

## DIAGNOSTIC EVALUATION PROCEDURE OF FONDATION AUTISME LUXEMBOURG (FAL)<sup>1</sup>

The Fondation Autisme Luxembourg (FAL) makes every effort, as a reference centre specialised in autism, to offer a quality diagnostic evaluation procedure, in accordance with international scientific recommendations.

This procedure has four goals:

- ✓ To define whether or not the person being evaluated presents an autism spectrum disorder 2 (ASD) ;
- ✓ To perform a medical assessment and a competency assessment (if required);
- ✓ To provide practical information on ASDs;
- ✓ Referring the individual to the appropriate care and follow-up services for his or her needs, at the FAL or elsewhere, by proposing concrete and individualized educational paths and helping parents to implement them.

Diagnostic assessments are offered in Luxembourgish, French, German and English and are accessible to all ages. Anyone interested is invited to contact the secretariat of the "Service Evaluation Diagnostique" (Tel 26.91.11-1 or [autisme@fal.lu](mailto:autisme@fal.lu)) for more information on the conditions of access to this service.

Each procedure is treated by at least two FAL psychologists, in collaboration with Dr. Jacques Bernard (doctor specialising in child psychiatry, qualified psychotherapist, consultations for children, adolescents and young adults) in order to guarantee the objectivity of the diagnostic opinion issued.

The main tools used are :

- The ADI-R: "Autism Diagnostic Interview-Revised": Interview for the Diagnosis of Autism, revised version
- The ADOS-2: "Autism Diagnostic Observation Schedule - Second edition": Autism Diagnostic Observation Scale, Second Edition
- The DSM-V: "Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition": Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

These are assessment tools specific to the diagnosis of autism that are used in international reference centres to diagnose autism. Other tools may be used in addition if deemed necessary.

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### <sup>i</sup> FOOTNOTE:

1 This procedure reflects as closely as possible the conduct of a diagnostic assessment as proposed by the FAL. However, we reserve the right to make the necessary adaptations during implementation, in particular, if international scientific recommendations or the framework set by our agreement with MIFA should change.

2 The term "Autism Spectrum Disorder" (ASD) has been used since the publication of the DSM V (Diagnostic and Statistical

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Manual of Mental Disorders, 2013) and is to be understood as equivalent to and encompassing the terms "autism", "pervasive developmental disorder" and "Asperger's syndrome" referenced in the previous version of the manual (DSM IV-TR, 2000). The terms "autism" and "ASD" are used interchangeably in this document for the sake of readability.

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Several steps are necessary for a successful diagnostic assessment:

## 1. FIRST CONTACT AND WRITTEN REQUEST

When a request for a diagnostic evaluation is sent to the FAL, it is processed by the "Diagnostic Evaluation, Support and Training" service. The person to be assessed is **directly placed on the waiting list** on a provisional basis and the family / the person him / herself / the guardian is **informed of the progress of the assessment procedure, the financial coverage of the cost and the estimated waiting time** before the assessment begins.

An **initial meeting** with a psychologist from the service is arranged within one to two months of the application. This meeting provides an initial contact with the person to be evaluated and/or, if applicable, his or her parents, family or guardian, in order to discuss the reasons and goals of the diagnostic evaluation, to explain the various steps required for the diagnostic evaluation and to answer the first questions of the persons concerned.

An **SCQ** screening questionnaire (Social Communication Questionnaire, Rutter, Bailey & Lord, 2003) is also completed jointly with the psychologist during this meeting. This questionnaire makes it possible to identify and screen for symptoms associated with autism spectrum disorders and provides a basis for discussion during the initial exchanges.

Various **documents to be sent back to the FAL, completed and signed**, are also given at this first meeting:

- An **official written request** form
- An **anamnesis**
- An "**Authorisation for the transmission of information and reports to the FAL**" form, allowing FAL professionals to request the various reports (medical, psychological, school reports, etc.), if any, from the professionals who have taken or are still taking care of the person to be assessed. If approved by the family / person / guardian, this authorisation is also to be returned to FAL completed and signed.

**The request for assessment and the authorization must be signed by the person him / herself, or his / her legal representative if applicable (parents or guardian).** If this is not the case, no intervention can be carried out. The person himself / herself, his / her family or guardian takes as much time as he / she wishes to decide whether he / she wants to begin this diagnostic evaluation procedure or not.

