Disabilities and child protection:

rights for invisible children

2015 Report devoted to the rights of the child
Synthesis
This year, we have chosen to devote our thematic report on children's rights to a subject that is little-known, little-studied and rarely dealt with, even though it concerns particularly vulnerable children: disabled children who have been taken into care of the child protection system.

It is precisely the mission of the Defender of Rights to make sure that the most vulnerable persons have access, and that this access be re-established if necessary, to their fundamental rights as recognised in international agreements duly ratified by France and written into the laws of the Republic.

The International Convention on the Rights of the Child, over which the Defender of Rights controls the effective application, protects the best interests of the child in all decisions concerning him/her. Article 20-1 states in particular that when a child cannot be left in his/her family environment in his/her own interest, he/she is entitled to the protection and aid of the State. Disabled children are the subject of specific provisions: access to care, entitlement to education and notably Article 23 recognises their entitlement to "live a full and decent life, under conditions which ensure their dignity, favour their autonomy and facilitate their active participation in the life of the community".

Furthermore, the Convention on the Rights of Persons with Disabilities emphasises the principle of non-discrimination against disabled children (preamble), respect for the principle of the evolving capacities of the child (Article 3) and respect for his/her best interests (Article 7). Furthermore, the situation of disability cannot justify the separation of the child and the parents (Article 24-5) or prevent access to free and mandatory education or access to treatment. Article 25 recommends early diagnosis of the disability and preventive actions.

Having had numerous individual complaints referred, coming from parents, associations or professionals, and relatives of disabled children who are supported or taken into the care of child protection authorities, we have been able to observe the great complexity of their situations and the specific difficulties with which they are confronted.

We have been able to assess the extent to which the extreme insecurity of these children, and their families, exposed them specifically to denials of their rights: to healthcare, schooling, a family life, and protection against violence in all its forms, among others.
Children who are "invisible" in public policies on support for the disabled and on child welfare, as they are not covered by the existing information systems and are therefore neither quantified nor identified. Yet, according to the estimates used in the report, which are conservative and only take into account the disabilities recognised by the MDPH (Departmental Disability Support Centres), **70,000 children assigned to Child Welfare Services are estimated to be concerned**, with a significant over-representation compared to the general population.

**Children in very varied situations**: according to the nature and gravity of the disability: physical, sensory, mental, cognitive or psychological, and associated problems; according to the procedures for their case management in the medico-social and health sector and in the social sector: ordinary or open environment, institution or foster family; also according to the type of protection, administrative or judicial.

Children who are twice as vulnerable, who should logically benefit from twice as much attention and protection, but who, paradoxically, because they are at the intersection of different public policies, are victims of the inability to cross institutional boundaries, the duplication of systems and the large number of players, as well as differences in professional cultures, notably concerning the place of parents and work with the families; consequently running the risk that the interventions carried out with them cancel each other out.

It is the vocation of our institution to be able to identify, through cases referred, the requirements of children in our country and infringements of their fundamental rights; it is also a strength to be able to rely on the transversal nature of the missions assigned to us by Organic Law and the synergy of competences at the service of access to rights; it is also the ability to look beyond individual treatment to highlight more general problems, the aim being to propose useful recommendations to sustainably develop policies and practices.

To do this, we rely on civil society and institutional players with whom we are in constant dialogue.

Thus, to prepare the present report, we carried out more than 40 hearings and interviews, received more than 20 contributions, including those of the European Network of Ombudspersons for Children, and lastly carried out a survey amongst all of the Departmental Councils.

We were struck by the interest aroused by our project, from our various interlocutors, associations, departmental councils, ministerial departments, national institutions (CNSA -National Solidarity Fund for Autonom, etc.) and local institutions (MDPH, ARS-Regional Health Agency, etc.), as well as the shared awareness of the necessity of treating these children differently.

In this year of many celebrations: the 25th anniversary of the ratification of the International Convention on the Rights of the Child, the 10th anniversary of the Act of 11 February 2005 on the Rights of Persons with Disabilities and the 15th anniversary of the institution of the Defender of Children, we hope that this unprecedented report, the first of its kind in France, will bring the presence of these 70,000 children to the attention of society as a whole, and encourage the various players to tackle the problems and specific issues thus identified.

May it also identify concrete ways to improve arrangements and practices aimed at disabled children in care that are appropriated at all levels, thus enabling their fundamental rights to be effectively respected.

For our part, we are certain that progress made for the weakest has a leverage effect in favour of change that is beneficial to all.
The Defender of Rights
Jacques Toubon

The Defender of Children
Geneviève Avenard
For reasons of ease of writing and reading, the terms "disabled child", "child with a disability" and "child in a disability situation" will be used equally throughout the present report.

In all cases, the children referred to are those whose disability has been recognised by the MDPH.

Furthermore, given the magnitude and complexity of the subject, several topics, although identified, have not been specifically dealt with in the present report: these include the status of ward of court and the question of the adoption of disabled children, the prevalence of mental disorders, the multi-cultural question, the action of lawyers acting for children, institutional abuse, and the various problems related to the allocation of financial aid (particularly the AEEH-Disabled child education allowance and PCH) to families.
Arthur, aged 10...

Arthur’s schooling was complicated from the first class in primary school, as the child had difficulties in learning and concentration such that his mother arranged for psychological and child psychiatric monitoring and speech therapy. The child received specialist support for children in difficulty but behavioural problems gradually became pervasive, preventing learning. The difficulties became increasingly pressing in class CM1 (around the age of nine), when dialogue between the mother and the educational team worsened even though Arthur’s difficulties increased. Deprived of recreation, then educational outings, his presence at the school gradually lessened, until there was a total interruption of schooling for more than six months. In spite of the case management set up by the mother, the school reported information of concern, raising questions about the conditions of parental management. An assessment by the Departmental Council concluded that, although Arthur’s behavioural troubles were real, they were not due to family shortcomings. This report of information of concern provoked a very sharp reaction from the family, who had been asking for help from the school for years. It is interesting to note that the school only recommended referral to the MDPH in the last year during which the child was present. The parents, who were poor, did not know about this system beforehand.

The parents wished to give their testimonial to the Defender of Rights, concerning what they describe as “an assault course”.

The matter was referred to the Defender of Rights by Arthur’s mother.

Lena, aged 14...

Lena’s parents had just discovered that their adolescent daughter had been assessed as schizophrenic. After numerous procedures, they found an organisation adapted to receive her. They explained that before being able to obtain a diagnosis, they consulted a very large number of doctors who knew little or nothing about the disability and were not able to guide them concerning the procedures to be carried out (particularly referral to the MDPH). It was by using their personal resources that they managed to find relevant information and met specialists who were able to support them in their procedures.

The case was referred to the Defender of Rights by professionals from the hospital.

Marie, aged 13...

Marie was hospitalised for nearly a year, as it was impossible to find a living environment adapted to her behavioural problems. The hospital wanted to re-mobilise the child support services, which provided the child with temporary reception support. The ASE’s teams are aware that the hospital is not an appropriate and sustainable environment for the adolescent. They stress that they are not withdrawing support but they emphasise that they are expecting the young girl’s state of health to stabilise, so that they can find an appropriate referral. They state that difficulties were caused for them by the contradictory instructions of different child psychiatrists: some of them stated that Marie should go into a foster family while others stated that no links should be favoured with anyone in particular and that it would be better to seek a small organisation. The ASE contacted an association to enable the child to have outings and, in the medium term, have her case managed overall: medico-social institution, day hospital or accommodation in an organisation run by the ASE. A summary was organised with all players concerned to enable everyone to renew their actions in a coordinated manner.

