

# People with Intellectual Disabilities Going Missing

## Key points

- The proportion of Missing People's cases where an intellectual disability is indicated has risen constantly from 2005 to 2009, and decreased slightly in 2010.
- In 2009-10 three-quarters of missing people with an intellectual disability (searched for by the charity) were male, compared to one-quarter female.
- In nearly one-third of Missing People's cases where an intellectual disability was indicated, there was also a concern for the missing person's mental wellbeing.
- In 15 per cent of Missing People's cases with an intellectual disability indicated there was evidence that the missing person had a fascination with public transport, or that they had been familiar with a particular route but a journey had been disrupted.
- In 22 per cent of cases with an intellectual disability indicated there was evidence that the missing person had arranged to meet a stranger; a number of which had been contacted via the internet.

<b>1. Context</b>	<b>2</b>
1.1. Introduction	2
1.2. Missing people definition and numbers	2
1.3. Missing People	2
1.4. Policy context	3
1.5. Intellectual disability definition and numbers	3
1.6. Intellectual disabilities policy	4
1.7. Intellectual disabilities and missing	4
1.7.1 Running away	4
1.7.2 Bullying and sexual abuse	5
1.7.3 Mental health	5
1.7.4 Dementia	6
1.7.5 The police	6
<b>2. Methodology</b>	<b>7</b>
<b>3. Findings</b>	<b>8</b>
3.1. The relationship of cases over time	8
3.2. Demographic trends	9
3.3. The duration of closed cases	11
3.4. Other characteristics for the cases of people with intellectual disabilities	12
3.4.1. Accommodation	12
3.4.2. Risk assessment and vulnerability	12
3.4.3. Previous missing incidents	13
3.4.4. Mental health	13
3.4.5. Physical health issues	13
3.4.6. Medication issues	13
3.4.7. Addiction	13
3.4.8. Being understood	14
3.4.9. Behavioural problems	14
3.4.10. Problems with the law including prison and stealing	14
3.4.11. Homelessness	14
3.4.12. Transport	14
3.4.13. Strangers and the internet	15
3.4.14. The end of the case	15
<b>4. Recommendations</b>	<b>15</b>
4.1. Policy recommendations	15
4.2. Further research	16
<b>5. References</b>	<b>17</b>

# 1. Context

## 1.1 Introduction

There has been very little previous research exploring the relationship between intellectual disabilities and going missing. This paper aims to describe the terms 'missing' and 'intellectual disabilities' and to examine the cases, held by Missing People, of missing people with intellectual disabilities. By increasing understanding in this area, the research aims to improve the support for people with intellectual disabilities who go missing, as well as those left behind.

## 1.2 Missing people definition and numbers

Defining a missing person is problematic. The Association of Chief Police Officers (ACPOS, 2010:17) state that a missing person is *"Anyone whose whereabouts is unknown whatever the circumstances of disappearance. They will be considered missing until located and their well being or otherwise established"* This provokes the question to whom the circumstances are unknown. Biehal, Mitchell and Wade (2003:2) define a missing situation as *"a break in contact which **either** the missing person **or** someone else defines as going missing, and which may either be intentional or unintentional"* (emphasis added).

As there is no completely accepted definition of 'missing' it is impossible to be precise about numbers. In addition, Biehal et al (2003:4) refer to Rogers (1991) and Verhoeven et al (2000) whose studies suggest that not all people who go missing are reported to the police. A series of studies by The Children's Society have found that around two thirds of young runaways are not reported missing to the police (Rees, 2012, Rees and Lee, 2005). This means there is a dark figure of missing people that can never be precisely calculated.

A recent Home Office Task Force report estimates the overall number of missing persons in the UK to be around 250,000 per year. This includes an estimated number of unreported missing people, and people reported missing to agencies other than the police. (Home Office, 2010: 4).

## 1.3 Missing People

Missing People provides free 24 hour confidential support, help and advice by phone, email, text and online, including the opportunity to reconnect, for missing people and their families. The charity works alongside the police where they are involved, and can also undertake family tracing work, where appropriate, for families who have lost contact.

The charity coordinates publicity and media appeals for missing people, and coordinates a UK-wide network of people, businesses and media to join the search for missing people. We also provide a free and confidential way for anyone to pass on sightings or information about a missing person. All information is shared with the relevant police force.

If missing people want to reconnect in a confidential and safe way, Missing People can reconnect them to family, carers, police or social care services.

#### 1.4 Policy context

The aim of the charity's *Missing Rights* campaign has been to ensure that the relatives of missing people have the same right to emotional, practical and legal support as victims of crime. In June 2011 an All-Party Parliamentary Group (APPG) for Runaway and Missing Children and Adults (for which Missing People is Secretariat) conducted the UK's first ever inquiry into support for families of missing people. The inquiry's final report made a number of recommendations.

In December 2011 the APPG inquiry's overarching recommendation was acted upon after the publication of a cross-government strategy on Missing Children and Adults. As Chief Executive of Missing People, Martin Houghton-Brown has said this was the first time the Government had devised an overarching policy on the issue of missing. The policy had three broad aims: prevention; protection and provision.

**Prevention** relates to reducing the number of people who go missing as much as possible through education and various other strategies. **Protection** looks at reducing the potential harm faced by those who do go missing, and closing cases expediently. Finally, **provision** pertains to making sure that the missing person and the family and/or carers left behind understand how and where to access support, and that it is consistently offered. In order to achieve these roles the government has put a strong emphasis on co-ordination between all services at a local and national level.

#### 1.5 Intellectual disability definition and numbers

The term intellectual disability will be used in this paper as it has less stigma attached to it than previous terms (Mental handicap, Learning Disabilities or Learning Difficulties) and has both biological and social implications. It can also include conditions such as autism where someone does not necessarily have a mental illness or a significantly lower than average intelligence but still perceives the world in a different way from most people. Dyslexia is also included as there can be repercussions if a person is not given the right support to address it. The definition of intellectual disability used in this report is from the World Health Organisation.

*"Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society."* (World Health Organisation website 2011)

As there is no universally accepted definition, it is not possible to give a completely accurate statistic for the number of people with intellectual disabilities in the UK. The Learning Disability Coalition states that the number of people with an intellectual disability in the UK is about 1.5 million. The British Institute for Learning Disabilities estimates that 1,198,000 people in England, or 2 per cent of the population, have a learning disability. (Holland, 2011: 1).

