

## Summary

### **Impaired and detained?**

#### **A study into the feasibility of prevalence studies into intellectual disabilities in the prison system**

##### **Reason**

The wish to develop policy and to initiate programmes for research with respect to detainees with moderate intellectual disabilities (LVB) has long been held by the world of politics and the Correctional Institutions Agency (DJI). Not much research has been performed in this area in the Netherlands. The studies that have been carried out so far contain significant substantive and methodological limitations, but at the same time strengthen the perception that LVB problems in detention are considerable enough to be taken seriously. Due to the limitations discovered during previous prevalence studies, it was decided that, prior to commencing any new prevalence measurement, it was necessary to map out the possible bottlenecks and assess whether there are any solutions to these bottlenecks. Bottlenecks and solutions have been found via a literature study and by consulting experts. The present report is the result of said study.

##### **Structure of the report**

Chapter 1 deals with the background and relevance of prevalence studies into LVB problems in detention. In order to design a useful study, it is necessary to have a clear image of the ultimate goal of the study. That is why the study deals with the impact of LVB problems in general and the various moments and ways these can be important within a detention setting. Chapter 2 provides a description of Dutch research in the field of LVB in detention, which focuses on methodological bottlenecks. Chapter 3 subsequently provides an overview of a number of foreign prevalence studies. This chapter also focuses on the measuring methods applied and the considerations that played a role with respect to the decisions that were made. Chapter 4 deals with the question of whether a prevalence study in the Netherlands is feasible. The question focuses on the measuring instruments that are available for measuring LVB in a detention setting. And finally, Chapter 5 provides a recap of the conclusions of the previous chapters. This leads to a number of considerations that are relevant to the determination of the research agenda in the field of LVB and the criminal justice system.

##### **Background and relevance**

An intellectual disability applies if there is a significant limitation in both the intellectual performance and the social adaptability of the person, and when that limitation manifests itself before the age of 18. In practice, in the Netherlands, we speak of a moderate intellectual disability if the relevant person has an IQ of between 50-85 in combination with a reduced capacity for social adaptability. Abroad the IQ limit is often set at 70. A moderate intellectual disability is relatively often accompanied with additional problems such as learning disabilities, psychiatric and medical problems, and problems in a social context, which often lead to behavioural problems. The group of persons that satisfies these criteria is not homogenous. There are several general characteristics that have to be taken into account when dealing with such people – such as language and comprehension deficiency, a limited working memory, difficulty with abstract thought, and naïveté – but the individual need and

possibilities for care can deviate strongly. It is nevertheless clear that in general, an adjustment in the way such persons are treated is desirable.

The condition of having an intellectual disability can lead to problems at various moments in the criminal justice system. A recent English report gives an account of a study among detainees with a suspected moderate intellectual disability. The study shows that detainees with LVB in England encounter a broad spectrum of problems in the legal system. They often do not understand what is going on during the legal proceedings, what they are precisely being charged with, and what they may expect during the trial and thereafter. Once in prison, they have trouble understanding the information provided to them, which means that they do not understand what is happening around them there either, and what is expected of them. Many detainees with an intellectual disability have trouble filling in forms that are required for applying for family or doctor's visits, for ways of spending leisure time, or for passing on daily matters such as the choice of menu and the laundry list. In addition, many persons with LVB indicate that they find it hard to make it clear to others what they want to say. Frustration about not understanding and not being understood often leads to (feelings of) aggression. Detainees with LVB often had trouble gaining access to facilities such as treatment programmes, and spent a relatively large amount of time alone in their cell. Their chance of receiving sanctions was five times higher, and the chance of spending time in segregation was three times higher. Slightly less than half of the persons with LVB indicated that they had been a victim of bullying at one time or another, by fellow detainees as well as by staff.

It should be noted in this connection that we do not yet know to what extent findings abroad will also apply to the situation in the Netherlands. It is clear, however, that the problems surrounding LVB in detention deserve our attention. After all, many things are still unknown: it turns out that we cannot say much with certainty about the size of the LVB group, nor about the nature and extent of their problems and the manner in which these can be best handled within the detention context. Research into LVB in detention is necessary to gain more insight into these matters. The following paragraphs describe the research performed in the past in the field of the prevalence of LVB in detention, and the lessons that can be learned for new research projects to be initiated.

### **Previous Dutch research**

A previous study into the prevalence of LVB problems in the Dutch prison system did not lead to the desired result. Two considerable problems were found: (1) a high degree of non-response and (2) problems when measuring social adaptability. The response when administering an abridged intelligence test as initial screener (phase 1) was only 55%. The response was even lower during the second phase (administering a comprehensive intelligence test): less than a quarter of those who qualified on the basis of the screening were subjected to said test. Such a non-response impairs both the validity and reliability of the findings. It also turned out that the instrument that was used to measure social adaptability was not suitable to be used in detention: there proved to be no suitable 'informants' who could answer the questions about the detainees, and the question largely concerned situations that do not arise in detention.