The case was referred to the Defender of Rights by professionals from the hospital.

Foreword: the situations have been anonymised.
Anne-Laure, aged 10...

Anne-Laure suffers from behavioural problems and has autistic traits. The MDPH notified referral to an IME (Medico-educational Institute) in 2011, confirmed in 2012. However, since the age of five, the little girl has not received any schooling, as no organisation was able to receive her, either due to lack of space or because of her pathology. So, as the child was totally dependent on her family, her mother had to rearrange her working time to continuously monitor her at home. When she was absent, her elder brothers took care of her. The family is constantly living in a climate of anxiety and distress. As an example, Anne Laure was hospitalised after falling out of the window: she saw her school friends playing in the courtyard and jumped out.

Some educative assistance at home was put in place for several months, but presentation of the situation of Anne-Laure to the critical cases commission has not provided a long-term solution. This is because referral to an ITEP (Therapeutic, educational and pedagogical Institute) in a partial manner, accompanied by case management in hospital during the day, was a failure; the MDPH lamented the fact that there was no overall case management, so the health recommendations of the commission were not able to be put in place.

The matter was referred to the Defender of Rights by the parents.

Roméo, aged 15...

Roméo developed psychotic disorders from the age of two or three and the CDAPH(Commission for the Rights and Autonomy of People with Disabilities) referred him to an IME. His mother sought help from the Departmental Council, as she could no longer manage the violent behaviour of her son, which had repercussions for his siblings. He was therefore taken in by the ASE under administrative monitoring. While waiting for an available place in an IME, the adolescent was managed as follows:

- Monday: morning in a care home, afternoon in the CATTP (Part-time therapy centre).
- Tuesday: morning in the care home, afternoon in the hypnotherapy centre, followed by an evening at home.
- Wednesday: day in the care home.
- Thursday: morning in the hypnotherapy centre, afternoon in the CATTP followed by one night at home.
- Friday: morning in the CATTP, afternoon in the care home.
- Weekend: care home or at home, alternating one weekend in two.

Furthermore, Roméo is no longer educated in his primary school due to his state of health, which implies regular hospitalisation in specialist hospitals. Although he receives educational courses when he is in hospital, only a few hours of French and mathematics are given by his youth worker at the care home. For its part, the secondary school does not envisage being able to receive Roméo because of his potentially violent character towards his schoolmates and teachers.

The case of Roméo, concerning the lack of acceptance in a specialised institution, was referred to the Defender of Rights by his mother.
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PROPOSAL 1:

Currently, numerous disabled children, due to the lack of solutions adapted to their requirements for compensation, have to remain at home or are received by default in organisations relating to child protection, and are therefore deprived of some of their fundamental rights. The Defender of Rights therefore recommends:

- the systematic use of liaison forms between the ASE (Child Welfare Services) and the MDPH for each minor taken into care, as well as the creation of an ASE contact person within the MDPH, and reciprocally, in order to facilitate the monitoring of decisions on referrals;
- implementing a system inventorying the needs of children with disabilities and providing information on what is available at each establishment so that objective data may be obtained in real-time at national level;
- supporting the creation of places in specialised institutions and the development of mobile health and medico-social teams to support organisations and host families of the ASE;
- that the Departmental Disability Support Centres be assisted in setting up a mechanism for monitoring their decisions on referrals;
- defining objective criteria for the management of waiting lists by specialised institutions and setting up external monitoring of the implementation of the admission procedures and conditions;
- ensuring regional equality of access by families to diagnostic organisations: early diagnosis should be considered as a priority for public policies;
- taking measures to reduce inequalities in access to child psychiatric care nationwide, stepping up the training of medical personnel in child psychiatry issues, and guaranteeing that minors receive treatment in a medical department specifically designated for them, from personnel who have been specifically trained to provide such treatment.
- ensuring the coherence of developments to the range of services provided by the departments and the ARS in order to avoid interruptions that are harmful to the interests of the children.

PROPOSAL 2:

It has been found that lack of knowledge about disabilities could lead to a judgement of danger, particularly for those involved in the National Education service. As such, the Defender of Rights recommends:

- strengthening the links between school medical care and PMI services, within the framework of protocols and cross-functional training on disability;
- educating players in the National Education services in disability and the specifics of case management through the child protection system;
- the generalised provision, for teachers, of guidebooks containing information relative to the various partners, on referrals to diagnostic organisations, the prevention of harassment of disabled children, awareness of how to notice and manage behavioural problems, etc.
### PROPOSAL 3:

Although entrance into the child protection system is based on the concept of danger, the specifics related to the expression of the effects of disability on the child and his/her family are insufficiently considered during the various assessments. Consequently, the Defender of Rights recommends:

- that the tools for collecting information of concern systematically include the item “disability”;
- that the question of disability be included in the national standard for assessing information of concern provided for in the parliamentary bill on the protection of children; that a unique and multidisciplinary CRIP (Collection unit for information of concern) be established in each department;
- educating those involved in assessing danger in the specifics related to disability;
- encouraging recourse to experts on disability, notably within the CRIP and at the various stages of assessment of the situation of the child by the child protection services.

### PROPOSAL 4:

Pervasive developmental disorders, such as disorders on the autistic spectrum, remain difficult to comprehend and require appropriate responses, not only at the stage of entry into the child protection system, but also during case management. Consequently, the Defender of Rights recommends:

- that all social workers be educated concerning disorders on the autistic spectrum, both during initial and continued training; this education could be based on the production of a table that is clear, readable and compliant with the recommendations of the HAS (National Authority for Health) in order to allow the identification and detection of signs of autism intended for those involved in childcare (PMI-Maternal and child Welfare, social workers, national education service, etc.);
- including, in the initial and continued training of judges, modules on awareness of disability and particularly pervasive developmental disorders;
- ensuring that the organisations and experts who intervene with the courts meet the compliance conditions set by the HAS/ANESM (National Agency for the Evaluation and the Quality of Medical and Social Establishments and Services) recommendations;
- setting up a network of experts identified and trained in partnership with the diagnostic centres, which can be mobilised by the various players contributing to child protection assessment (CRIP professionals performing judicial measures for educative investigation, court-appointed experts);
- that the questions of enforceability and the extent to which the recommendations of HAS/ANESM best practices can be relied upon be clarified for the benefit of all professionals intervening within the scope of these recommendations.

### PROPOSAL 5:

The situations pointed out in the report highlight shortcomings in terms of early prevention and support to parents. In addition, there is the fact that the players involved in prevention are numerous and they intervene in areas which do not necessarily intersect. Furthermore, the vulnerability of families in the case of disability is worsened when they have numerous vulnerabilities (economic, social, etc.). The Defender of Rights therefore recommends:

- that the various players ensure that they put the best interests of the child at the focus of studies and professional practices in order to guarantee the rights enshrined by the International Convention on the Rights of the Child and especially by Articles 5, 6, 14, 18, 20 and 23, emphasising the place of parents and the place of the child, which is a decisive approach for optimal case management;
- that diagnosis is performed early and that the announcement of the disability to parents is accompanied by support to the process of attachment and rapid case management;
- guaranteeing the long-term existence of Maternal and Child Welfare and of both its public health and medico-social missions;
- the provision of a simple document for the families presenting the various players, their roles and the time scale of the procedures and identifying the appropriate organisations in order to better support them. This document could also be accessible online;
- favouring diversified support measures for parents and improving the "early psycho-social interview" in particular in order to activate prevention networks and anticipate weakening of families or the occurrence of an additional disability;
- offering cross-functional training to all players concerned by the case management of these children who are at the intersection of several systems, in order to develop knowledge and a shared culture in the best interests of the child;
- considering the disability as a criterion justifying the intervention of a TISF (Family and social worker);
- formalising, organising and financing multi-disciplinary and multi-institution networks around disability, according to the logic of the "perinatal plan" networks;
- strengthening and developing support networks to parents and perinatal networks, directly associating all public institutions concerned and ensuring their funding;
- developing formalised links between departmental councils and prefects, in departmental plans or through agreements, to improve support to parents, particularly for the benefit of families with numerous vulnerabilities in order to simplify their procedures and improve the coordination of players and the information provided to them (REAPP-Parental support and guidance network- and PIF-Family information points);
- undertaking a study on the appropriateness of setting up, at local level, public interest groups responsible for running the systems for supporting disabled children in all environments (school, home, leisure activities, etc.)

