders:**

Challenging behaviour may be associated with various physical health problems e.g. Epilepsy, urinary tract infection, uncontrolled pain, constipation, hypo/ hyperglycaemia etc<sup>1</sup>. Challenging behaviour is more prevalent in people who have learning disability co-existing with (ASD) autistic spectrum disorder<sup>1</sup>.

## **DISCUSSION**

Challenging behaviour is common amongst people with learning disability with prevalence ranging from 10% to 60%. Variation in reported prevalence can be explained by variation in types of behaviours included in defining

challenging behaviour by various investigators at different settings. Current evidence indicates the needs for further epidemiological research with universally agreed definition of challenging behaviour indicating its exact prevalence at different settings, which would help to support accurate planning of future service provision.

Evidence suggests that challenging behaviour is more prevalent at younger age and reaches its peak at adulthood; necessitate the need to provide more adequate support at this level by expanding the existing child and adolescent services for learning disabled individuals. Expansion of services can be achieved by recruiting more staff e.g. Psychologist, social workers, occupational therapist, speech and language therapist, trained medical and nursing staff etc, to assess and manage patients with challenging behaviour more closely with multidisciplinary approach. Clinical care and support can also be improved by setting up more specialized clinics called 'challenging behaviour clinics' with staff trained in treating individuals displaying various challenging behaviours. Those individuals might also need to have earlier and more robust transition planning to adult services to prevent relapse or exacerbation of challenging behaviour.

Challenging behaviour is also more common in institutionalized individuals, possibly because people with learning disability are more likely to find themselves in residential services. Perhaps there is a need to provide improved support to carers involved in care of individuals with learning disability at different residential settings and families taking care of those individuals at home e.g. by developing 'Home based support services'.

Clinicians need to conduct a thorough assessment of individuals with Learning disability, presenting with challenging behaviour for any underlying mental health or physical health problems. Comprehensive history, mental state examination, risk assessment with diagnostic formulation should be considered in all individuals which will help in devising robust and holistic care plans in improving challenging behaviour. Prompt identification and management of coexisting psychiatric disorder can reduce the prevalence of challenging behaviour, as there is growing evidence that challenging behaviour may be caused or exacerbated by a coexisting psychiatric disorder e.g. Psychotic disorders, mood disorders, anxiety disorder etc. People with challenging behaviour should also have a detailed physical health assessment as it can also be associated with or caused by underlying physical illnesses e.g. constipation, epilepsy, infections, uncontrolled pain and hypo/hyperglycaemia.

In summary various social and demographic risk factors associated with challenging behaviour are male gender, adulthood, living at residential services and severe learning disability. People with learning disability may also present with challenging behaviour when they suffer with physical and or mental health problems. Challenging behaviour can be reduced in people with learn-

ing disability by providing adequate support, and robust management following comprehensive multifactorial assessment of identified risk factors. Commissioners and service providers especially in new NHS framework can improve the existing services by considering above mentioned risk factors for future planning and provision of care in this client group e.g. expansion of child and adolescent learning disability services, setting up specialized clinics, developing home based support services etc. Improved and well structured services would not only help in improving the quality of life of the individual and reducing burden of care on carers with improved and robust management of challenging behaviour, but also help in improving the long term cost effectiveness of service provision.

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