## 1.6 Intellectual disabilities policy

In 2001, the Government produced a white paper entitled “*Valuing People*” which outlined the situation of people with intellectual disabilities and how to improve it. The fact that the previous big policy initiative with people with intellectual disabilities was in 1971 demonstrates that this has been a politically neglected area. The four key principles were Rights, Independence, Choice and Inclusion. The Government set up a learning disabilities development fund in April 2002. A further paper came out in 2009 called “*Valuing People Now*”. It placed increased emphasis on health housing and employment. The emphasis in this paper was that there had been improvements in various sectors, but there was still a great amount to do.

Some have questioned the effectiveness of the 2001 Valuing People policy. *A Life like Any other* (2008) examines the topic of intellectual disability from a human rights perspective. The members of the House of Commons and House of Lords behind the 2008 paper state that “*evidence to the committee suggest that adults with learning difficulties are more liable to social exclusion, poverty and isolation and that efforts to improve their life have had little impact on them.*” (House of Commons and House of Lords 2008:5). The paper also contains information about a report from Values into Action. The head of this group writes, “*I think it is fair to say that in the fifty groups we visited, there is very little awareness of the Human Rights Act among the people with learning disabilities themselves or professionals*” (House of Commons and House of Lords 2008:81).

## 1.7 Intellectual disabilities and missing

### 1.7.1 Running away

The Still Running series is a project over time by The Children’s Society to monitor patterns of children running away in the UK. The survey includes information about children who reported that they have difficulties learning. In the most recent sweep of the survey, Still Running 3, 18 per cent of children who defined themselves as having difficulty learning had run away overnight. (Rees, 2011:13). The first Still Running survey found that “*young people in mainstream schools who regarded themselves as having difficulties with learning were significantly more likely to run away than average*” (Rees and Lee, 2005: 9). The second sweep found that around 20 per cent of young people who defined themselves as having difficulties learning had run away in the past year (Rees and Lee, 2005: 9).

Not all research on young runaways reveals a higher than average prevalence of children with intellectual disabilities. Smeaton (2009:4) in *Off the Radar* had a sample of 103 children who were or had been on the streets. Nine of these children (nine per cent) identified themselves as having dyslexia. A 2004 article of Postnote (the parliamentary office of science and technology) states that estimates for the prevalence of dyslexia vary a great deal (from 2 per cent to 15 per cent). This is because different studies are based on different cut off points on the continuum between mild and severe dyslexia. The figure of nine per cent puts the children in Smeaton’s group half way between the two extremes of the findings. A further three children in Smeaton’s report had attention deficit hyperactivity disorder (three per cent) The website ADHD Training and support for clinicians estimated that “*perhaps 5% of school aged children are affected – or 366,000 in England or Wales. Significant numbers remain undiagnosed.*”

Once again, the figure is not abnormally large. There was one child that had an undiagnosed intellectual disability and another who had Asperger's Syndrome. Such numbers are too small to be compared to any prevalence figures. There was also a child who had bipolar disorder but there was no mention that this was accompanied by an intellectual disability.

It is clear that more research is needed to clarify the relationship between intellectual disability and running away. With any research, including that above, there is always the dark figure of undiagnosed or unstated intellectual disability that can only be estimated.

### **1.7.2 Bullying and sexual abuse**

Research conducted by Mencap has shown the great extent to which people with intellectual disabilities suffer from bullying. Whether this makes them more likely to run away or go missing needs to be the subject of further research. In Mencap's 2009, report researchers with intellectual disabilities decided what the definitions of bullying should be. They described it in terms of certain forms of behaviour including *"kicking, biting, name calling, teasing, stealing, pushing, threatening, (and) having things thrown at you"* (Mencap 2009:3). Bullying also included sexual and racial harassment. Mencap found in a survey that 82 per cent of all children who have an intellectual disability have been victims of bullying (Mencap 2007:3). Mencap (2001:4) also suggest reasons why someone with intellectual disabilities is more likely to suffer from sexual abuse, and agrees with Muccigrosso (1991) that people with intellectual disabilities are around four times more likely to suffer sexual abuse than other people.

### **1.7.3 Mental health**

Research has found that people who go missing are more likely to suffer from mental health problems than those who do not. A report published by the Grampian Police (Gibb and Woolnough, 2007:1) states *"approximately 80% of adults who go missing are known to have some form of mental illness at the time. Those illnesses range from mild depression to severe psychosis"*. Other research (such as Biehal et al, 2003:11) also highlights mental health among missing people but they do not put the percentage as high as Gibb and Woolnough.

The website Understanding Individual Needs (2011) concludes that people with an intellectual disability are more likely to have a mental health problem (40 per cent compared to 25 per cent).

What is clear is that there can be purely physical causes for depression for some people with intellectual disabilities. Dennis and Marder (2006:1) discuss how people with Down's syndrome are more likely to have an underactive thyroid gland, which leads to depression, and lethargy. They estimate that 15-20 per cent of adolescents with Down's syndrome have a gland that is not working properly.

There can also be other reasons why people with intellectual disabilities are prone to depression. Qualitative research by the Foundation for People with Learning Disabilities (2005:45) illuminated the vicious circle of depression and under-stimulation that people with intellectual disabilities can experience. Often, people will have regular contact only with their families and caring professionals. Some of those interviewed pointed to the interviewer as the one person they could really talk to (2005:51).

Not all sources agree that people with intellectual disabilities are uniformly more likely to suffer from depression. Cunningham states, *“between 10 to 14% of mainly young adults with Down’s Syndrome have depressive episodes. This is less than in the general population. ..People with Down Syndrome have a higher chance of being happy and stress free than most people.”* (Cunningham, 2006: 306).

There is also evidence that people with intellectual disabilities are more likely to have schizophrenia. Doody (2001) states that people with a moderate learning disability are three times more likely to have schizophrenia than those without one. It is far from clear whether this is down to biological or social factors or a mixture between the two. The *See Me Scotland* website claims that of the general population nearly one in a hundred will experience schizophrenia.

There are potential causal elements in mental health and ‘missing’ when one of the two factors could create the other. There is also the potential for correlation where the two elements exist in tandem and there is no causation. This is a complex issue and requires further research.

