

## What services are useful for patients with intellectual disability?

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## What services are useful for patients with intellectual disability?

It is well-known that people with intellectual disabilities often face a host of health inequalities and co-morbidities. These include childhood obesity, mental health problems, and challenging behaviour. People with intellectual disabilities also have reduced life expectancy. GPs are uniquely placed to advocate for and signpost these patients, ensuring they have access to appropriate support. Yet it is often unclear what resources are, in reality, both available and beneficial. Here we aim to summarise some of the common inequalities and complexities when working with patients with ID and provide an overview of some potentially helpful services.

### **The RCGP curriculum and services for people with intellectual disability**

The role of the GP in the neurodevelopmental disorders, intellectual and social disability clinical topic guide is to:

- Identify, monitor and review all patients who have difficulties with communication, social relationships and managing their own affairs; this may require additional skills in diagnosis, examination and consultation, and an understanding of legislation and guidance on mental capacity
- Carry out annual health checks for people with intellectual disability
- Signpost patients and their families or carers to appropriate resources, knowing when and where to seek specialist help
- Advocate for people with intellectual and social disabilities; promote fairness and equity in the community, including equal access to health care.

The RCGP curriculum outlines knowledge and skills topics that may be relevant for GPs working with patients with intellectual disabilities. This paper will address the topics listed below:

- Diagnostic features and genetic causes of intellectual disability
- Common associated physical health disorders and mental health problems
- Annual health checks
- Secondary care and specialist services

### **Terminology**

Since the inception of psychiatric nosology, various terms have been used to describe conditions affecting cognitive and adaptive functioning. Some of these are now considered at best outdated and at worst stigmatising. Throughout this article, we will use the initialism (ID) to refer to “intellectual disabilities”, reflecting the language used in RCGP curriculum. In the UK and elsewhere many specialist services and indeed patients and families use the term “learning disability”. Despite sounding similar, there is a firm distinction between “learning disabilities” and “learning difficulties”, the latter being an umbrella term used to describe the broad spectrum of conditions which impact a specific area of learning such as literacy (dyslexia) rather than cognitive development or “intellect” and adaptive functioning as a whole.

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3 Understanding this distinction may be challenging for patients, families, and professionals  
4 alike. Therefore, it is important that GPs have a strong grasp of each group when making  
5 referral decisions.  
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## 8 **Definition, aetiology and prevalence of ID**

