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## Press release

### Intellectual Disabilities

#### A collective expert review by Inserm

According to the World Health Organisation and other recognised authorities, intellectual disability (ID) refers to an intelligence deficit (significantly reduced ability to understand new or complex information and learning and applying new skills) as well as limitations in adaptive functioning<sup>1</sup>. These limitations appear during the developmental period. Intellectual disability is common and affects about 1 to 2% of the population. The recent knowledge explosion regarding the causes of ID, as well as the underlying cognitive and adaptive processes, provides a better insight into the ability of people with intellectual disabilities to functional and develops appropriate strategies for learning, care and support.

In this context, the National Solidarity Fund for Autonomy (CNSA) has commissioned Inserm to conduct a collective expert review to provide the latest scientific expertise from international and multidisciplinary research on intellectual disabilities. The collective expertise approach has enabled a review of scientific data in the following areas: definition and epidemiology; assessment of individual skills and deficiencies; as well as care and support during key stages in life.

A multidisciplinary group of 12 experts, researchers and clinicians was formed and accounts for the complementary nature of the represented scientific disciplines. Inserm has established a literary collection with 2,500 references that have been critically analysed by a group of experts.

Among the various expert findings, the assessment of skills and limitations of individuals with ID, as well as support requirements, often remain incomplete. Furthermore, among the recommendations from this study, authors advocate an in-depth review regarding the development of **resource centres for intellectual disability**. These structures would bring together needed expertise in the form of multidisciplinary teams (general physicians, paediatricians, geriatric specialists, pain specialists, neurologists, psychiatrists, psychologists, nurses, special needs teachers, speech therapists, social workers, etc.) to ensure a multidimensional assessment of the limitations and abilities of the individual's activity, assess his/her needs in order to organise the required support, and provide coordinated and practical assistance that could contribute to the life course of an individual with intellectual disabilities and his/her family.

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<sup>1</sup> The literature today recognises the definition of adaptive behaviour as a complex concept based on three concepts: conceptual adaptive skills (language, reading, mathematical concepts, time, etc.), social skills (interpersonal skills, social responsibility, etc.) and practical skills (daily activities, occupational skills, etc.).

## Intellectual Disabilities: Main Findings

**Mild intellectual disability may affect between 10 and 20 people in 1000 throughout France, or 1 to 2% of the population. Severe intellectual disability is found in 3 to 4 people in 1000.**

The prevalence of intellectual disability reaches a plateau at age 15, due to the time needed to identify it. All studies show a higher prevalence in boys than in girls. The socioeconomic background plays a role in mild intellectual disability (MID) with a lower prevalence of MID in more privileged socio-economic backgrounds. This factor is much less significant for the prevalence of severe intellectual disability (SID). Regarding risk factors, ID is most frequently observed in infants born prematurely and those with intrauterine growth restriction. Excessive alcohol consumption during pregnancy is the most common environmental cause.

**Identification is based on the detection of developmental delays in the general population and monitoring at-risk populations. Intellectual disabilities can be distinguished from a simple variation in ordinary development. Screening tools exist, but are still not widely used.**

Several tools are available in France. Several parental questionnaires and early development scales have been established by different teams. However, these screening instruments are still rarely used in paediatric practice and current general practice in France or abroad.

**Diagnosis is based on the dual assessment of intellectual ability and adaptive behaviour. It should be established based on data collected using recent and validated tools.**

The assessment of intellectual abilities is an essential step in the diagnosis of intellectual disability. It allows specific learning difficulties to be distinguished. The assessment of adaptive capacity is crucial. It reduces the risk of over-diagnosis. It is also useful for shaping assistance programmes for individuals.

**The origin of ID remains unclear in almost 40% of cases.**

The causes of intellectual disability may be linked to the environment (infection, alcohol-related intoxication, etc.) or are genetic in origin. However, idiopathic ID (no known cause) represents the largest group (35-40%). Genetic causes are the most common and varied among identified causes.

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Premature birth complications	5 %
Environmental causes	13 %
Chromosomal abnormalities	15 %
Metabolic diseases	8 %
Identifiable syndromes	2 %
ID linked to the X chromosome	10 %
Other known monogenic diseases	10 %
Idiopathic ID	35-40 %

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**Health issues are more common than in the general population, but are under-diagnosed and poorly treated.**

Healthcare requirements for people with ID are significantly higher than the general population. Certain common health issues (dental, impaired vision and hearing) occur more frequently, are less well cared for and less detected in people with ID. Among the most common illnesses in this population are high rates of coronary heart disease, epilepsy, sleep disorders, etc. Some cancers also occur more often in people with ID.

**However, the health of individuals with ID can be improved by taking a better account of disability, healthcare coordination and professional training.**

Various experiences in different countries clearly show the beneficial impact of routine medical check-ups for people with ID. Several governments (Australia, Great Britain) have taken measures to implement an annual health check by the treating physician with subsidised initiatives, or by primary healthcare centres. The coordination of a care path has been developed for other diseases in France (Alzheimer's disease, cancer, etc.), but not for people with ID.

**Early intervention and education that promote development**

Existing studies show that it is vital to strengthen a child's skills, to focus on his/her ability to act and be autonomous rather than his/her "shortcomings". Research in the field of learning has shown that people with ID can progress at any age; the performance level depends on intellectual ability and available opportunities. It is also important to strengthen the parenting skills so that parents may see their child as a developing child and not just as disabled child.