PROPOSAL 6:

The recurring difficulties in recognising the profiles of children in care are worsened in the case of disability, making it difficult to prepare public policies that are effectively adapted to their requirements. The Defender of Rights recommends:
- that epidemiological studies be carried out on disabled children in care, thus aiming to improve knowledge of this population group;
- that the questionnaires sent by the DREES (Directorate for Research, Studies, Evaluation and Statistics) to the departments and ESMS (Social and medico-social establishments) in the context of annual and multi-year surveys be modified in order to directly question this population group on the combination of arrangements;
- that the system for reporting child-protection data from the departments to the ONED be effectively set up, particularly including data related to disability;
- that the reporting of data by the departments can be done under single authorisation n° AU-028 which enables the collection of certain data related to disability, and particularly disabled children who are the subject of information of concern;
- that requests for authorisation from the CNIL (French Data Protection Authority) to collect this data be made without delay, in accordance with Articles 25-1-1 and 7 of the 1978 Act, and Appendix 2.8 of the 2011 Decree.

PROPOSAL 7:

The preparatory work has highlighted difficulties relating to the sharing of information between professionals. The Defender of Rights recommends:
- that the file recording the case history of the child, retained by the child support services, be available for consultation by all professionals in charge of monitoring the child, in compliance with professional secrecy;
- that there be established, over the duration, the principle of dialogue necessary between professionals intervening with a child subject to multiple case management; that their points
of view, which may be diverse, are expressed and argued before the judge in charge of the situation of the child so that he/she can make, at each new stage, an informed decision, taking into account the overall situation of the child;

- the development of departmental charters on the sharing of nominative information in the field of child protection, a decisive condition for efficient case management. This charter would be signed by all professionals intervening with the child in the context of the child protection mission, as well as in the context of support to the disability. It would specify the outlines of the information sent, the conditions for the participation of users in their case management and the procedures for relationships and meetings between professionals in the various sectors;

- the organisation of training actions focused on the sharing of information while the charter is written and applied.

PROPOSAL 8:

Once a child has been taken into care, he/she is at the focus of several projects, run by diverse players without sufficient discussion of his/her fundamental requirements. Therefore, the Defender of Rights recommends:

- in accordance with its Decision MDE-2015-103 of 24 April 2015 making general recommendations concerning the project for the child, the generalisation of PPE (Project for the child) in all departments as a reference tool for all professionals, enabling the unification and clarification of multiple case handling (notably when PPS-Personalised schooling project and contracts for reception in institutions are established);

- that the PPE considers in particular the disability situation of the child and its consequences for the family environment.

PROPOSAL 9:

The preparatory work has highlighted the importance of facilitating relationships between the partners involved in child protection and those involved in disability, particularly concerning children with several vulnerabilities. Therefore, the Defender of Rights recommends:

- the signature of protocols between the main players intervening with disabled children and whose cases are managed by the ASE: within departmental institutions themselves, between the department and its partners and between the partners themselves. In any case, the signature of operational protocols between the ASE and the MDPH is considered as a priority;

- the organisation of training networks and cross-functional training between these players, including the Justice and National Education services;

- the development of support and sustained help for family assistants when receiving a disabled child, particularly through training;

- the production of a departmental guide to protocol concerning disabled children, an appropriate tool for inter-institutional clarification, which should be very broadly disseminated to professionals and notably the judicial authority;

- systematically identifying, within the departmental services, a team in charge of the most complex cases and relationships between the players;

- the establishment of a transversal body specific to the ODPE (Departmental Monitoring Service for Child Protection) relative to minors, located at the boundaries of the systems, in order to ensure transversal mediation work and the reporting of data;

- setting up multi-disciplinary commissions to assess and respond, as early as possible, to complex situations in order to favour the continuity of the child’s case management, as well as dialogue and mutual understanding between the players from separate sectors;

- encouraging the creation of experimental structures or systems combining medico-social and health interventions, enabling fungible budgets at the local level.
PROPOSAL 10 :

Difficulties in access to care for children whose cases are managed by the ASE are frequently found, which are aggravated for disabled children. The "health" dimension appears insufficiently taken into account within the organisation of the ASE's services. Therefore, the Defender of Rights recommends:

- setting up a computerised health record, firstly for disabled children in care, in accordance with rules on medical secrecy;
- the formalisation of health protocols between the department and general practitioners in order to encourage the exchange of information on the health of children;
- the appointment of a "reference doctor for child protection", designated within the department's services, the interlocutor of private doctors and hospital doctors;
- the establishment, within the ASE, of a medical platform in order to ensure access to, and continuity of, care for children who are the subject of child protection measures.

PROPOSAL 11 :

The educational dimension is decisive for children in care, even more so when they are disabled. Therefore, the Defender of Rights recommends:

- a revision to Article D. 351-10 of the educational code relative to the composition of the schooling and monitoring team (ESS) within the MDPH. It is essential that this Article expressly covers the case of children in care, making it obligatory to have a representative of the ASE in the ESS;
- strengthening the links between the national education service and the child support services in order to get the children involved in educational projects that are in accordance with their potential and allow them to succeed to the full extent of their capabilities.

PROPOSAL 12 :

Leaving the child protection system is generally a time of intense interruptions in the provision of services. The difficulties encountered by young people when their support by ASE ends are significantly worsened in the case of disability. Therefore, the Defender of Rights recommends:

- that a departmental body associating the various services (ASE, MDPH, PAPH) meets at least one year before the child's majority to examine the situations of disabled adolescents supported by the ASE, in order to promote their autonomy and anticipate difficulties and hindrances;
- that contracts for young people having reached majority be specially designed to organise the transition, to majority, of these disabled minors, whose journey towards autonomy must be particularly well-prepared, accompanied and supported;
- that teams for those aged 16-25 be set up within the MDPH in order to perform the preparations necessary for transitions without any break between the child and adult sections;
- that the departmental plans for child protection and autonomy be focused on exits from the ASE system;
- that networked working groups be set up by the departments and the ARS in order to bring together the disability and ASE sectors, as well as the child and adult sectors, so as to avoid service interruptions and offer real projects for moving towards autonomy.
Disabled children and child protection: invisible childrens
1 - Disabled children and child protection: invisible children

The finding is harsh and convergent: the first difficulty encountered when we take an interest in disabled children receiving child support services is that of having correct and accurate knowledge of these children. In other words, having an answer to the question “who are they?”.

These children thus appear as “invisible children”, forgotten from both policies for support to the disabled and those for child protection.

The effects of this situation are extremely harmful: insufficient consideration of the realities with which they are confronted, and difficulties encountered by the families and professionals in implementing support and aid adapted to their requirements.

The challenge is now to prepare relevant public policies and develop practices in an appropriate and efficient manner according to the assessment of requirements.