As soon as FAL receives the various above-mentioned signed documents, the person is definitely placed on the waiting list and a **confirmation letter / email** is sent to the family / person / guardian, in which the **waiting period** before the assessment begins is specified.

At the same time, the family / person being assessed or his / her guardian **is asked to send to FAL the existing psycho-educational and medical reports** received from professionals (doctors, psychiatrists, psychologists, psychomotor therapists, speech therapists, etc.) who have followed up the person being assessed. The family is advised to request reports that are not in their possession from the professionals concerned and to send them to FAL as soon as possible.

## 2. CONDUCT OF THE DIAGNOSTIC ASSESSMENT

### A. MAKING AN APPOINTMENT

Approximately two months before the start of the assessment, a FAL secretary contacts the family / guardian to arrange the various appointments necessary for the diagnostic assessment. The following are scheduled: 2 interviews with a FAL psychologist in order to complete the ADI-R scale, 1 appointment for the ADOS-2 test, 1 or 2 appointments for consultation with the psychiatrist Dr Bernard (depending on whether or not an intellectual evaluation is required), and 1 appointment for a complementary evaluation. This contact is an opportunity to answer any questions that the family / individual / guardian may have, and to remind them of the different steps of the diagnostic evaluation. In the event of specific questions that the secretary cannot answer, a professional from the diagnostic team may contact the family / individual / guardian again at their request.

### B. THE TWO INTERVIEWS WITH A FAL PSYCHOLOGIST

The first two interviews take place on the FAL site, in Capellen, Rambrouch or Munshausen, and have several objectives:

- To gather information on the development and functioning of the person being evaluated. The interview is carried out according to the assessment tool specific to the diagnosis of autism called ADI-R (Autism Diagnostic Interview, revised version). It is administered in the form of an interview with the person concerned, ideally accompanied by a parent or a person who is very familiar with his or her developmental history. The ADI-R scale consists of a series of questions designed to collect the information needed to help assess the characteristics of the autism spectrum and make a possible diagnosis.
- Review any medical, psychological, and educational reports about the person being assessed, including childhood reports, as necessary.

Each interview lasts approximately two hours and does not necessarily require the presence of the person to be assessed. If the person being evaluated is a teenager or an adult who is able to express himself or herself and follow a conversation, it is preferable that he or she participate in these interviews, as he or she will then be able to give his or her opinion in relation to the questions asked and his or her experience. However, if the appraisee is a child, or is a teenager / adult who is not able to speak / understand language or follow a conversation, his / her presence is not mandatory. However, if the person or child wishes to attend these interviews (even if not directly involved), he or she is of course welcome to do so. This can of course be discussed beforehand with the psychologist who will be conducting the interview.

### C. USE OF AN ASSESSMENT TOOL SPECIFIC TO THE DIAGNOSIS OF AUTISM SPECTRUM DISORDERS (ASD)

This involves using with the individual an assessment tool specific to the diagnosis of autism called **ADOS-2** (Autism Diagnostic Observation Schedule - Second Edition; Autism Diagnostic Observation Scale, Second Edition).

While a psychologist interacts with the person being assessed (e.g., by suggesting various activities), another member of the diagnostic team observes the interaction. The handover may be videotaped, if the individual and / or family / guardian gives verbal consent. Videos made as part of a diagnostic assessment are strictly confidential (they are never shared outside the Diagnostic Assessment, Support and Training Department), and are intended solely to allow the professionals involved to watch the test again if necessary in order to provide the most objective scoring of the test.

This evaluation is carried out in a room at the FAL provided for this purpose. In Capellen, a camera system enables the person(s) accompanying the person being assessed to follow the assessment live. If a film is made, the family can thus see the evaluation from another room. In Munshausen, there is the possibility to follow the evaluation live through a two-way mirror.

This step takes about one to two hours (depending on the behaviour, concentration, or fatigue of the person to be evaluated).

### D. COMPLEMENTARY TOOLS USED

An **intellectual assessment** is also necessary to refine the diagnosis. If an intellectual assessment has already been carried out beforehand, the FAL professionals will decide whether this can be sufficient. If a more current assessment is to be carried out, the family / person / guardian will be informed and an additional appointment will be made, either with Dr Bernard or with a psychologist from the team. Two tests are mainly used. The **CFT- 1R / CFT-20R** (Culture Fair Intelligence Test, Rudolf H. Weiss & Jürgen Osterland, 2012 / Rudolf H. Weiss, 2012) is a non-verbal intelligence test (in its revised version for children or adults). The **LEITER-3** (Roid, Miller, Pomplun & Koch, 2013) is a tool specifically developed to reliably and validly measure non-verbal intellectual skills, memory and attention in individuals for whom traditional intelligence tests generally do not provide such a measure. Other cognitive tests can be implemented.