#### **1.7.4 Dementia**

It is well documented that people with dementia can go missing through getting confused and wandering (Alzheimer’s Society 2011b). It is also well documented that people with intellectual disabilities are more likely to have dementia and to have it at an earlier age than most other people (Alzheimer’s Society, 2011a). This could be a reason why some people with intellectual disabilities go missing. Once again, there needs to be more research to find out how true this is.

The Alzheimer’s Society also quotes Prasher (1995) who found that by the time they reach 60 to 69 years old, 55 per cent of people with Down’s syndrome will have dementia (Alzheimer’s Society, 2011a). Sometimes the onset of dementia can be as early as 30. For people with Down’s syndrome there could be a genetic aspect to the dementia, which comes from their extra chromosome. For people with other intellectual disabilities the figure for dementia is still very high – 22 per cent of them have dementia at the age of 65 or over (Alzheimer’s Society, 2011a). The issue has become increasingly important, as medical advances mean more people are living longer in the UK.

#### **1.7.5 Seeking help**

The police are the main search agency for missing persons. There is evidence from the National Policing Improvement Agency (NPIA) that people with intellectual disabilities may find it hard to talk to the police. The reasons this document gives are as follows.

*“People with mental ill health or learning disabilities might find it difficult to approach the police for help because they do not know how to complain, are afraid they will not be believed or will be perceived to be a nuisance, have difficulty in communicating, have low self esteem, are unaware of their rights or are afraid of having to cope with a stressful environment or situation. In cases of abuse it may be because they are dependent on the person who is abusing them”* (NPIA 2010:31)

The document gives no examples to back up this statement but even if partially true, it has strong implications for people with intellectual disabilities who remain missing. A person with intellectual disabilities could leave home because of a crisis or get lost within the community, and not approach the police or others for help for the reasons given above. It can also be detrimental if a person with intellectual disabilities wants to report someone missing, or has seen someone they think is missing.

## 2. Methodology

For the information source, the researcher used Missing People’s internal database Hermes, which contains information of all the missing person cases worked on since April 1993. This database was not primarily designed as a research tool, but rather a case management tool. This means some information is missing from it and this had implications for what research can be done. For instance, it was impossible to collect information on ethnicity and nationality of the missing people because of all the gaps in the records. It would be too resource intensive to examine every case in Hermes to identify intellectual disability. The samples used were as follows.

- (1) Cases opened in the third quarter of the years 2005-2010 (i.e. from October to December)
- (2) Cases opened in the financial year 2009-2010
- (3) All open cases open when the sample was drawn (20<sup>th</sup> May 2010)

**Table 1: The proportion of cases where the person had an intellectual disability, all samples**

Sample	Number of cases	Number of cases where the person had an intellectual disability	Percentage of cases where the person has an intellectual disability
Cases opened in the third quarter of the years 2005-10	1,763	61	3.5%
Cases opened in the financial year 2009-10	725	34	4.7%
Open cases on 22 <sup>nd</sup> May 2010	722	11	1.5%

These samples overlapped. A case, for example, could appear in both the third quarter for cases from 2005 to 2010 and in the financial year 2009 to 2010. This means the total number of intellectual disability cases will be less than the sum of the “Total number of Intellectual Disability cases” column.

After cancelling all duplicate records, the total number of cases in this study with intellectual disabilities was 104.



Estimates of the number of people with intellectual disabilities in the UK population vary. The British Institute of Learning Disabilities (2011) estimates that the number of people with intellectual disabilities is two per cent of the population. In comparison, five per cent of cases in the most recent sample (2009-10) involved a person with an intellectual disability.

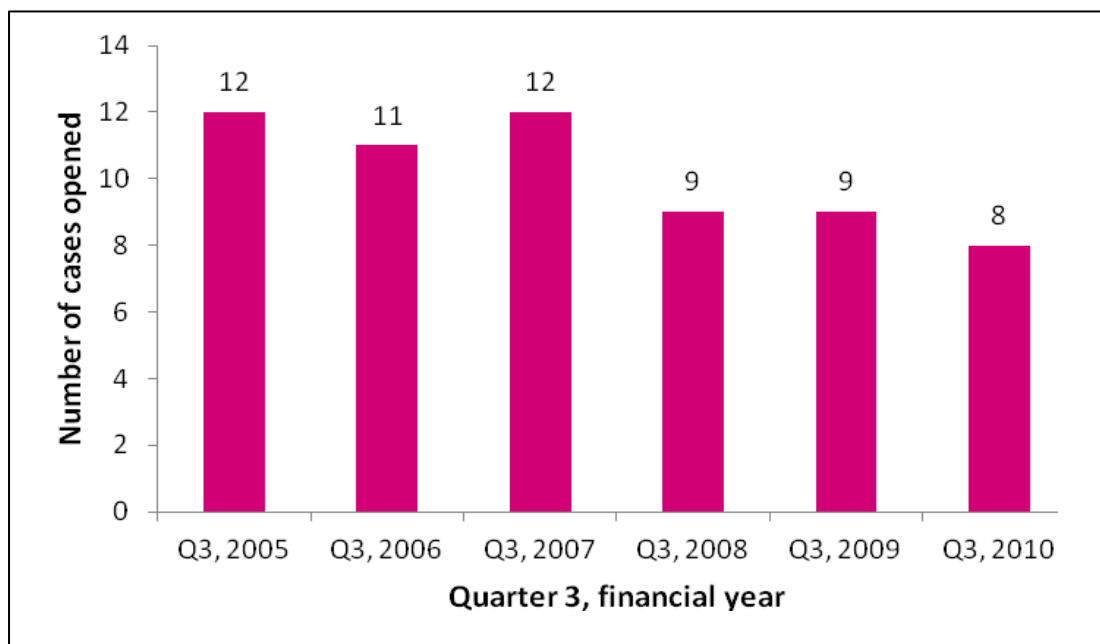
This research can never be completely accurate, as the database does not always note when a missing person has an intellectual disability. The absence of this information can be for several reasons such as families providing the details may not have considered it relevant. Also, the person themselves may not think it relevant and/or may have not made it known. A person may also have an undiagnosed intellectual disability.