These are in fact two of the priority recommendations of the Defender of Rights’s assessment report presented in February 2015 to the UN Committee on Rights of the Child in view of France’s forthcoming hearing, namely “to continue with efforts already undertaken and free up the resources needed to finalise the centralised data collection system for children at risk as quickly as possible” and “to fix, as a priority, the consolidation at national level of all information relating to each of the rights of the child enshrined in the Convention”.

As such, we currently have only very patchy estimates, in spite of their intrinsic benefits, because they are limited to a few regions, for example a recent epidemiological study published in the “Archives de Pédapiatrie” assessed problems in accessing care for children managed by the ASE and benefitting from recognition by the MDPH in the Bouches-du-Rhône department.

As such, it proved to be an essential priority, in order to satisfactorily comprehend the situation of these children, to initiate a survey in June 2015 amongst all departments, so as to carry out an initial appraisal of conditions.

The exploitation of this survey showed that 30 questionnaires out of a total of 43 received responded to requests for statistical information, but in a highly diverse manner and never comprehensively. This finding was significant in itself. The departments questioned on this subject during supplementary interviews expressed regret at the lack of relevant tools and mentioned the difficulty of being able to cross-reference data held by the MDPH and the ASE in the absence of authorisation from the CNIL.

In any case, based on 18 questionnaires replying to the question concerning the proportion of children managed by the ASE and recognised by the MDPH, it is possible to estimate that the rate of disabled children in care stands at around 17%. Moreover, this rate is broadly supported by the contributions received, with estimates on average of around 25%.

This rate is particularly high and approximately 7 times higher than the rate of prevalence of disability, of 2% to 4%, for the general population.

From this estimate, which is intentionally prudent and which concerns only recognised disability, it is possible to state that nearly 70,000 children are estimated to be concerned, out of the 308,000 children subject to measures from the child support services (data from the DRESS, June 2015).

It is therefore a reality which affects the child support services and authorised services and establishments, and needs to be taken into consideration to its full extent.

Also, the questionnaires show that, for the great majority of children in care, the disability recognised by the MDPH is a psychological and mental disability, with behavioural troubles in particular, often severe, being over-represented. Sensory or motor disabilities are less present.

This observation is corroborated by the responses to the questions concerning “critical situations” commissions, put in place by a Circular of 22 November 2013, and which by definition are addressed to children with the most complex problems, endangering their integrity, their safety or that of their families, and requiring the mobilisation of all institutions.

Thus, in nearly 66% of cases, the children referred to the “critical situations” commission are children who are monitored for child-protection purposes, with strong variations depending on regions, with the rate rising as high as 100%. 
Yet it is precisely these situations which cause the most difficulties for the departmental teams in best responding to the needs of these children.

Concerning the experiences of the children, the survey shows that for around half of them, they are monitored in the context of a measure in an open environment (AEMO-Educational assistance in an open environment and AED-Parental Support at Home) and half of them under a fostering measure (judicial or administrative).

Lastly, concerning the procedures for receiving these children, their case management, which is complex, takes place in several places (foster family, MECS -Social centre for Children, IME, ITEP, etc.), depending on variable configurations, and with a combination of solutions provided at the medico-social, social, health and educational levels: IME during the week, MECS or foster family during weekends and school holidays; SESSAD (Specialised education and home treatment service) and foster families, etc.

In any case, it is striking to note that most case management is conducted in organisations that are mainly non-specific (children's homes of a social character (MECS) and foster families, public or associative). Yet these structures or foster families do not have sufficient technical resources in terms of functional re-education or psychological or psychiatric case management. Furthermore, the professionals are not specifically trained in disability.

They will consequently find themselves poorly adapted for providing satisfactory support to disabled children, even though they will be contacted concerning children with the most serious problems.
Disabled children and child protection: children who are doubly vulnerable
2 - Disabled children and child protection: children who are doubly vulnerable

In any case, the diagnosis of child disability is a time of profound upheaval for the family and therefore presents a risk of extreme vulnerability for the child.

This transitional period must therefore be supported as humanely as possible in order to meet the requirements for understanding and support of the parents and the feelings of powerlessness or even injustice that they will feel.

The child must also be supported intensively and quickly, notably through appropriate prevention measures, otherwise imbalance may arise in the parent-child relationship causing long-term weakening of the family.

However, the family may also experience numerous difficulties (economic, social and educational), before or after the diagnosis of the disability, which will cause a situation where the child is vulnerable and justify the intervention of the child protection service, particularly in its preventive aspect.

A disabled child who then comes under the child protection service is therefore doubly vulnerable and has a double insecurity which requires sustained and appropriate action.

2.1 - Vulnerability related to entry into the world of disability

Today, the question of disability still remains difficult to comprehend. In spite of progress arising from the 2005 Act on the depiction of disabilities, difficulties remain both for families and professionals, which can create inextricable situations.

Hence the importance of efficient systems for early prevention and networked case management, as well as the importance, broadly mentioned during the hearings, of having sufficiently early diagnosis.

Diagnose the disability as early as possible

Most disabilities can be diagnosed during the first three months of the child's life. This is the case of motor disabilities, neuro-sensory impairment and pervasive developmental disorders.

Difficulties in obtaining a diagnosis or identifying the competent organisation for performing it are, however, not rare, as well as waiting times that may be between 6 months and two years, sometimes more, which, in relation to the age of the children, is considerable.

Furthermore, while we might expect that a diagnosis would be the beginning of programmed and organised case management, it can, on the contrary, be a time of interruptions in support for families who are already weakened. In this area, the shortages in child psychiatric care, combined with a reduction in preventive actions, are a particular source of concern.

According to the professionals met with during the production of the report, this situation is even more delicate in the case of people with "numerous vulnerabilities" and they should consequently be anticipated: non-attendance at obligatory medical consultations, lack of follow-up to a diagnosis, difficulty in accessing information about available aid, etc.

By developing early detection of these situations, the worsening of certain disabilities could be limited through the establishment, according to the players questioned, "of aid measures other than physical reception" (fostering). Prevention is integrated here into a project that associates the parents.

The ANESM and the HAS also stressed the importance of very early identification and screening in order to better anticipate the risks of danger for the child.

Provide support to families when a disability is announced

The players consulted stress the fact that the time of the announcement of the disability is an essential factor likely to weaken the family and, if it has not been previously supported by the services of the ASE, make it more likely that it will come under the child protection system.

The arrangements for announcing the disability to the parents must therefore come within a more overall approach supporting parenthood that is humane, respectful and empathic, based
on the potentials and resources of the families, which encourages them to establish relationships with other parents confronted with the same difficulties, as part of a "peer support" approach.

The professionals must be able to have sound training for this purpose, particularly those coming under the ASE, in order to overcome the effects of perceptions harmful to the interests of the children. As an example, situations were reported in which the educational teams felt a fear of "sticking a label" of disability on the child, which could result in delaying the referral of the family for diagnosis and early intervention. Yet a certain number of these families already had feelings of guilt due to the perceptions associated with child protection. In this context, the choice of educational support alone may be preferred, to the detriment of appropriate medico-social and health case management.

**Coordinate those involved in prevention**

The support must be provided in cooperation with the family and with professionals working in networks, which is not yet sufficiently the case. The large number of players and their specific and compartmentalised approach to intervention are not easy to understand for the families, particularly those with a combination of problems.

The challenge is to combine the approaches towards perinatal prevention, the prevention of parental educational difficulties and medico-social prevention, within the more general context of Article 1 of the Act of 5 March 2007 reforming child protection.