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10 Intellectual disability (ID) is a neurodevelopmental condition which begins in the  
11 developmental period and is characterised by atypical cognitive development and differences  
12 in conceptual, social or practical adaptive functioning which are two or more standard  
13 deviations below the population mean (World Health Organisation, 2019). In the UK, the legal  
14 definition of disability comes from the Equality Act (2010), wherein differences in adaptive  
15 functioning are considered a core feature of disability. For ID specifically, the General Medical  
16 Services (GMS) contract Quality and Outcomes Framework (QOF; 2019) describe ID by three  
17 criteria: an intelligence quotient (IQ) of less than 70, impairments in social or adaptive  
18 functioning, and onset in childhood. Yet it is important to note that the range and severity of  
19 cognitive and functional differences are diverse. In an attempt to describe this diversity,  
20 psychiatric nosologies use terms such as “mild”, “moderate”, “severe” and “profound”. Most  
21 people (approx. 85%) with an ID fall under the categories of mild to moderate (Boat et al.,  
22 2015). Many of these patients are able to live independently though may require some  
23 additional support (e.g. when making health or legal decisions). People with severe ID, in  
24 contrast, may require greater support with tending to care needs and may need a flexible  
25 approach to communication. People in the “profound” category often require assistance with  
26 all aspects of care and might also have difficulties with symbolic communication and  
27 reasoning. However, it is essential that all decisions regarding support must be made on an  
28 individual basis rather than on the category of functioning, using appropriate approaches to  
29 allow the patient and their family to indicate preferences and make choices.  
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38 The aetiology is diverse, ranging from birth complications, prenatal substance exposure, brain  
39 injury and severe neglect, to genetic syndromes. It is estimated that in 60% of people with ID,  
40 the genetic aetiology can now be established (Vissers et al, 2017). Such genetic aetiologies  
41 include Trisomy 21 (Down’s Syndrome), paternal 15q11-q13 deletion (Prader-Willi  
42 syndrome), XXY (Klinefelter syndrome) and many others. Parents and patients might also  
43 benefit from support groups such as [www.rarechromo.org](http://www.rarechromo.org). Some syndromes associated with  
44 ID have specific patterns of cognitive and general abilities associated with them although show  
45 considerable individual variation among individuals (e.g. Mulder et al., 2017).  
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50 In England, it has been estimated that there are 1,087,100 people with ID (Public Health  
51 England, 2015). This figure stands in stark contrast with the number of people with ID on GP  
52 registers, which is approximately 252,446 (Public Health England, 2015). This equates to 4.4  
53 people with ID per 1,000 people registered with a GP (Public Health England, 2015).  
54 Speculating on the causes for these discrepancies, Public Health England (2015) suggests that  
55 one factor may be that people tend to use GP services sporadically. Yet this is cause for concern  
56 considering that free annual health checks are recommended for everyone over the age of 14  
57 with an ID (Public Health England, 2016). Another explanation offered by Public Health  
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3 England (2015) is that the majority of adults with ID are not known to ID services. In support  
4 of this claim, Public Health England cites national prevalence figures that show a marked  
5 difference between the numbers of children with ID in the education system (2.5%) and the  
6 number of people in their twenties known to services (around 0.6%). Such a distinct drop-off,  
7 it is reasoned by the national body, might be due to increased thresholds for entry to adult  
8 specialist health and social care services, or less obvious impairments in non-educational  
9 settings. Nevertheless, there are signs that things are moving in a positive direction. That is, the  
10 numbers of people with ID on GP registers been growing at a rate of around 5% per year. This  
11 is likely the result of non-aetiological factors such as more accurate recording-keeping. Still, it  
12 is consequential that many patients with an established ID may not have this marked in their  
13 health records or making use of potentially important or beneficial services.  
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## 20 **Health inequalities/multimorbidity**

### 21 *Overview*

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23 Previous work has established that people with ID and associated conditions often face a  
24 number of health inequalities across the lifespan relative to typically developing peers. Such  
25 disparities might include greater risk of respiratory problems (e.g. Chang et al., 2017) and a  
26 reduced life expectancy (Thornton, 2019). In an analysis of 1,424,378 primary healthcare  
27 records, Cooper and collaborators (2015) identified a number of physical health comorbidities  
28 which were more prevalent in people with ID relative to people without an ID. These included  
29 epilepsy (odds ratio = 31.03), constipation (odds ratio = 11.19), and visual impairment (odds  
30 ratio = 7.81). Yet it is important to note that the extent to which these outcomes will be  
31 expressed may be more or less linked to genetic aetiologies. That is, certain conditions (e.g.  
32 Prader-Willi Syndrome or Down's syndrome) might confer a particular risk of said co-  
33 morbidity (e.g. obesity).  
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40 Regarding mortality, in a review of the deaths of 247 people with intellectual disabilities,  
41 Heslop and colleagues (2014) reported that the median age of death for men and woman with  
42 ID is, respectively, 13 years and 20 years lower than that in the general population. Moreover,  
43 37% of these deaths were classified as "avoidable" through good quality healthcare. The  
44 percentage of avoidable deaths in the general population is approximately 13% (Heslop et al.,  
45 2014). Such alarming findings underscore the importance of annual health checks in this  
46 population. These checks are recommended for anyone aged 14 or older who has an established  
47 ID (Public Health England, 2016). Yet in 2017-2018 only just over half of patients with an ID  
48 received their annual health check (Thornton, 2019). The RCGP offers a step-by-step guide to  
49 conducting these checks (RCGP, n.d.). This guidance covers a range of topics relevant to both  
50 physical and mental health. Helpfully, this guide also offers a number of practical  
51 communication tips, which have been developed in conjunction with a patient with an ID. In a  
52 systematic review, Robertson and colleagues (2011) concluded that health checks are an  
53 effective method of recognising previously unidentified health problems in this population.  
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3 Health checks are thus an evidence-based and effective service that GPs can offer their patients  
4 with ID.  
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### 8 ***Mental health problems***