Various characteristics of the missing people with intellectual disabilities were calculated using different samples. For discovering possible historical trends the 2005-2010 sample was used. For obtaining the most up-to-date information about age and gender, the 2009-2010 sample was used. The researcher also used the 104 cases of missing people with an intellectual disability as a sample. Sometimes the researcher excluded the open cases from here (thus leaving 77 cases).

### 3. Findings

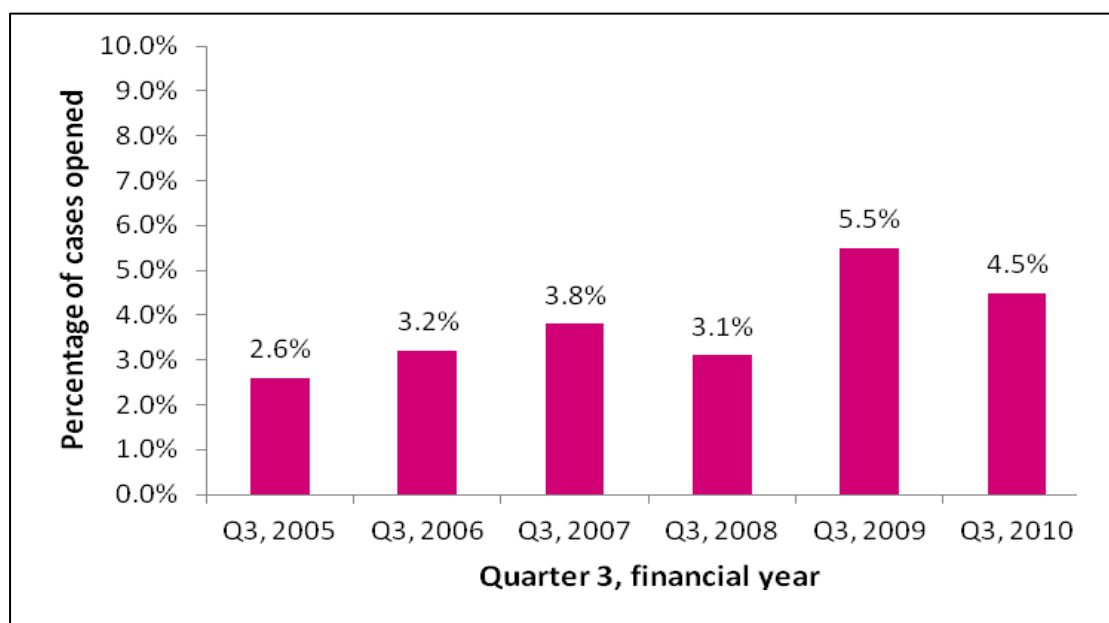
#### 3.1. The number of cases opened

Figure 1 below shows the number of cases involving people with intellectual disabilities that the charity Missing People has investigated.



There was an increase in the percentage of the people with intellectual disabilities going missing during the years 2005-9 (with the exception of the year 2008) after which it declined slightly.

**Figure 2: The percentage of cases opened by the charity Missing People in the third quarters of financial years 2005-06 to 2009-10 in which an intellectual disability was indicated**



### 3.2. Demographic trends<sup>1</sup>

#### Sex

The Missing Persons Bureau has found that 52 per cent of missing adults are male and 48 per cent female compared to the general population, where 49 per cent are male and 51 per cent female (Missing Persons Bureau, 2011:11). In contrast to this, the 34 cases with intellectual disabilities in the 2009-10 financial year had far more men than women. Twenty-five (74 per cent) were male and only nine (26 per cent) were female.

#### Age

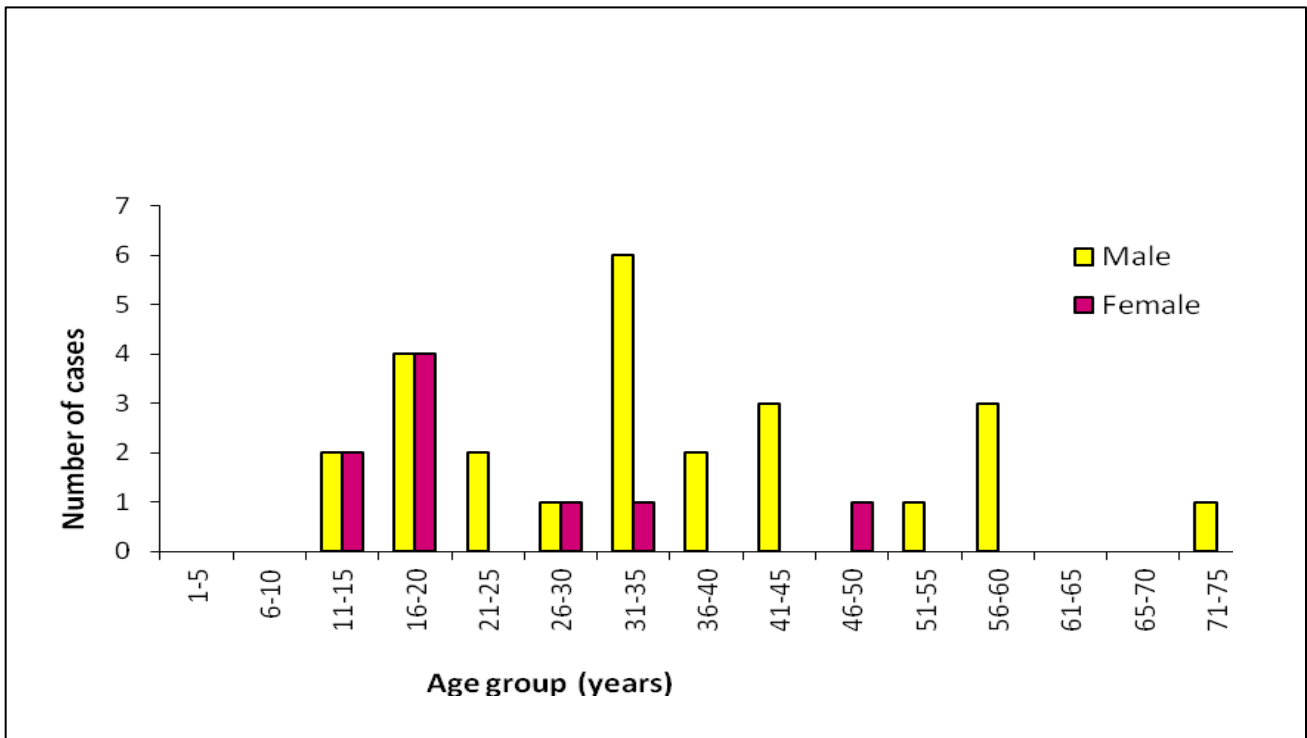
Like non-intellectual disability cases, there were many 'missing' cases involving teens with intellectual disabilities. However, the pattern for young people with intellectual disabilities is slightly different to those without. The peak age group for going missing for people with learning disabilities is older: 16-20 instead of 11-15. There was another peak age for people with learning disabilities: 21 per cent of the people with learning disabilities who went missing were aged 31-35 age group, compared to just seven per cent of those missing people without a learning disability.