As noted by the child protection support group in 2011: "the effectiveness of actions carried out to prevent difficulties that may confront parents therefore assumes a partnership approach, regional or as part of a network".

Amongst those involved in prevention, particular mention should be made of the interventions and missions of the PMI, the CAMSP (Early medico-social action centre) and the TISF, as well as the relevance and efficiency of the perinatal networks, as it is precisely them who will bring together the players in each of the fields concerned: health, social and medico-social.

Lack of knowledge about certain disabilities also results in a lack of training for social or medico-social workers.

Thus, professionals in the medico-social field report that "disabled children monitored by the ASE are often sent relatively late for treatment in CAMSP, or are only identified after the age of 6, even though the difficulties were present previously". As an example, it is regularly mentioned that disability is often only detected in the case of health problems and not through a primary intention to screen for disability.

Conversely, the professionals in the child support services may mention lack of knowledge of the child protection system by professionals in the health, medical and medico-social fields. They state that this lack of knowledge can delay the transmission of certain information of concern, which consequently worsens the situation of the child.

Thus, everyone seems to regret that the ignorance of one's "neighbour" has repercussions for the case management of the child, yet without necessarily themselves being aware of the procedures for learning the scope of intervention of the "neighbour".

It therefore seems essential to equip everyone with, and share, the tools necessary to enable better overall case management of the child and his/her family.

### 2.2 - Vulnerability related to entry into child protection

Entry into the child protection system is a decisive time for the future of the child, depending on the reasons, but also the conditions under which it will take place and, lastly, the type of measures that will be decided (open environment or fostering).

For disabled children, the reasons that give rise to the intervention of the ASE's services appear more complex to comprehend, because they are of a more multi-factor and interlinked nature. They will also involve a breathtaking number of players with very different professional cultures, who do not share the same perceptions of disability, of danger and of the place of families.

The high percentage of disabled children amongst the beneficiaries of the ASE, as estimated above, can only make us wonder about the experiences of these children, before and at the
time of their arrival in the child protection system: whether the disability is a cause in itself, direct or indirect, justifying an intervention in this respect and, if so, for what reasons.

There again, we see a lack of statistical data concerning information of concern, the current cornerstone of the system for identifying situations of danger or risk of danger.

Qualitative elements were nevertheless able to be collected in the survey conducted amongst the departments and during supplementary interviews, which provided some answers to these questions.

What do we know about the information of concern (IP-Report of suspected Child Abuse or Neglect) relating to disabled children?

At a quantitative level, the GIPED "Enfance en danger" was able to provide data on information of concern received during 2014 by the SNATED (National Hotline Service for Children in Danger).

This showed an increase, between 2012 and 2014, in the share of the item "physical illness/disability" in the calls made, as well as rates of IP which rose, in the same period and for the same item, from 53.1% to 56.5% of calls. Furthermore, disability was at the origin of 33.1% of cases of psychological violence, 22.1% for physical violence and 20.6% for gross negligence.

At a more qualitative level, the National Education service is identified by the players consulted as originating much information of concern about these children. The reasons given are highly diverse:

- a situation of conflict between the teaching team and the family concerning the monitoring of the schooling and the referral of the child, notably due to the child's behavioural problems;
- a situation of conflict arising from arrangements that are not appropriate or not put in place: for example, non-compliance with a referral by the MDPH deciding to provide a school life auxiliary (AVS - School life auxiliary) for a child with hyperactivity problems, which may lead to the child having school phobia and dropping out of school; referral to the MDPH deciding an AVS due to lack of an appropriate referral to a specialised class or to a SESSAD;
- a situation of absenteeism and dropping out of school;
- a situation of a diagnosis that is too late and sometimes denied by the teaching team: for example, an autistic child whose case management in a day hospital or in a CMP (Medico-psychological centre) is no longer recommended following the diagnosis, but for which the change of case management is disputed by the school.

The difficulty is precisely in assessing the danger, or risk of danger, for the child. As such, the composition of the team collecting information of concern (CRIP) is a decisive issue.

Yet, based on investigations carried out by the Defender of Rights, the CRIP do not have appropriate tools in the matter because they do not have experts specifically informed about disability, who could be called upon in case of need, notably by agreement with the MDPH. Neither do they have any external coordinators who could be contacted under partnerships with the CAMSP, the CMP or the CRA (Autism Resource Centre).

Another difficulty is the lack of indicators or specific tables which could be taken into account to evaluate the situation of danger, or risk of danger, incurred by the child.

In this respect, the prospect of creating a national standard for evaluating information of concern, as envisaged in the ministerial roadmap on child protection, appears urgent. This was already one of the recommendations of the Defender of Rights's report on the Marina case in 2014.

However, this standard should contain provisions concerning disability and its impact on family functioning. Furthermore, the composition of the CRIP should be broadened rapidly, providing recourse, permanently or specifically, to experts who could be certified, particularly in the field of pervasive developmental disorders and autism.

What do the departments say?

The question was expressly asked in the survey in preparation for the report.

Out of 43 responses received, an overwhelming majority stated that disability can be a reason for entry into the child protection system, with only 5% of them not identifying it as such.
**Family weakening, the primary factor concerning entry into child protection**

The Departmental Councils state that it is not the disability itself which is necessarily a factor in entry into the system, but it may be or become so due to weakening of the family unit following the diagnosis of a disabled child, coming within a broader problem related to educational difficulties.

This weakening may take different forms as well as that of impoverishment of families related to a worsening of the conditions of socio-economic life, as well as a certain degree of social isolation or the appearance of difficulties, to a greater or lesser degree, within the parental couple. It is even more problematic in families that are already weakened and may worsen difficulties, particularly at the educational level.

But the Departmental Councils have also identified two main reasons why the child’s disability contributes to entry into the system: a danger relating to inappropriate or late referrals to MDPH, or institutional shortcomings.

**Late or inappropriate referrals:**

Several concrete problems have been found: referrals that are not compliant with the approvals of organisations (type of disability or age of the person received), or refusal by the designated organisations to take charge of the child because he/she does not correspond to the “profile” of the establishment on the grounds of “insufficient” supervision.

As the educational response is compartmentalised or absent, this may lead to situations of danger for the child.

Also, notifications from the MDPH may only relate to periods that are too short or concern medico-social organisations that do not allow the child-parent relationship to be maintained: this is particularly the case for children who are referred to Belgium, by the departments or at the initiative of the parents, due to lack of appropriate places available in France.

It should also be noted that, in the context of the notification obtained, the parents are the main players in finding an establishment and are often confronted with refusals, but without being sufficiently supported in their applications. And yet the MDPH is responsible for providing people with the help necessary to implement the decisions taken by the CDAPH.

Yet, due to lack of resources dedicated to this support, the MDPH are, in reality, unable to monitor and support families in implementing the referral decisions taken by the CDAPH.

Consequently, it may be found that the child support services were contacted solely due to the absence of case management appropriate for the requirements of the child.

**Institutional shortcomings**

Tangibly, this concerns inappropriate supply of services, with a shortage of resources available for child psychiatric care; also with limits to the solutions offered by the medico-social services and establishments.

The Departmental Councils thus emphasise the worrying lack of organisations adapted to physical disabilities, multiple disabilities and pervasive developmental disorders, as well as the reduction in the number of places in boarding establishments under the redeployment policies conducted by the ARS.

Moreover, entry into the ESMS runs up against a second difficulty, namely long waiting periods, notably due to a lack of transparency in managing waiting lists. Concerning the situations submitted to it, waiting lists of two to four years were reported to the Defender of Rights. As there are no rules defining objective criteria for managing priorities, we see very different practices between the establishments, which proves to be highly problematic both for children with the most serious disabilities and for children from the ASE.