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10 Like anyone else, people with ID can experience psychiatric illness such as depression or  
11 anxiety disorders. Common symptoms of these conditions include feelings of low mood,  
12 isolation, or anxiety. In contrast, conditions such as autism spectrum disorder, attention deficit  
13 hyperactivity disorder, and indeed ID are lifelong developmental differences. Grasping this  
14 distinction is important for a number of reasons, not least because it helps practitioners  
15 understand the configuration of service pathways and decision-making in prescribing.  
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19 Due to methodological variation between studies, there is a range of reports of the co-morbidity  
20 of ID and mental health problems. Nevertheless, the available research strongly indicates that  
21 children with ID experience rates of mental health problems which are comparable to or higher  
22 than neurotypical peers (Einfeld et al., 2011). Similar findings also extend to adults and  
23 adolescents with ID, with recent meta-analytic evidence estimating 33% comorbidity (Mazza,  
24 Rossetti, Crespi, et al., 2019). Cooper and collaborators (2015) also describe specific co-  
25 occurring mental health conditions which people with ID experienced relative to people  
26 without an ID. These include schizophrenia (odds ratio = 7.16), anxiety or other stress disorders  
27 (odds ratio = 2.62) Dementia (odds ratio = 2.22), and depression (odds ratio = 1.88). Best  
28 practice guidelines thus recommend that a mental health review be completed as part of the  
29 patient's annual health check. (National Institute for Health and Care Excellence (NICE),  
30 2016). The markers of a potential psychiatric disorder in people with ID are very varied, and  
31 include loss of skills, social isolation, avoidance, challenging behaviour, or loss of interest in  
32 activities the individual previously enjoyed (NICE, 2016). It is important to note that autism  
33 and ADHD, without ID, are themselves associated with increased psychiatric comorbidity.  
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### 42 ***Challenging behaviour***

43 Challenging behaviour is also more common in people with ID (Emerson et al., 2010).  
44 Challenging behaviour is typically defined as “culturally abnormal behaviour(s) of such  
45 intensity, frequency or duration that the physical safety of the person or others is likely to be  
46 placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result  
47 in them being denied access to ordinary community facilities” (Emerson 1995, p. 4). Several  
48 lines of evidence suggest that antipsychotic/psychotropic medications are commonly  
49 prescribed for people with ID, even in cases where the patient does not have a psychiatric  
50 diagnosis (Lunsky et al., 2018). Furthermore, in their study of UK primary care practices,  
51 Sheehan and colleagues (2015) observed challenging behaviour is independently associated  
52 with psychotropic prescribing after controlling for recorded psychiatric diagnosis. There is thus  
53 strong evidence that antipsychotics are used to manage behaviour in primary care without  
54 psychiatric indication.  
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3 In response and as part of a wider national agenda to improve care for persons with an ID, the  
4 “stopping over medication of people with a learning disability, autism or both with  
5 psychotropic medicines (STOMP)” project was established (NHS England, n.d.). This project  
6 represents a collaboration between NHS England and other professional organisations  
7 including RCGP, The Royal College of Psychiatrists and The Royal Pharmaceutical Society.  
8 The core aims are as follows: a) promote regular check-ups about medication, b) ensure  
9 professionals involve patients and families in decision-making about medications c) inform all  
10 key stakeholders about alternative modes of intervention and responding to challenging  
11 behaviour (e.g. Positive Behavioural Support). It is therefore important that practitioners are  
12 aware of the various functions of challenging behaviours. That is, these behaviours very often  
13 serve a communicative or sensory function (National Institute for Health and Care Excellence,  
14 2015). Moreover, the behaviours may be contextual or environmentally specific. NICE (2015)  
15 thus recommends that antipsychotic medication should only be offered if a) psychological or  
16 behavioural interventions have not been effective, b) treatment of any comorbid condition  
17 (psychiatric or otherwise) has not reduced the behaviour, c) there is significant risk to the safety  
18 of the individual or others (p15). The guidance goes on to state that these medications should  
19 only be offered in conjunction with psychological or other interventions. Further guidance and  
20 information on prescribing in primary care can be found in the RCGP annual health checks  
21 guide.  
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### 30 ***Diagnostic overshadowing***