#### Age and sex

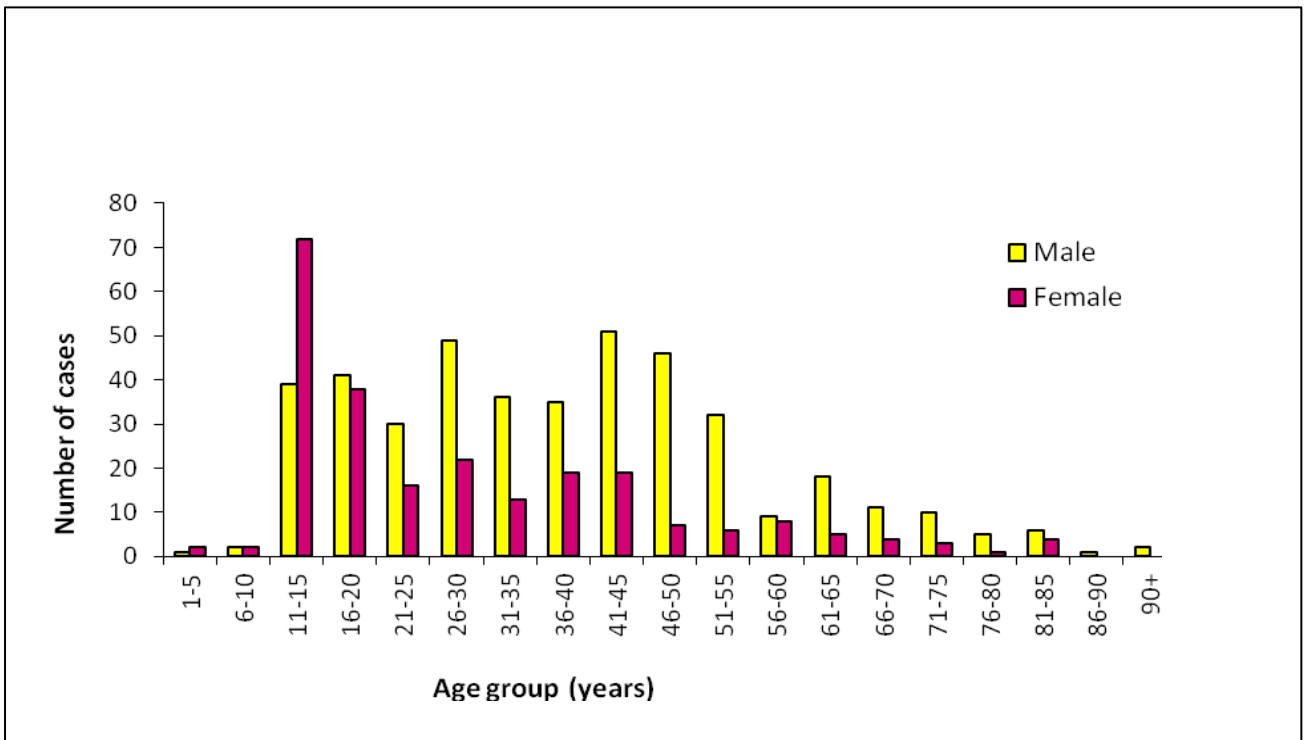
Age by itself disguised some important gender-specific trends in the results. Female missing people were concentrated in the younger age groups, while over the age of 20 years there were more male than female missing people.

<sup>1</sup> The cases opened in the financial year 2009-10

**Figure 3: The age and sex of missing people with intellectual disabilities in cases opened in the financial year 2009-10**



**Figure 4: The age and sex of missing people without intellectual disabilities in cases opened in the financial year 2009-10**



### 3.3. The duration of closed cases<sup>2</sup>

**Table 2: The time taken for missing person cases to be closed, where an intellectual disability was indicated.**

Duration	Number	Percentage*	Cumulative percentage*
Up to 24 hours	8	10.4%	10.4%
25-48 hours	15	19.5%	29.9%
49 hours to 1 week	18	23.4%	53.3%
1 week to 1 month	23	29.9%	83.2%
1 month to 2 months	5	6.5%	89.7%
Longer	8	10.4%	100.1%
Total	77	100.1%	

\* Column does not sum to 100% because of rounding.

The calculations for the table above used only cases where there had been a definite outcome (ie they were closed, not open). Missing people can be found by the police, relatives, the charity Missing People and other interested parties or any combination of the above. Some people within this sample turned up of their own accord. 53 per cent of the people were found within one week and 83 per cent within a month. Only 10 per cent took longer than two months.

**Table 3: The time taken for missing person cases to be closed, where an intellectual disability was indicated, by sex.**

Duration	Male (number)	Male (percentage)	Male (cumulative percentage)	Female (number)	Female (percentage)	Female (cumulative percentage)
Up to 24 hours	4	8.0%	8.0%	4	14.8%	14.8%
25-48 hours	9	18.0%	26.0%	6	22.2%	37.0%
49 hours – 1 week	12	24.0%	50.0%	5	18.5%	55.5%
1 week – 1 month	15	30.0%	80.0%	8	29.6%	85.1%
1 month – 2 months	4	8.0%	88.0%	2	7.4%	92.5%
Longer	6	12.0%	100.0%	2	7.4%	100.0%
Total	50	100.0%		27	100.0%	

<sup>2</sup> The 104 Intellectual disability cases minus the 27 Open and Open Review Cases equals 77 cases

Dividing the cases by sex reveals that cases involving girls and women tended to be resolved more quickly than cases involving boys and men. This is most apparent with the people who were found within 48 hours: 37 per cent of found women and girls were found in this time scale, compared to just 26 per cent of found men and boys. For cases solved within a week, the percentages begin to get closer with 50 per cent of males being found by this time, and 56 per cent of females. Twelve per cent of male cases took longer than two months to close but only seven per cent of female cases took this long.