For example, language acquisition may be promoted through early and targeted intervention in children with ID. Interventions that promote preverbal communication are the subject of a growing number of clinical studies. The idea is that by increasing the frequency, readability and complexity of gesture-based interactions, such as coordinated gazing and vocalisation, the child will quickly learn to communicate verbally. Intervention methods focussing on verbal communication enhance the verbal environment of the child in turn, from both a quantitative and qualitative perspective. They also aim to increase the incentive to communicate.

**Inclusive education facilitating children and adolescents with ID must be based on defining individualised learning goals.**

The debates of the past decade on educating children with disabilities have focused on so-called "inclusive" education, i.e. mainstream schooling. International literature questions these guidelines by comparing the effects of special education *versus* those observed in inclusive education among groups of children with special needs, and sometimes with ID. Assessments and meta-analyses of studies mainly developed in the United States show contrasting results. Several surveys show that children with DI can benefit from inclusive situations, such as literacy or adaptive skills, provided that they are set out in an individualised programme with similar objectives to those of the class that are adapted to meet the learning pace. In any case, this is to avoid having a class within the class, but rather allow the student with ID to participate in all activities.

**The transition between education and access to employment are sensitive periods that require continued support.**

The transition to adulthood among young people with DI remains little known and poorly studied. Young adults with ID are frequently at a disadvantage by the restrictions imposed on them by their disability. Constraints, such as opportunities for social participation, are less common with a more limited social network with a bigger or longer focus on the family environment, restrictive environmental conditions (insufficiently adapted environments that are poorly accessible or where prejudice remains), an educational environment with a tendency to overprotect, as well as the presence of cognitive impairment and adaptive behaviour, increase the risk of social exclusion and/or reduced quality of life in adulthood. The path to individualisation, reinforcing one's own identity, becoming independent, building

a network of relationships outside the family and/or institutional environments, the development of professional skills, or participation in a training project or working life may be slowed down, prevented or complicated.

**Employment in a normal working environment is very difficult people with DI to access**

Statistics are inadequate for observing how workers and assets with DI are divided into different professional areas (protected or not protected). However, it is estimated that ESAT, work assistance establishments and services (e.g. occupational support centres), receive about 70% of people with ID. However, the ESAT need to be modernised in order to be more attentive to the training needs of those admitted and to enhance their autonomy for example. Many innovative experiments exist in this regard: bridges between specialist institutions and employment in an ordinary environment, recognition of people's skills ("different and competent"). They are a means of facilitating people's access to the right to work, provided that the attitudes and behaviour of partners involved in ordinary work environments change regarding people with DI.

**The prevention of situations of neglect, mistreatment and abuse involves a set of measures that are connected in a systemic approach.**

It is now clearly established that people with ID are particularly vulnerable to the phenomenon of child abuse, where they are up to four times more likely at risk than the general population.

The exposure of individuals with ID to bullying is also clearly established. Bullying affects all ages; however, it especially affects teenagers.

There are 3 types of recommended preventive measures: prevent the onset of abuse, decrease risk factors and increase protective factors that strengthen the capacity of the environment to identify warning signs and, finally, remove the victims from the abusive situation and help restore well-being and health. Abuse can profoundly affect people who are victims in different ways. At present, specific therapeutic programmes aimed at preventing or mitigating the psychological impact of abuse in people with ID are still rare.

# Intellectual Disabilities: Key Recommendations

## Recommendations for actions:

- **All actions are carried out as part of the international definition of intellectual disability**, whether through public policy, professional practice or research.
- **Better early identification of neurodevelopmental disorders** by promoting early detection in “ordinary” children and improving systematic screening for neurodevelopmental disorders during mandatory examinations.
- **Develop a multidimensional and personalised assessment for better diagnosis and appropriate support** by improving the assessment of intellectual abilities, supplementing it with adaptive behaviour assessment that assesses social and emotional capabilities as well as cognitive and language skills. Finally, enable access to genetic aetiology.
- **Develop the skills of the individual with ID throughout his/her life** by promoting the development of communication and language, the acquisition of numeracy and literacy, and the development of self-determination.
- **Support the individual throughout his/her life, from infancy to adulthood**, by promoting the right to early intervention and education, as well as access to common childcare services available to everyone. Support access to employment and social participation in adulthood and encourage transitions throughout life.
- **Improve access to care and the diagnosis of somatic diseases** through screening and regular monitoring of diseases often associated with DI by developing close medical follow-up and improving admission and healthcare conditions in hospitals and clinics .
- **Create “intellectual disability resource centres”**. These structures would bring multidisciplinary teams together to provide coordinated and practical assistance that could contribute to the life course an individual with intellectual disabilities and his/her family.
- **Provide appropriate and adjustable graduated support to families** by developing their own skills through adequate support at the time of diagnosis and by considering the psychological detachment between the individual with DI and his/her family during the onset of adulthood.
- **Develop and promote training on intellectual disability for all professionals with an inclusive approach.**

## Research recommendations:

- **Validate and develop diagnostic tools and individual assessment.**
- **Learn about intellectual disabilities and trajectories of individuals.**
- **Better understand the development of skills in individuals with DI.**
- **Better understand the different aspects of adapted support.**

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