31 The now-popular clinical phrase “diagnostic overshadowing” has its provenance in early ID  
32 research. It is used to refer to situations where a symptom is misattributed to the patients' ID.  
33 This occurs throughout medicine but is particularly relevant in patients with ID when there is  
34 a well-documented and dangerous tendency for comorbidities such as constipation, epilepsy,  
35 infection are not sought as reasons for changes in behaviour. This can be fatal. Healthcare  
36 professionals thus have a moral ethical and professional responsibility to ensure that a patient's  
37 diagnosis of ID doesn't mean that they miss symptoms of underlying medical conditions. For  
38 instance, challenging behaviour in the form of head-banging might be how the individual  
39 expresses that they have a toothache, constipation, seizures, depression, sepsis or brain tumour.  
40 This is a significant contributor to avoidable death in people with ID (see Learning Disability  
41 Mortality Review 2019)  
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47 This can occur in the other direction, with ID not being sought because of other issues such as  
48 ASD or epilepsy. Therefore, GPs and other healthcare professionals also need to keep in mind  
49 that some patients with ID may reach adulthood without a diagnosis. Given the nature of the  
50 general practice, GPs are often well-placed to offer colleagues in other services a holistic view  
51 of the patient's physical and mental health. This level of insight can be operationalised to  
52 safeguard against possible diagnostic overshadowing in both primary care and specialist  
53 services.  
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### 57 **Service provision**

### ***Context***

In the 1970s, several clinical initiatives were established with the goal of deinstitutionalising of services for persons with mental health difficulties and or ID (Killaspy, 2007). Consequently, much of the responsibility for meeting the social and healthcare needs of such patients were gradually transferred to community-based teams. Often, however, community services were under-resourced and unable to respond to some of the specialist needs of this population. This contributed to many of these patients experiencing long stays in inpatient settings. In 2011, this issue came to the fore following the airing of the BBC Panorama documentary featuring Winterbourne View Hospital. This programme highlighted significant emotional and physical abuse committed by some staff against patients who had an ID. While the abuse was obviously abhorrent, it was also of great concern that patients with ID were spending long periods in inpatient units, rather than in the community. In response, the Department of Health (2012) developed the “Transforming care” plan wherein it pledged “all current placements will be reviewed by 1 June 2013, and everyone inappropriately in a hospital will move to community-based support as quickly as possible, and no later than 1 June 2014” (P9). Unfortunately, however, this target was missed (Bubb, 2014).

Ultimately and despite the abuse uncovered at Winterbourne View Hospital, public outrage and subsequent policies and programmes, the numbers of patients with ID in inpatients units in the UK has remained at a similar level. Health and social care services for people with ID are still not delivering appropriate and timely support to enable people to lead flourishing lives in their local communities. It is the responsibility of all stakeholders, including GPs to ensure that whenever possible the needs of these patients are met in community-based settings which promote opportunities for inclusion, choice, and autonomy in a supportive environment. Moreover, frontline healthcare professionals such as GPs may be able to advise patients and families about the services available locally. GPs are also uniquely placed, given professional expertise and authority, to advocate for these patients both individually and at policy level.