Faced with this impasse, the parents may then be overwhelmed by the behavioural problems of the child that are associated with the disability, especially when this has been diagnosed and referred very late. The waiting times for obtaining a place are too long, resulting in the child being kept in the family home and dropping out of school, contrary to the child’s interests and entitlements, but also, for the parents, causing a reduced quality of life and a loss of social links, caused by them possibly being obliged to give up any professional activity. In this regard, the aggravated consequences for single-parent families must be emphasised.
Furthermore, the closure of medico-social establishments, IME and ITEP each weekend and during the school holidays means that alternative accommodation solutions have to be found by the child support services, whether this concerns institutions (children's care homes in particular) or foster families: all this even though the disability would normally require the maximum stability around the child, who will be the victim of repeated disruption in his/her accommodation, treatment and schooling. We may wonder whether the interests of the child are really taken into account and about the assessment that we can make of this: when his/her acceptance is primarily dictated by the solutions existing in terms of service provision, or when all that can be envisaged for him/her is institutional case management, due to lack of places in foster families.

Furthermore, for various reasons, relating firstly to the type of disability of the child and the associated behavioural disorders and secondly to difficulties in cooperation with the families that are most socially disadvantaged, the medico-social establishments, in particular the ITEP, regularly have to make temporary or definitive exclusions, resulting in the issue of reports of information of concern or alerts.

The referral of certain situations to the judge of a juvenile court fully illustrates the attempts by the families or services of the ASE to overcome institutional shortcomings by appealing to the courts, either with the objective of obtaining a court order that would require the organisation to provide a place, or while waiting for assistance provided by the services of the ASE, which would facilitate access to appropriate case management.
Between multiple players and insufficient cooperation: fragmented child care
3 - Between multiple players and insufficient cooperation : fragmented child care

There are hardly any reports on child protection or disability compensation which do not emphasise the inter-institutional difficulties in getting the various players to meet and talk to one another; nor are there many reports which do not emphasise the breaks in the process of care provision, schooling and educational support.

However, our finding is that all of these difficulties are particularly sensitive and aggregated for disabled children in care.

Yet it is clear that the double vulnerability that these children have must require these institutional divides and different professional cultures to be overcome.

Due to lack of sufficient coordination, simultaneous intervention in these different areas may have the effect of splitting up the case management of the child to the detriment of an overall and shared view of requirements.

The coordination of these players is a complex question as it relates to the problems which underlie child protection. Effectively, it means ensuring the protection of the best interests of the child while respecting the rights of parental authority; encouraging the transmission of information while ensuring the participation of users and the right to privacy and professional secrecy; relating national policies to the reality of local and regional issues; and reconciling the existence of the standard laid down by the legislature or regulatory power with the necessary contracting of the (medico-) social action.

It is also complex due to the compartmentalisation of the various public policies, the organisation of which is separate and which ignore one another: child protection policy, disability policy, parental support policy, education and schooling policy and the policy on the fight against poverty and exclusion.

Lastly, this question relates to the compartmentalisation of the professional cultures of the players based on various histories which in fact create difficulties in communication and understanding.

These different levels of complexity result in insufficient or unsatisfactory collaboration and hinder the cooperation that is essential in order to offer the child a support programme that effectively takes into account his/her best interests.

Lastly, there is another factor, which is the recomposition of the range of services, both social and medico-social or health, which, over the last few years, has been undergoing structural developments carried out simultaneously by the institutions (Departmental Councils and ARS), without evaluation or assessment of their respective impacts on the case management of children.

3.1- The difficulties of players’ cooperation

Overall, numerous inter-institutional difficulties are found by the various contributors to the report, which are related to a lack of reciprocal knowledge, and therefore recognition, of those involved with children and disabilities.

The professional cultures of players in the social field, the medico-social field and the health field are different, which does not favour the mutual understanding which is essential in coping with the complexity of individual situations.

Therefore, the training of social workers is a decisive matter, and, more specifically, the provision of common training to the various players, notably those related to disability and child protection.

More ambitious than coordination, cooperation implies finding a space and a time where the players can talk to one another and, together, construct a solution to the requirements of children based on a shared assessment. It aims to overcome the reciprocal views of those involved and their impact on the assessment of the disability.

It also assumes laying down rules concerning the sharing of information relative to child protection as well as sharing information relative to the disability and the health and medico-social action.
The preparatory work has highlighted the importance of a function regulating the relationships between the partners in child protection and those involved with disability, in order to limit situations of conflict related to difficulties in mutual understanding. As well as being the person in charge of the continuity of the case management of children in care, the President of the Departmental Council seems a legitimate figure to perform this function.

The project for the child (PPE), made obligatory by the Act of 5 March 2007, perfectly illustrates these difficulties. Once a child has been taken into care, he/she is at the focus of several projects, made obligatory and established in accordance with the Act of 2 January 2002, the Act of 11 February 2005 and the Act of 2007.

Benefiting from social, medico-social and health case management, the holders of parental authority must relate to no less than six projects with at least as many players, circuits and therefore potential interruptions: a project for the child, a personalised compensation project, a personalised schooling project or an individualised home project, a reception and support project or, again, an individualised support project. To these must also be added the residency contract or the individual case management document, or the reception contract in the case where the child resides in the home of a family assistant, etc.

In its Decision No. MDE-2015-103, the Defender of Rights expressly declared its support for the effective generalisation of the PPE to the entire national territory, as a central enabler for coherence and continuity of experience, allowing everyone, parents, children and professionals, to be stakeholders in it.

Radical simplification seems necessary to limit the number of projects to be established for each child, to the benefit of the project for the child which must be the main theme of all interventions in his/her favour, whether administrative or judicial.

The challenge is significant: the preparatory work has shown that no department is currently planning any connection between the PPE and the documents relative to the child’s disability.

The issue is decisive: to promote the development of child protection practices towards greater transparency, and towards better mobilisation of the resources of families.

Several possible actions were mentioned by the departmental services questioned to make experiences coherent: cross-functional training projects enabling the development of a common culture; specialised systems dedicated to coordination; projects for transversal working bodies; multidisciplinary commissions for the most difficult situations.

Although the mediation role of the child support services is decisive, it must nevertheless not lead to disengagement by its partners, but to a dialogue and genuine cooperation and collaboration in the child’s project.

### 3.2 - The fragmentation of circuits and case management

The difficulties in dialogue between the various areas of intervention and the complexities of connecting projects and teams are, as we have seen, a source of harmful discontinuities and interruptions.

Thus, the experiences of disabled children in care seem to be fragmented threefold concerning accommodation, treatment and schooling. For each of these circuits, their situations seem to be unequal compared to those of other children.

This is even more so in the case of serious disabilities and significant behavioural disorders.

**The fragmentation of accommodation circuits**

Broadly, children in care are subject, for half of them, to fostering measures, either in an administrative framework "negotiated" upon request of the parents, or in an "imposed" judicial framework, even if the judge seeks the support of the family.

In the case of disabilities, these children will be accommodated in an organisation authorised by the ASE: MECS, foster family or children’s care home for emergency accommodation, or in an ITEP or an IME, to be supported by a SESSAD or benefit from case management in a day hospital.

Tangibly, several non-exhaustive cases can be identified:
- children referred to an MDPH waiting for reception in an establishment,
- children accommodated in an IME or an ITEP during school term time and who are accommodated for the rest of the time in a MECS (weekends, school holidays, or more, if subject to partial case management),
- children supported by a SESSAD,
- children accommodated full-time after IME/ITEP exclusion.