There are also a number of other studies that have devoted attention to the intellectual capacities of detainee subpopulations. These studies were all performed among (problematic) detainee subpopulations. Information about intellectual capacities was

not the main objective of these studies, but was collected through an indirect question in a broader context. These studies generally did not pay much attention to the official definition of the term 'intellectual disability', or the methodology used. The prevalence figures found in a number of studies were based on estimates by, for example, psychologists, and not on systematic screening. When screening did take place, only the IQ was used as an indicator. There were no studies at all that included any reports on social adaptability. The data do present a uniform picture with regard to the fact that the intellectually disabled are overrepresented in the subpopulations that were studied. However, due to the methodological limitations referred to above, these studies do not provide insight into the prevalence of LVB in the prison system as a whole.

We can conclude that research into intellectual disability among detainees has quite a few limitations and problems, not just in the field of the choice for certain measuring instruments, but also where it concerns the realisation of a practically feasible research structure. A high, non-selective non-response will strongly influence the degree of validity and reliability of the findings of a prevalence study. The chance of a low response rate during a prevalence study into LVB is high: it concerns a subject which may deter many detainees, and which is moreover an intensive experience for the participants. This is compounded by the fact that the members of the target group, those with LVB, are often suspicious. This makes research into intellectual disability even more difficult than research into detention already is, in any case. Serious investments into efforts to limit the degree of non-response are therefore necessary. In this connection, it is very important to structure the research such that it does not deter people with a moderate intellectual disability from participating. It is also recommended in that connection to start a pilot at a single ward, to resolve all 'teething problems', and to assess whether the various assumptions about measures that could influence response are actually correct. Only when it is clear that all parties involved can work with the structure, will the research have a chance of being successful.

### **Foreign prevalence research**

Five English-language reviews of research into the prevalence of LVB in detention and seven recent original studies were assessed in order to establish if we can perhaps learn from experiences gained elsewhere. It appears that foreign prevalence research also has experienced problems. A great variety of measuring instruments were used to measure IQ, varying from (parts of) various intelligence tests, to clinical diagnoses, self-reporting and various screening instruments. In almost none of the studies were any measurements made with respect to social adaptability. The response was, however, higher in the foreign studies than in the Dutch study, and various aspects were mentioned that could have contributed to that. The selection of respondents, the way in which respondents were approached, the moment at which the tests were administered, the experience of the persons conducting the tests, and the attractiveness of participation in the study are important aspects.

The prevalence found in the literature studied varied greatly; presumably this was mainly caused by differences in the study design and the measuring instruments used. The reviews show that the most accepted measuring instruments in foreign prevalence research are the Wechsler Adult Intelligence Scale (WAIS) and the Vineland Adaptive Behavior Scale (VABS). These instruments were also often found in more recent studies. There is, however, no golden standard for establishing prevalence. Opinion is divided on the use of abridged intelligence tests. Two screening instruments, LIPS and HASI, do present themselves as possible options for estab-

lishing prevalence. These instruments were developed to quickly establish, in practice, whether someone may have an impairment. Experiences with HASI do not, however, inspire the confidence that it can also be used for prevalence research, and in this context considerable questions were raised in literature. As regards adaptive skills, it has to be concluded that measuring them is not possible in a detention setting, due to the need for an informant (parent, care provider). Only two of the seven recent studies reported on adaptive skills, and both on the basis of a self-reporting version of the VABS. There is, however, no clarity about the reliability of this instrument.

### **Available measuring instruments**

The response problem has to be resolved in order for a prevalence study of LVB in detention to be successful, and we have provided various directions for this purpose. A measuring instrument must be chosen that distinguishes persons with LVB from the rest of the population in a valid and reliable manner. The choice of measuring instruments is not a simple one. Self-reporting – whereby persons are asked whether they have limitations – was not actually used anymore in most recent studies, and many critical comments can be made with respect to this method. Self-reporting nevertheless has some advantages, and it would go too far to immediately eliminate this method. The self-reporting method may also help discover persons who do not satisfy the definition applied abroad ( $IQ < 70$ ), but who nevertheless prove to *experience* more limitation than those who do not report limitations. It is, for that matter, doubtful what group you will find when you relate the findings to the broader definition of LVB as it is applied in the Netherlands ( $IQ < 85$ ).