### ***“Reasonable adjustments”***

There are various ways in which adjustments can be made to help patients with ID access GP surgeries. Regarding physical impairments, there is a need for practices to be accessible by alternative modes of transport such as wheelchairs and scooters. In addition, in a context where some patients with ID may have accompanying sensory issues, some patients may benefit from access to a sensory space whilst waiting. Such spaces may have special lighting or tactile objects designed to meet the sensory needs of these patients. People with ID may also benefit from communication passports to help professionals make reasonable adjustments. Organisations such as Promoting a More Inclusive Society (PAMIS) have developed such resources (see table 1). Further, people with ID should be given information in a form and through a media which is accessible to them and in line with their cognitive ability. This might include co-producing videos or leaflets about common health procedures. While many services have such information on their websites, a report by Turner and Robinson (2011) states that this information is not routinely offered. Crucially, these adjustments may benefit a wider group of patients, For instance, better, accessible information, thoughtfulness and tools to help with communication would help young adults, other marginalised groups like asylum seekers,

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3 members of the travelling community, homeless people and ex-drug users, people with  
4 dementia or people for whom English is not a first language. Other adjustments include  
5 extending and prioritising appointments. Further, GPs and other frontline staff may encourage  
6 patients with ID to write down or otherwise communicate what adjustments would make it  
7 easier for them to use the service prior to their visit. This is particularly important because of  
8 differences in experiences and assessment of pain in this population. For further reading on  
9 pain assessment for people with ID see Doody and Bailey (2017). Additional examples of  
10 adjustments to practice can be found at the General Medical Council website: [www.gmc-uk.org/ethical-guidance/ethical-hub/learning-disabilities#learning-disabilities](http://www.gmc-uk.org/ethical-guidance/ethical-hub/learning-disabilities#learning-disabilities).  
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16 Recently, Dimensions (2018) conducted a survey of 252 GPs about their experiences caring  
17 for people with ID. The results indicated that 48% of GPs were unclear when to make a  
18 “reasonable adjustment” and 74% suggest that they would benefit from further training. This  
19 suggests some training on “reasonable adjustments” may be beneficial. The survey also showed  
20 that 64% of GPs surveyed had less than 1 day’s face-to-face training focused responding to the  
21 needs of patients with ID. And around 98% indicated that they would like more training. Such  
22 training is available through charities and advocacy groups such as Dimensions or British  
23 Institute of Learning Disability (BILD). For a useful and accessible report on making  
24 reasonable adjustments see Turner and Robinson (2011).  
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### 30 ***Services for people with ID across the lifespan***

31 When deciding which services may be beneficial for patients with ID, it is important to consider  
32 the nature of the ID (i.e. mild, moderate, severe, or profound) and the age of the patient.  
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35 Early intervention can be beneficial for some children with ID particularly in supporting carers  
36 and schools to understand and manage communication via behaviour, and in early  
37 identification and treatment of comorbidities. However, there is some geographical variation  
38 in the services that are available locally. Organisations such as the Early Intervention  
39 Foundation offer information regarding such services (see table 1 for details). Nevertheless, it  
40 is crucial that GPs understand the configuration of local ID services. For instance, some do not  
41 have a lower age limit but may only work with children up to the age of 18 with a moderate to  
42 a profound learning disability. Other community teams may work with any child with an ID  
43 (i.e. mild to profound) up to the age of 18 or 19. And some adult services may accept referrals  
44 from people 17 years and older with a learning disability or autism. Ensuring there is a  
45 continuity of service between child and adult services, is vital not only for patients with  
46 moderate to profound ID but also for patients with mild ID who may require support in  
47 activities of daily living as well as financial or legal decision-making.  
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53 Like anyone else, it is crucial that patients with ID have their wishes respected when it comes  
54 to their care, including end-of-life care. Groups such as the Marie Curie Foundation offer  
55 accessible guidance for professionals on a range of topics including communication of issues  
56 regarding end-of-life, supportive decision-making, and identifying distress. For further  
57 information see [www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/learning-disability](http://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/learning-disability).  
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### ***Working with carers and people with ID who attend independently***

It is important to consider that some patients with ID will attend appointments with carers, whereas others will attend independently. As described in The RCGP toolkit, carers can be valuable sources of information and can help practitioners restructure questions in a way that will be best understood by the patient. In addition, they can also help to confirm whether the information has been understood by the patient and suggest alternative modes of communication which the patient might prefer. Nevertheless, it is crucial that the patient is given the space and modes of communication to express their needs. And the carer should not answer for the patient when the patient is capable of expressing themselves. For patients with an ID who attend appointments without a carer, it is important that frontline professionals are mindful of when they had their last annual health check and allocate increased time to ensure that they are being understood and the patients have access to information in an accessible form. In this circumstance, it is particularly important that practitioners are proactive in offering and making reasonable adjustments.