Consequently, there are many educational and therapeutic teams who will intervene with the child, with significant differences in approach and clinical evaluation of his/her situation and needs, or even contradictions, at the risk of seriously harming the overall approach to his/her fundamental requirements and therefore his/her best interests, for example by postponing acceptance of his/her case or referrals.

The impact of the approaches of players is also identified as a decisive factor in the fragmentation of case management and support.

According to the responses from the departments, there is also a difference in the treatment of disabled children under the care of the ASE and the others. Problems identified are the non-priority of reception in EMSS as the child is already receiving educational support from the ASE, disguised refusals, much longer waiting lists for obtaining a place, and the cessation of specialised case management at the time of entry into care for the child's protection, among others.

Several reasons are put forward to explain this difference in treatment and denial of rights: negative perceptions which remain associated with the families of children in care (poverty, violence and lack of parental monitoring, in particular); a shifting of responsibilities towards the ASE when there is no immediate response; priority given to children who are not in care, etc.

Lastly, as the associated behavioural troubles are often significant, the medico-social organisations leave the child protection services to manage these difficulties alone.

Conversely, medico-social players note a trend amongst the child support services to not always monitor children received in the ESMS, on the grounds that the child already receives support, and to neglect the involvement of parents. This is also the case for those monitored by an SESSAD for example, or by a CAMSP, in which case the ASE's teams offload the entire situation onto them.

Furthermore, the departments observed that the difficulties are worsened for children coming under the ASE in certain regions, with placement by default and a "domino effect" between the various care organisations, towards the medico-social services, and then from the medico-social services towards the child protection services.

Lastly, the functioning procedures of the ESMS are widely questioned by the departments, which point out the effects of restructuring the range of health and medico-social services, characterised by redeployment of boarding places towards services in an ordinary environment, which are not necessarily suitable for the most severe disabilities.

Furthermore, questions are raised about the practices of professionals and their support, notably when there are significant behavioural problems amongst the children, which cause difficulties for the teams. Unilateral decisions on exclusion are thus taken, mainly in emergencies: without evaluating the direct consequences for the child, without preparing the contacts necessary and without preparing a "return" project.

The question is then one of knowing who must take charge of these children during these "intervals" or "interludes", with what resources and what project.

Thus the multiplicity of social, health and medico-social case management stems more from institutional and financial reasons than the interest of the child.

Bearing in mind that in all these cases, these exclusions, even temporary, will be disruptive for the child, often with negative consequences for self-confidence and trust in adults, and risk causing long-term hindrance to the educational work carried out with him/her.

Faced with these complex issues which undermine conventional organisations and standardised functioning, the report was able to identify several innovative arrangements put in place by the departments, even though the players themselves admitted that they were emergency and compromise solutions: arrangements which put the social sector into contact with the health sector; arrangements which put the health sector into contact with the social sector, arrangements which put the medico-social field into contact with the social field; and an adaptation to the authorisation procedures for medico-social establishments.
The fragmentation of treatment circuits

Breaks in the treatment circuits are themselves strongly related to breaks in accommodation. In fact, partial case management or exclusion from ESMS will contribute to fragmenting, or in certain cases suspending, therapeutic case management.

But they are also related to the available range of services and their organisation and functioning procedures, particularly in terms of waiting lists (CAMSP, CMPP - Medico-psychological-educational centre, etc.).

The departments state that they then have to resort to the private sector, with high costs of case management, on their initiative or upon request from the ESMS, which argue that this is required by the specific disorders of a particular child and that it is impossible for them to organise case management internally.

Various problems have been found concerning access to treatment for children in the care of the child support services: lack of a case history covering their treatment (insufficient content of the medical file, loss of health record), lack of monitoring and coordination of those involved (changing medical personnel, having the effect that there is very partial knowledge of the child; low awareness of the specific issues facing these children amongst attending physicians), lack of appropriate case management, particularly psychiatric, but also the lack of a medical coordinator for the child, and more generally of a medical function within the ASE.

The fragmentation of school circuits

In 2013, the DREES carried out an appraisal of the school failures and backwardness of children received by the child support services, particularly the phenomenon of dropping out of school in the year following fostering. Furthermore, at the age of 15, i.e. just before the end of mandatory schooling, three times as many children supported by the social aid services have dropped out of school than children in the general population, with this school dropout rate increasing with age. Moreover, 2/3 of these children, when entering secondary school, are one year behind the school programme.

Amongst these children, is not specified how many of them are disabled, as conversely, no mention is made of specific groups under care in the national statistics on the education of disabled children.

Even so, it is clear that, as for treatment, the fragmentation of education is associated with breaks in the accommodation circuit of children (for example, in the case of exclusion from ESMS or changes in the place of accommodation), particularly for the most serious disabilities or the most complex to handle, which are precisely those which characterise a significant share of children in care.

The 2013 and 2014 reports from the IGAS (Inspectorate General of Social Affairs) concerning support to disabled pupils thus comment that “the arrival of a pupil in a medico-social establishment therefore constitutes, in most cases, an interruption to the educational circuit that was ongoing, whatever it is”.

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... And subsequently?
4 - ... And subsequently?

Children’s exit from care has, over the last few months, been the subject of greater awareness and specific attention, and has given rise to numerous reports and studies.

But what is the situation of disabled children in care who find themselves in this situation? How can support be provided to these young people, who are doubly vulnerable and have been confronted over varying periods, more or less seriously, with the fragmentation of the interventions carried out with them?

The question is made complex by the variable nature of disability, which will have very different consequences concerning the conditions under which the ASE’s case management will end, and where a project for the young adult will be put in place.

Thus, the prevalence of severe disabilities found in the report, notably mental disabilities and character and behaviour disorders, leads one to believe that the project for autonomy or social and professional inclusion for the young people concerned will be even harder to define and implement, and will sometimes remain a theoretical project far removed from reality.

Added to this first complexity, and in a very tangible manner, is that of the age thresholds used, depending on the systems, for delimiting the transition between childhood and adulthood (or young adulthood).

Is adulthood reached at the age of 16, 18, 21 or 25? The age 16 marks the end of mandatory schooling, 18 marks the transition to majority, 21 the end of “young adult” contracts and 25 is the age of the first social benefits. Moreover, in the medico-social field, the case management of disabled children will stop when they reach 20 years old, sometimes before, depending on the type of approval delivered to the ESMS, but also afterwards, in the case of the “Creton amendments”.

How can a disabled child leaving care be autonomous and manage these various temporal barriers? How can the exit from the system be adapted to the realities of each person’s experience?

To respond to these questions, it seems absolutely crucial to set up specific support and to anticipate these numerous transitions sufficiently early.

As such, it is a specific task of preparation, as early as possible, to leave the system and become autonomous, which must drive all of the services of the departments and the ARS.

Ultimately, the present report has highlighted numerous and diverse problems concerning disabled children assigned to the ASE and identified ways to make progress based on four key questions: anticipation, the training of those involved, multidisciplinarity and assessment.