An IQ score would, at first sight, appear to be a uniform measuring unit, but a closer study shows that this not the case, in any way. An IQ score is an estimated measuring unit with, in some cases, considerable reliability intervals, a low degree of generalisability and usually a poor standard for lower IQ's. The reviews show that the WAIS is the measuring instrument that is most accepted abroad to determine the IQ. There are various IQ tests available in the Netherlands for measuring the intelligence of adults of Dutch heritage. WAIS-III-NL, the Groninger Intelligentie TEST (GIT-2) and the Kaufman Adult Intelligence Test (KAIT) are the measuring instruments used most often. Opinion is divided about the advantages and disadvantages of each of these three tests. Studies whereby the three tests were administered alongside each other showed significant differences in IQ. The three tests each demand a considerable investment in time (60-90 minutes), which is why there is an abridged version of all three tests. Opinion is also divided about their usefulness. A large number of the detainees with a non-Dutch background are not suited to the above tests; for these persons, the Snijders-Oomen Niet-verbale intelligentie test (SON) would seem to be the most logical test to use.

The foreign research only rarely devoted attention to adaptive skills. When it was investigated, use was made of a self-reporting version of the VABS in respect of which it is unclear whether it is reliable. All questionnaires available in the Netherlands that chart the degree of social adaptability (including the Dutch version of VABS) are proxy questionnaires, which means that they require an informant. This is problematic in a detention setting, as there is no one available who knows the detainee well enough. Letting prison staff fill in the list proved impossible in previous Dutch research. One of the suggestions made in literature is that if a person is in a closed setting where he can display few skills and there are no possibilities of interviewing family or acquaintances, it is possible to make a rough estimate of the per-

son's self-reliance on the basis of the life history and interviews with the person himself. It is clear that this method does not provide an objective assessment.

Apart from establishing LVB by means of a comprehensive diagnosis, it may also be possible to try to make an estimate with the aid of a screening instrument, such as the previously mentioned HASI or LDSQ recently developed in England. Such screening instruments are not yet available in the Netherlands, and would first have to be validated in the Dutch context before they can be used here. No other Dutch alternatives are available either. A list of points for attention from De Borg, listed specifically for police and judicial employees, social services and the probation and after care services, comes closest, substantively, to the screening instruments known to be used abroad, but does not offer the possibility of objective assessment. The use of screening instruments is interesting, for that matter, because an assessment can be made as to how many detainees would qualify for further study, but it does not provide reliable data on the prevalence of LVB.

### **Final considerations**

The present report explored the bottlenecks and solution directions when structuring a study into the prevalence of LVB among detainees. Experience from previous research, both in the Netherlands and abroad, was used for this purpose. The conclusion has to be that the valid and reliable determination of the prevalence of LVB in detention may be impossible. The literature study also makes it painfully clear that very little is known, in any case in the Netherlands, about people with moderate intellectual disabilities in detention. Not just the size of the *population* is unclear; the precise extent of their *problems* and how to handle these within detention is not known either. The question that now faces us is which knowledge deficit deserves most priority: (1) the size or (2) the nature and approach.

In view of the above, it is important to assess the benefits of a prevalence study in a best case scenario. Despite the problems described above when determining the LVB problems in detention, an attempt may be made to determine the prevalence of LVB among detainees as defined in literature, therefore: the number of people with a significantly lower IQ and limited adaptive behaviour. This will result in a rate with a high degree of uncertainty. The subsequent assumption is that it may be assumed, with respect to these persons, that there is an increased chance of problems occurring in detention. It is also known that the group is in no way homogeneous; the mere conclusion that the group that satisfies the definition has a certain size, does not establish the (various) problems of the individuals and how these should be handled. The above consideration is not just related to the score of an IQ test. Although there will be a certain correlation between the level of support required and the IQ, a low IQ may be accompanied by a relatively low need for support, and the type of support may also differ, depending on the environment of the person involved or his additional handicaps.

From this perspective, it may also be decided to place more emphasis on the question of what problems will be encountered by people suspected of having LVB during their stay within the prison system. Such a study within a Dutch context would yield valuable information about the nature of the problems faced by people with a moderate intellectual disability in detention in the Netherlands. Moreover, such a study would provide insight into the question of whether such problems occur with some frequency, or whether they occur sporadically, despite the fact that it does not provide any prevalence figures. And finally, such a study would provide

more starting points for policy to be developed as regards the treatment of persons with a moderate intellectual disability in detention.

The knowledge that a more or less sizeable group of persons within the prison system is experiencing problems as a result of a (intellectual) limitation, subsequently suggests that it would be useful to identify this group and to subsequently offer the support required. A screening instrument may chart who may need additional support and adjusted treatment, but not what this should consist of; this requires, if the screening so indicates, an assessment in more detail to discover the strong and weak points of the detainee. Such an instrument is not available at this time.

The report therefore concludes that these two tracks – (1) studying the nature of the problems of persons with moderate intellectual disabilities in detention and (2) the development of a screening instrument for identifying detainees with suspected LVB problems – seem to generate more than the risky process of a prevalence study. The policy choices to be made require more substantive input than can be provided by a prevalence study alone.