Relatedly, issues around parenting and birth control might come to the fore when working with patients with ID. This raises a number of complicated moral and interdisciplinary issues regarding consent, patient autonomy, confidentiality, and attending to needs for support for both the parents as well as their children who may or may not also have ID. Such issues have been discussed elsewhere (e.g. Schuengel et al., 2017).

Despite being able to parent successfully, some mothers with ID report discrimination and not having their communication needs met during maternity consultations (Malouf et al., 2017). In addition to the material presented above, the Working Together with Parents Network also offers helpful resources that might be helpful when considering some of these issues - [www.bristol.ac.uk/sps/wtpn/forparents](http://www.bristol.ac.uk/sps/wtpn/forparents).

### ***Independent groups***

Independent charities and advocacy groups have done remarkable work pushing forward the disability rights agenda whilst offering specialist and important services to people with an ID. Such services include health and social care, housing, legal advice, employment, online chat forums, support groups, social activities and sports. Some of these groups are described in Table 1. This list is not exhaustive. Moreover, it is crucial to remember that, like anyone else, patients with ID can benefit from involvement in the suite of community activities, groups, and sports teams with people across the cognitive and behavioural spectrum.

[Insert Table 1 here]

## **CONCLUSION**

Responding to the health inequalities faced by patients with an ID is a complex task that requires a coordinated and multi-pronged approach involving policymakers, health care

professionals and clinically focused researchers. It is most important that patients and families are at the centre of decision-making about the services which are indeed “beneficial”. GPs have a key role in reducing some of these health inequalities and can offer important services such as the annual health checks. Further, it is crucial that health care professionals across the care pathway are mindful and aware of potential abuses and overmedication of patients in this vulnerable population. At an individual level, staff training may prove a useful supplement to wider policy changes and clinical initiatives.

#### Key Points

- It is important that patients with an ID have this recorded in their health record
- People with ID often face a host of health inequalities and co-morbidity is common
- The annual health check is an important and effective services which GPs can offer their patients with ID
- Challenging behaviour is a complex multidimensional phenomenon which often serves a communicative or sensory function
- People with ID will benefit from person-centred support offered through community whenever possible
- Diagnostic overshadowing can be fatal

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**Table 1: Independent groups**

<b>Organisation</b>	<b>Services</b>	<b>Link to website</b>
British Institute of Learning Disability (BILD)	Bild is a national charity who advocate for the rights of people with ID. They offer training courses for professionals and organisations.	<a href="http://www.bild.org.uk/about-bild/aboutbild">www.bild.org.uk/about-bild/aboutbild</a>
Dimensions	Dimensions are a national charity who provide a range of personalised services for people with ID and their families. These include supporting employment, responding to challenging behaviour and professional training.	<a href="http://www.dimensions-uk.org/what-we-do">www.dimensions-uk.org/what-we-do</a>
Early Intervention Foundation	Early Intervention Foundation is a charity who advocate for early interventions as a means to promote development	<a href="http://www.eif.org.uk/about/who-is-eif">www.eif.org.uk/about/who-is-eif</a>
Mencap	Mencap is often considered the flagship ID advocacy group in the UK. They offer a range of services including, social care, housing, employment, and an online support group.	<a href="http://www.mencap.org.uk/advice-and-support/services-you-can-count">www.mencap.org.uk/advice-and-support/services-you-can-count</a>
PAMIS	An organisation dedicated to offering training and support for people and families with complex and profound ID	<a href="http://pamis.org.uk/services/digital-passports">http://pamis.org.uk/services/digital-passports</a>