It is an inaugural work, which must serve as a basis for greater awareness of the extreme vulnerability of these children and, through collective work and studies carried out in common, enable enhanced cooperation and ongoing dialogue, with the aim of improving the solutions provided for their fundamental needs and for accessing their entitlements.
Acronyms
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AED</td>
<td>Aide éducative à domicile (Parental Support at Home)</td>
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<tr>
<td>AEEH</td>
<td>Allocation d’éducation de l’enfant handicapé (Disabled child education allowance)</td>
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<td>AEMO</td>
<td>Assistance éducative en milieu ouvert (Educational assistance in an open environment)</td>
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<tr>
<td>ANESM</td>
<td>Agence nationale de l’évaluation et de la qualité des établissements et services sociaux et médico-sociaux (National Agency for the Evaluation and the Quality of Medical and Social Establishments and Services)</td>
</tr>
<tr>
<td>ARS</td>
<td>Agence régionale de santé (Regional Health Agency)</td>
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<tr>
<td>ASE</td>
<td>Aide sociale à l’enfance (Child Welfare Services)</td>
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<tr>
<td>AVS</td>
<td>Auxiliaire de vie scolaire (School life auxiliary)</td>
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<td>AVSI</td>
<td>Auxiliaire de vie scolaire individuel (Individual school life auxiliary)</td>
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<td>AVSM</td>
<td>Auxiliaire de vie scolaire mutualisé (Shared school life auxiliary)</td>
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<tr>
<td>CAF</td>
<td>Caisse des allocations familiales (Family Allowance Fund)</td>
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<tr>
<td>CAMSP</td>
<td>Centre d’action médicosociale précoce (Early medico-social action centre)</td>
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<td>CASF</td>
<td>Code de l’action sociale et des familles (Social Action and Family Code)</td>
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<tr>
<td>CATTTP</td>
<td>Centre d’accueil thérapeutique à temps partiel (Part-time therapy centre)</td>
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<tr>
<td>CDAPH</td>
<td>Commission des droits et de l’autonomie des personnes handicapées (Commission for the Rights and Autonomy of People with Disabilities)</td>
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<tr>
<td>CDPH</td>
<td>Convention relative aux droits des personnes handicapées (Convention on the Rights of Persons with Disabilities)</td>
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<tr>
<td>CE</td>
<td>Code de l’éducation (Education Code)</td>
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<tr>
<td>CESE</td>
<td>Conseil économique, social et environnemental (Economic, Social and Environmental Council)</td>
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<tr>
<td>CIDE</td>
<td>Convention internationale relative aux droits de l’enfant (International Convention on the Rights of the Child)</td>
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<td>CIM 10</td>
<td>Classification internationale des maladies (International Classification of Diseases)</td>
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<tr>
<td>CMP</td>
<td>Centre médico-psychologique (Medico-psychological centre)</td>
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<tr>
<td>CMPP</td>
<td>Centre médico-psycho-pédagogique (Medico-psychological-educational centre)</td>
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<tr>
<td>CNCPH</td>
<td>Conseil national consultatif des personnes handicapées (National Consultative Council for Disabled Persons)</td>
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<tr>
<td>CNIL</td>
<td>Commission nationale de l’informatique et des libertés (French Data Protection Authority)</td>
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<tr>
<td>CNSA</td>
<td>Commission nationale pour la solidarité et l’autonomie (National Solidarity Fund for Autonomy)</td>
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<tr>
<td>CPAM</td>
<td>Caisse primaire d’assurance maladie (Primary Sickness Insurance Fund)</td>
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<tr>
<td>CPOM</td>
<td>Contrats pluriannuels d’objectifs et de moyens (Multi-year contracts covering objectives and resources)</td>
</tr>
<tr>
<td>CRA</td>
<td>Centre de ressource autistique (Autism Resource Centre)</td>
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<tr>
<td>CREAI</td>
<td>Centre régional d’études, d’actions et d’informations en faveur des personnes en situation de vulnérabilité (Regional Centre for Study and Action on Disability)</td>
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</tbody>
</table>
CRIP : Cellule de recueil des informations préoccupantes (Collection unit for suspected Child Abuse or Neglect)
CSP : Code de santé publique (Public Health Code)
CTRA : Comité technique régional autisme (Regional Technical Committee on Autism)
DEPP : Direction de l’évaluation, de la prospective et de la performance (Directorate for Assessment, Forecasting and Performance)
DREES : Direction de la recherche, études, évaluation et statistiques (Directorate for Research, Studies, Evaluation and Statistics)
DTPJJ : Direction territoriale de la protection judiciaire de la jeunesse (Regional Directorate for the Legal Protection of Youth)
EN : Education nationale (National Education service)
ESMS : Etablissements et structures médico-sociaux (Social and medico-social establishments)
ESS : Equipe de suivi et de scolarisation (Educational and monitoring team)
GEM : Groupe d’entraide mutuelle (Mutual support group)
GEVA : Guide d’évaluation des besoins de compensation des personnes handicapées (Guide to assessing the compensation requirements for disabled persons)
HAS : Haute Autorité de santé (National Authority for Health)
IEM : Institut d’éducation motrice (Institute of Motor Education)
IGAS : Inspection générale des affaires sociales (Inspectorate General of Social Affairs)
IME : Institut medico-éducatif (Medico-educational Institute)
INSEE : Institut national de la statistique et des études économiques (National Institute of Statistics and Economic Studies)
IP : Information préoccupante (Report of suspected Child Abuse or Neglect)
ITEP : Institut thérapeutique, éducatif et pédagogique (Therapeutic, educational and pedagogical Institute)
MDA : Maison des adolescents (Advice Centre for Adolescents)
MDPH : Maison départementale des personnes handicapées (Departmental Disability Support Centres)
MDS : Maison des solidarités (Solidarity Centre)
MECS : Maison d’enfants à caractère social (Social centre for Children)
MJIE : Mesure judiciaire d’investigation éducative (Judicial educational investigation measure)
ODPE : Observatoire départemental de la protection de l’enfance (Departmental Monitoring Service for Child Protection)
ONED : Observatoire national de l’enfance en danger (National Monitoring Centre for At-risk Children)
ONFRIH : Observatoire national sur la formation, la recherche et l’innovation sur le handicap (National Monitoring Centre for Training, Research and Innovation on Disability)
OPEPS : Office parlementaire d’évaluation des politiques de santé (Parliamentary office for the assessment of health policies)
OPP : Ordonnance de placement provisoire (Provisional placement order)
PAA : Projet d’accueil et d’accompagnement (Reception and support project)
PAI : Projet d’accueil individualisé (Individualised reception project)
PIA : Projet individualisé d’accompagnement (Individualised support project)
PPIF : Points info famille (Family information points)
PJ : Protection judiciaire de la jeunesse (Youth legal protection)
PMI : Protection maternelle et infantile (Maternal and Child Welfare)
PPE : Projet personnalisé de compensation (Personalised compensation project)
PPS : Projet pour l’enfant (Project for the child)
**PRIAC** : Programme interdépartemental d'accompagnement des handicaps et de la perte d'autonomie (Interdepartmental programme for support to disabilities and loss of autonomy)

**REAAP** : Réseau d'écoute d'appui et d'accompagnement des parents (Parental support and guidance network)

**SAF** : Syndrome d'alcoolisation foetale (Foetal alcohol syndrome)

**SESSAD** : Service d'éducation spécialisée et de soins à domicile (Specialised education and home treatment service)

**SNATED** : Service national d'accueil téléphonique de l'enfance en danger (National Hotline Service for Children in Danger)

**SROMS** : Schéma régional de l'offre médico-sociale (Regional plan for the supply of medico-social services)

**TDAH** : Trouble du déficit, de l'attention avec ou sans hyperactivité (Attention deficit disorder, with or without hyperactivity)

**TED** : Troubles envahissants du développement (Pervasive developmental disorders)

**TISF** : Technicien en intervention sociale et familiale (Family and social worker)

**TSA** : Trouble du spectre autistique (Autistic spectrum disorder)

**UE** : Unité d'enseignement (Teaching unit)

**ULIS** : Unité localisée pour l'inclusion scolaire (Localised unit for school inclusion)