### **3.4. Other characteristics for the cases of people with intellectual disabilities**

#### **3.4.1. Accommodation<sup>3</sup>**

The largest group of cases involved people who went missing from their family home (40 cases or 39 per cent). Women were more likely to have gone missing from this type of accommodation than men (50 per cent compared to 33 per cent). The second largest group involved those who had gone missing from a hostel or a residential care home. The overall total was 28 (or 27 per cent). There was no difference between the percentage of men going missing from here and the percentage of women. The number of people missing from their own home was only 10 (or 10 per cent) with the female and male cases once again being roughly equal. Six of the cases were also missing from hospital.

#### **3.4.2. Risk assessment and vulnerability**

A risk assessment of high, medium or low was already in the database used for this research. In addition to this, those writing the case notes sometimes used the term "vulnerable" in the text.

Thirty-six of the cases (35 per cent) were high risk missing people. There were 23 medium risk cases (22 per cent) and 45 low risk cases (43 per cent).

These categories were often at odds with cases which were recorded as vulnerable. 28 per cent of the high-risk cases had been written up as vulnerable and yet, for the low risk cases, the total was slightly more (29 per cent).

There were thirteen low risk cases that had been noted as vulnerable. Six out of the thirteen involved people with mental ages significantly lower than their biological age. In addition to this, three of the cases were written up as being easily led or very easily led.

Female missing people were more likely to be considered as vulnerable. Eleven out of 32 of these cases (34 per cent) were noted as being vulnerable. The percentage of male missing people believed to be vulnerable was not so great (17 out of seventy-two or 24 per cent).

Females were also likely to have a high risk assessment. Fourteen out of thirty-two female cases (44 per cent of all female cases) had high-risk status. The percentage of male cases categorised as high risk was 31 per cent.

---

<sup>3</sup> Based on analysis of all 104 cases where an Intellectual Disability was indicated.

### **3.4.3. Previous missing incidents**

Thirty-five (34 per cent) of people involved in the cases had been missing before. In the charity's sample, men were more likely than women to have been missing before (38 per cent compared to 25 per cent). The percentage for people with intellectual disabilities going missing was slightly higher than it was in *Lost From View* (Biehal et al.2003:13) where 28 per cent of their sample had been missing more than once.

### **3.4.4. Mental health**

The number of cases that had noted mental health issues in the study was 30 (or 29 per cent). This included people who had combinations of mental health issues or a mixture of mental health and physical health issues. It should be noted that this is based on cases where a mental health problem was reported by family, carers or the police. It does not suggest that a formal diagnosis has been made. There may also be under-reporting in the sample.

The most common form of mental illness in the cases was depression. There were sixteen cases where this was directly mentioned (15 per cent of the total.) The percentages for women and men experiencing it were roughly equal. This is slightly lower than cases involving depression in the general survey *Lost From View* where 22 per cent of the cases reported this condition (2003:11). The section on mental health problems earlier in this paper has discussed how some authorities have concluded that people with intellectual disabilities are more prone to mental illness. This in itself does not mean that people with intellectual disabilities who go missing are more likely to be clinically depressed. It could also be possible that people with intellectual disabilities are less likely to be labelled as depressed, because of the emphasis on the intellectual disability. Indeed symptoms of depression can be confused with characteristics of having an intellectual disability.

There were other cases labelled "general mental health Issues." These cases involved people with mental health problems where the nature of these problems remained undefined. There were overall eleven of these cases (11 per cent), the vast majority of which involved males (nine or 13 per cent of all male cases). Only two cases involved females (six per cent of all female cases). Some of the other mental illnesses that appeared in the case notes were schizophrenia (five cases or five per cent) and eating disorders (four cases or four per cent). Only three cases (three per cent of the total) involved people known to be suicidal.

### **3.4.5. Physical health issues**

There were ten examples of physical health issues. This was ten per cent of all cases. This issue could be anything from having cancer to having a heart condition. There were also ten examples of people having a physical disability (for instance having a bad back or finding it difficult to walk).

### **3.4.6. Medication issues**

There were also at least ten examples of people with intellectual disabilities going missing without their correct medication. The percentage of male cases where this was true was nearly the same as the percentage of female cases. The medication could be for physical and/or mental health problems.

### **3.4.7. Addiction**

In ten cases it was noted that the missing person with intellectual disabilities had an addiction. This could be with alcohol or with any other non-prescribed drug. These cases split evenly between male and female. Seven per cent of all males had addiction problems and 16 per cent of all females.

### **3.4.8. Being understood**

Fourteen cases (13.4 per cent of the total) involved people who definitely had language and communication problems. Twelve of the cases were male (making up 17 per cent of all the male cases) and only two were female (making up only six per cent of all female cases).

### **3.4.9. Behavioural problems**

Those writing case notes sometimes used the term “behavioural problems” when describing a case involving intellectual disabilities. In addition to this, the researcher also labelled cases where there was a history of violence as having behavioural problems. The issue of behavioural problems is often given the title of “challenging behaviour”. The definition of “challenging behaviour” that this report will use comes from the 2007 report ‘*Challenging Behaviour: A unified approach*’ by the Royal College of Psychiatrists (RCPsych), British Psychological Society (BPS) and Royal College of Speech and Language Therapists (RCSLT). They define it as follows:

*Behaviour can be described as challenging when it is of such intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.*

(RCPsych, BPS and RCSLT, 2007:10)

There were 18 (17 per cent) examples of cases where the missing people concerned had behavioural problems or challenging behaviour. Eight of these were men (11 per cent of the total male cases) and ten were women (31 per cent of the total female cases).

### **3.4.10. Problems with the law including prison and stealing**

Ten (ten per cent) of the people with intellectual disabilities had been in trouble with the law. This could be any combination of having a negative relationship with the police, having been to prison, or having stolen items. Nine of these cases were men and only one was a woman.