Depending on the need and relevance judged by the team, a complementary assessment scale can also be used: the **CARS-2** (Childhood Autism Rating Scale, Second Edition, Schopler E. et al., 2010). This scale was developed to identify individuals with autism spectrum disorders and to distinguish them from individuals with other developmental disorders without associated autistic syndrome. The rating scale is based on the observation of behaviours in 15 different domains. It does not require an additional appointment.

An **assessment of socio-adaptive behaviours** is also carried out if deemed relevant by the team. The socio-adaptive behaviours are assessed using the semi- structured questionnaire called **Vineland-3** (*The Vineland Adaptive Behaviour Scales, Third edition; Sara S. Sparrow, Domenic V. Cicchetti, Celine A. Saulnier, 2016*).

This questionnaire assesses adaptive behaviour in four main areas: Communication, Daily Life, Socialization and Motor Skills, in all persons aged 1 to 90 years. This assessment can be used to identify problem behaviours. A person's adaptive behaviour is inadequate if the skill does not manifest itself at the right time. The test assesses what people usually do, not what they are capable of doing. The results depend on the information given by the person responding to the assessment scale, and are therefore not related to direct observations.

The professionals on the diagnostic team reserve the right to conduct **further assessments and / or make additional appointments if deemed necessary.**

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#### E. OBSERVATION IN THE LIVING ENVIRONMENT AND INTERVIEW WITH A PROFESSIONAL

If deemed necessary by the diagnostic team, a FAL professional **will observe the person being evaluated in one or more of the living environments he or she attends** (crèche, school, home, work,...), and possibly film him or her (with the written agreement of the family / the person him or herself / the tutor), in order to form a complete picture of the person.

This is only possible **with the agreement of the institutions concerned, as well as that of the person, his / her parents or guardian.**

As far as possible, the FAL professional **combines observation with an interview with a person who knows the person being evaluated well** (teacher, classroom assistant, educator, employer, etc.) in order to obtain information on the person's daily functioning. Sometimes an interview without observation may be sufficient.

It is the FAL professionals who arrange the appointments with the institution where the observation takes place and the persons concerned. Once the appointment has been made, a confirmation letter/email is sent to the family and to the establishment concerned, stating the date and time of the appointment, as well as the name of the FAL professional who will carry out the observation and/or interview.

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#### F. DIAGNOSTIC CONSULTATION WITH DR JACQUES BERNARD

As part of the diagnostic evaluation, **at least one consultation with Dr. Bernard is required**, the date of which is set by the FAL at the same time as the other appointments. This meeting takes place in Capellen, in the FAL buildings.

Certain **medical examinations may also be necessary** in order to rule out diagnostic leads whose symptoms may resemble an ASD (e.g. a visual check-up, an auditory check-up and a genetic karyotype (via a blood test)). The family/individual/guardian is asked to provide Dr. Bernard or FAL with reports of medical examinations already performed. Dr Bernard then assesses whether or not additional tests are necessary (missing results, not recent enough, or need for additional tests (e.g. EEG, **MRI**, intelligence test, concentration test...)). He or she may also decide to review the person being assessed at an additional consultation at the FAL.

If a consultation should take place outside of the diagnostic evaluation (e.g. for therapeutic follow-up), Dr. Bernard will arrange these appointments himself, which will take place in his private practice.

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#### G. CONSULTATION MEETING AND DIAGNOSIS

Once all the steps described have been completed, **the psychologists on the diagnostic team and Dr. Bernard** decide whether they have enough information to make a diagnostic opinion, or whether further steps are still necessary. If necessary, they can request additional appointments or complementary examinations. Once they have all the necessary data, **they pool the various information gathered in a consultation meeting to define a global diagnosis**, referring to the DSM-V (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) criteria for autism spectrum disorder.

**The person being assessed / family / guardian is not present at this consultation meeting.**

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#### H. THE DELIVERY OF CONCLUSIONS

When the diagnostic conclusion has been formulated in the framework of the consultation meeting between FAL and Dr Bernard, a FAL secretary contacts the family / person / guardian **to fix an appointment to deliver the conclusions**. This will take place at the FAL office in Capellen, Rambrouch or Munshausen, **with one of the psychologists involved in the evaluation**. This appointment has several objectives:

- To inform the family/person/guardian of the diagnosis made,
- Answering questions from the family/person/guardian,
- If the diagnosis of ASD is made:
  - support the family/individual following the diagnosis,
  - explain and provide information on ASDs practices as well as some concrete recommendations on this subject,
  - explain the different FAL services available to the family / family / person / guardian
- If necessary, refer the family / assessed person to other services that can provide the required assistance or adapted accompaniment, whether it be to the FAL or elsewhere
- Provide the family / individual / guardian with a diagnostic certificate.

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#### I. THE DRAFTING AND TRANSMISSION OF THE REPORT

After the diagnosis is made, **a detailed report** is drawn up. It contains the conclusion of the diagnostic evaluation and the results obtained with the various tests proposed.

This report, the content of which will have been discussed orally when the conclusions are given, is **given to the family / person / guardian as soon as possible**. This report is transmitted only to the family/person/guardian, and is therefore



free to pass it on to third parties or not. We stress that this report can be a valuable tool for the further support of the person concerned.

#### J. THE POSSIBLE POST-ASSESSMENT FOLLOW-UP BY THE FAL IN CASE OF DIAGNOSIS OF AUTISTIC SPECTRUM DISORDER

**In the case of a diagnosis of an autism spectrum disorder**, it seems to us essential that the support plan for the person with an autism spectrum disorder be as coherent as possible. In order to do this, a FAL professional contacts the family / the person him / herself / the guardian a few weeks after the delivery of the conclusions, to propose a "**post-diagnosis**" **appointment**. The purpose of this appointment is to answer questions and provide information about the diagnostic assessment, Autism Spectrum Disorders and possible support.

In addition, the professionals of the FAL's "Diagnostic Evaluation, Support and Training" service are **also at the service of families** who wish to do so **for** :

- **Answering their questions and supporting them** in their difficulties with the announcement of the diagnosis;
- Carry out a **skills assessment** (development, psychomotricity, communicative skills) of the person every year or two years, in order to note his or her progress and readjust the support programme put in place;
- Propose **concrete support** to the family/person in various forms according to needs (PSI, social skills groups, training, etc.);
- Meet with the various people who care for the person being evaluated (day care, school, SIPO, EMP, workplace, etc.) in order to adapt and **coordinate** the care as well as possible;
- Participate in **school meetings**, in particular to support, if necessary, the child's integration project in regular school;
- Putting the family in **contact** with the various professionals and networks likely to provide assistance in daily life and in administrative procedures (long-term care insurance, social worker, parents' association, leisure services, etc.).

These services are provided on a case-by-case basis, according to the needs and requests of the families.

The person with ASD and his / her family / guardian can also contact a reference person within each FAL service. The professional concerned will be able to **organise and coordinate the person's overall project**. He / she can supervise the support provided through the different services offered by the FAL, also **over the years**. On the other hand, he or she can ensure the link between the different external support services, i.e. those not offered by the FAL, through coordination meetings between the professionals, the family/person him/herself/guardian and the FAL.

### 3. THE COST OF THE DIAGNOSTIC PROCEDURE

- **Intervention by the FAL diagnostic team :**  
For all persons residing or paying contributions in the Grand Duchy of Luxembourg, the cost of a diagnostic assessment procedure at the FAL is fully covered by the Ministry of Family and Integration and the Greater Region.
- **Intervention by Dr Bernard and complementary medical examinations :**  
Dr Bernard's fees in connection with the diagnostic assessment (consultations and attendance at the consultation meeting with FAL professionals) and any additional medical examinations are paid according to the normal procedure of the competent health insurance fund and to be carried out by the family. These services are billed directly by Dr Bernard or the professional who performed the examinations concerned.
- Any other costs incurred by the family/person concerned (travel, etc.) are borne by the family / person themselves.

### 4. CONFIDENTIALITY OF THE DIAGNOSIS AND REPORTS

**The FAL ensures the confidentiality of the diagnosis and reports concerning the person being evaluated.** These are communicated by the FAL only to Dr. Bernard and to the person himself or, if applicable, to his family or guardian, unless the person himself, his family or his guardian explicitly requests in writing that we transmit the report to others.