### **3.4.11. Homelessness**

The case notes mention twenty-one missing people with intellectual disabilities (20 per cent of the 104 cases) as having or potentially having a homeless lifestyle whilst missing or on a previous missing episode. Eighteen of these cases involved males and only three involved females. There were 11 cases overall where the person both had homeless issues and had been missing before. This covers 52 per cent of all homeless cases. Of these eleven cases, nine involved male and only two involved females. The age range varied from 19 to 50 with the average (mean) being 32.

### **3.4.12. Transport**

15 per cent of the missing person cases have a strong relationship with transport. The total number is 16 with a strong emphasis on men (11 men and 5 women). There are examples of people being obsessed with public transport and riding around on it whilst neglecting to care for themselves. There are also examples of people who are knowledgeable about a certain transport route but something stops them from alighting in their usual place. They then get lost. There is a particular link between Autism and transport with five out of these sixteen cases involving strong transport issues. Four of these cases were male and only one female.

### **3.4.13. Strangers and the internet**

Twenty-three (22 per cent) of all cases demonstrated that the missing person was going to meet up with someone. The people they were meeting up with were dangerous or had the potential to be so. Eighteen were female. This was 56 per cent of all the female cases. When it comes to internet use once again more women were involved than men – seven women (22 per cent of the female total) and only two men (three per cent of the male total). Of all the 18 women involved in meeting people, Missing People had knowledge that six were extensive internet users. None of the five men involved with meeting people had (as far as we know) this relationship with the internet. The women who were going out to meet someone tended to be young. The oldest was 37 and the youngest 15. The (mean) average age was twenty.

There are questions over the relationship of this piece of evidence and the general trend for young people meeting up with others on line. There needs to be more research to understand this.

### **3.4.14. The end of the case<sup>4</sup>**

In 50 of the 77 cases that had a definite ending the police either found the missing person themselves or announced the finding. Only three out of 77 missing people said they wanted to go back to their old accommodation. Another five said they did not but for the rest it is not clear. Only three cases (three per cent of the total) involved people who were found deceased.

## **4. Recommendations**

### **4.1. Policy recommendations**

This is a list of proposals, drawn from the research discussed, that aim to make sure that missing people with intellectual disabilities, and their families and carers, receive the best possible service from all professional organizations that are concerned with their welfare:

- This research encourages the police and other relevant professionals to discuss a strategy for grading the risk for people with intellectual disabilities that go missing. There needs to be clearer criteria for describing a missing person as vulnerable. When a missing person is described as vulnerable, the case needs a medium or high-risk assessment.
- This research supports movements by the police: (1) To discover whether the person with intellectual disabilities has been missing before. (2) To discover the geography and other characteristics of any previous missing episode(s). (3) To share this information with other organisations where appropriate.
- This research would support policies in the police force to train police officers in how to support people with intellectual disabilities who have gone missing, or who are concerned about a missing person. It would be especially relevant if the person who had intellectual disabilities had communication problems. Here it would be useful if among the ranks of the police there were more who understood Makaton and sign language. To help improve general communication police could visit care homes for people with intellectual disabilities for informal meetings, to emphasize who they are and that they are there to help. Questions could follow.

---

<sup>4</sup> The 104 Intellectual Disability cases minus the open cases, leaving 77 cases



- This research indicates that Missing People might explore, with transport authorities, the best ways to support people with intellectual disabilities who get lost on transport systems. These could be local transport systems or inter city services. This research could support identity cards for people with intellectual disabilities who find it hard to express themselves and could possibly get lost. This research might also support transport lessons for people with intellectual disabilities that go beyond just showing them how to do one route. That way, wherever possible, people with intellectual disabilities can solve their own transport problems.
- These conclusions would also support Missing People working jointly with CEOP and other internet charities/organizations to explore how best to help people with intellectual disabilities understand the dangers of the internet. The emphasis here might be on teaching people that they need to be careful when meeting anyone they get to know online.

#### **4.2. Further research**

The research discussed earlier in this paper is brief, but hopefully opens the way for further research that will inform Missing People and interested parties about people with intellectual disabilities going missing. There are four key areas that would benefit from further research:

- **Personal**

Further research should consider the patterns of age, sex and ethnicity amongst missing people with intellectual disabilities, in comparison to all missing people. In particular, it would be helpful to know whether there are any differences in the patterns, and what might cause any differences.

- **Health and care**

This study has indicated that there may be connections between dementia and going missing, and mental wellbeing and going missing, among people with intellectual disabilities. Further research could explore whether there are any special circumstances for people with intellectual disabilities that may affect their likelihood of going missing, or their experiences while missing. Further research could also seek to identify any patterns through which people with intellectual disabilities go missing and are found, in order to inform care and search strategies.

- **Social**

This study has highlighted some particular social issues that need further examination. In particular, issues surrounding people with intellectual disabilities using public transport and the internet, and potential connections to their likelihood of going missing, or experiences while missing. Other relevant social issues include homelessness and accommodation, gambling, substance use, bullying and abuse. It would be important for further research to explore whether these social issues might cause a person with intellectual disabilities to go missing, or to be more vulnerable while missing.

- **Returning home, and repeat missing incidents**

Further research might explore whether people with intellectual disabilities face any distinct experiences when found, and whether they are any more likely to go missing on a subsequent occasion than people without intellectual disabilities. Increased understanding of any patterns would inform response, support and prevention strategies.

## 5. References

- ACPO (2010) *Guidance on the management and recording and investigations of missing persons* (2<sup>nd</sup> Edition) (London: National Policing Improvement Agency on behalf of the Association of Chief Police Officers).
- [http://www.acpo.police.uk/documents/crime/2011/20110301%20Management\\_Recording%20and%20Investigation%20of%20Missing%20Persons%202010\\_2nd%20Edition.pdf](http://www.acpo.police.uk/documents/crime/2011/20110301%20Management_Recording%20and%20Investigation%20of%20Missing%20Persons%202010_2nd%20Edition.pdf)
- ADHD Training and Support for Clinicians (2011) *Introduction to ADHD in children and adolescents* (online). Available at [www.adhdtraining.co.uk/about.php](http://www.adhdtraining.co.uk/about.php) (accessed February 2011).
- Alzheimer's Society (2011a) *Fact Sheet 430: Learning disabilities and dementia* (online). Available at [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=103](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=103) (accessed February 2011).
- Alzheimer's Society (2011b) *Fact Sheet 501: Walking and moving about* (online). Available at [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=152](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=152) (accessed February 2011).
- Biehal, N., Mitchell, F. & Wade, J. (2003) *Lost From View: Missing Persons in the UK*. Bristol: The Policy Press.
- Cunningham, C. (2006) *Down Syndrome: An Introduction for Parents and Carers* (3rd Edition). (London: Souvenir Press)
- Dennis, J & Marder, L. (2006) *Thyroid disorders among people with Down's syndrome: Notes for parents and carers* (London: Down's Syndrome Association)
- Department of Health (2001) *Valuing People a new strategy for learning disability for the 21<sup>st</sup> Century* (London: The Stationery Office)
- Doody (2001) *Mental Health Services for people with learning disabilities People with co-morbidity can fall between two stools* BMJ. 2001 February 3; 322(7281): 301.
- Gillen, S. (2006) *Special Investigation: How the police are letting down people with Learning Disabilities* (online) Available at <http://www.communitycare.co.uk/Articles/13/10/2005/51232/Special-Investigation-How-police-are-letting-down-people-with-learning.htm> (accessed February 2011)
- Giraud-Saunders, A. (2011) *Mental health in people with intellectual disabilities* (online) Available at [http://www.mentalhealth.org.uk/content/assets/PDF/policy-archive/Mental\\_health\\_in\\_people\\_with\\_learning\\_disabilities.pdf](http://www.mentalhealth.org.uk/content/assets/PDF/policy-archive/Mental_health_in_people_with_learning_disabilities.pdf) (accessed September 2011).
- Grampian Police (2007) *Missing Persons: Understanding Planning Responding*. (Aberdeen: Grampian Police).
- Hedges, C. (2002) *Missing you already – A guide to the investigation of missing persons* (London: Home Office).

Holland, K. (2011) *British Institute of Learning Disabilities Fact Sheet: Learning Disabilities* (Kidderminster: British Institute of Learning Disabilities).

Holmes, L. (2008) *Living in Limbo. The experiences of and impacts on the families of missing people* (London: Missing People).

Home Office Missing Persons Task Force (2010) *A report with recommendations for improving the multi-agency response to missing incidents* (London: Home Office).

House of Lords House of Commons (2008) *A Life like any other? Adults with learning disabilities seventh report of the session 2007-8 Volume 1* (London: The Stationery Office).

Housing Learning and Improvement Network (2009) *Valuing People Now and Housing for people with learning disabilities* (London: Housing Learning and Improving Network)

Learning Disability Coalition (2008) *Key Statistics: Funding of Social Care for People with Learning Disabilities* (online). Available at <http://www.learningdisabilitycoalition.org.uk/policyandstatistics.asp> (accessed February 2011).

Mencap (2007) *Bullying Wrecks Lives: the experiences of children and young people with a learning disability*. (London: Mencap) <http://www.mencap.org.uk/document.asp?id=164>

Mencap (2009) *Living in Fear (2<sup>nd</sup> edn.)*(London, Mencap)  
<http://www.mencap.org.uk/sites/default/files/documents/2009-10/Livinginfear.pdf>

Mencap (2001) *Behind Closed Doors: Preventing the sexual abuse of adults with a learning disability* (London: Mencap) [http://www.mencap.org.uk/sites/default/files/documents/2008-03/behind\\_closed\\_doors.pdf](http://www.mencap.org.uk/sites/default/files/documents/2008-03/behind_closed_doors.pdf)

Missing Persons Bureau (2011) *Missing Persons Data and Analysis 2009-10* (London: National Policing Improvement Agency)

National Health Service (2009) *Depression* (online). Available at <http://www.nhs.uk/Conditions/Depression/Pages/Introduction.aspx> (accessed February 2011).

Newiss, G. (2011) *Learning from Fatal Disappearances. A report by Missing People* (London: Missing People).

Newiss, G. (1999) *Missing Presumed...? The police response to missing persons Police Research Series Paper 114* (London: Home Office).

NPIA and Department of Health (2010) *Guidance on Responding to people with mental ill health and learning disabilities* (London: National Policing Improvement Agency)

PACT (2005) *Every Five Minutes: A review of the available data on Missing Children in the UK* (London: PACT)

Parliamentary Office of Science and Technology (2004) *Postnote Number 226: Dyslexia and Dyscalculia* (London: The Parliamentary Office of Science and Technology)

Prasher, V.P. & Routhi, S.K. (2003) 'Psychiatric Morbidity in Adults with Down's Syndrome' in *Psychiatry*, Volume 2:8.

Rees, G. & Lee, J. (2005) *Still Running 2: Findings from the second national survey of young runaways* (London: The Children's Society).

Rees, G. (2011) *Still Running 3: Early findings from our third national survey of young runaways* (London: The Children's Society)

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging Behaviour: A unified approach* (London: Royal College of Psychiatrists).

Safe on the Streets Research Team (1999) *Still Running – Children on the Streets in the UK*. (London: The Children's Society).

See Me (2011) *Schizophrenia* (online). Available at <http://www.seemescotland.org.uk/findoutmore/aboutmentalhealthproblemsandstigma/schizophrenia> (accessed February 2011)

The Foundation for People with Learning Disabilities (2005) *Making us count. Identifying and Improving mental health support for people with learning disabilities*. (London: The Mental Health Foundation).

Understanding Individual Needs (2011) *People with learning disabilities: Ageing and dementia* (online). Available at [http://www.understandingindividualneeds.com/page.php?identity=ageing\\_and\\_dementia](http://www.understandingindividualneeds.com/page.php?identity=ageing_and_dementia) (accessed March 2011)

Understanding Individual Needs (2011) *Care & Support Services - Understanding Health: Health and Wellbeing* (online). Available at [http://www.understandingindividualneeds.com/page.php?identity=health\\_and\\_wellbeing](http://www.understandingindividualneeds.com/page.php?identity=health_and_wellbeing) (accessed March 2011)

World Health Organisation (2011) *Definition: intellectual disability* (online). Available at <http://www.euro.who.int/en/what-we-do/health-topics/diseases-and-conditions/mental-health/news2/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability> (accessed January 2011).

## Report author

Richard Rickford, Research Assistant

2012