Chapter 1

Introduction

This chapter is partly based on:
There are many recent studies concerning the nature, extent and impact of challenging behaviour in people with intellectual disabilities (Crocker et al., 2001; Emerson et al., 2001; Jones et al., 2008; Lowe et al., 2007; Lundqvist, 2013; McClintock et al., 2013; Olver, 2003; Rojahn, Matson, Lott, Esbensen & Smalls, 2001). Emerson (2001) defines the term challenging behaviour as ‘culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’ (Emerson, 2001, p. 3). It appears that challenging behaviour in people with intellectual disabilities is a common phenomenon. Studies show varying prevalences for challenging behaviour in people with intellectual disabilities, from 5 to 62 percent in large population-based studies (e.g. Emerson et al., 2001; Holden & Gitlesen, 2006; Lundqvist, 2013), to around 70 percent in specific settings (e.g. Csorba, Radványi, Regényi & Dinya, 2011; Rojahn et al., 2001). Challenging behaviours are therefore a major concern for a significant number of people with intellectual disabilities and their environment. The consequences of challenging behaviour can be far-reaching. Firstly, it can lead to physical harm to the person and his surroundings. In addition, challenging behaviour can hinder personal development and the establishment and maintenance of social relations (González et al., 2009). Furthermore, challenging behaviour could limit a person’s opportunities for integration into society (Rojahn et al., 2001). All these effects could substantially decrease quality of life.

Research shows that people with more severe intellectual disabilities are at greater risk of exhibiting challenging behaviour (Chadwick, Kusel & Cuddy, 2008; Chadwick, Piroth, Walker, Bernard & Taylor, 2000; Emerson, 2001; Holden & Gitlesen, 2006; McClintock et al., 2003; Wulffaert et al., 2009). The literature also shows that there is a relationship between the occurrence of challenging behaviour and various factors such as the presence of motor and/or sensory disabilities (Chadwick et al., 2000; Døsén, 2007; Holden & Gitlesen, 2006), seizure disorders (Døsén, 2007), communicative problems (McIntyre, Blacher & Baker, 2002; Totsika, Felce, Kerr & Hastings, 2010), sleep disturbances (Doran, Harvey & Horner, 2006), chronic pain and psychiatric problems (Døsén, 2007; Olver & Richards, 2010).

Although challenging behaviour has thus proved to be more common among individuals frequently suffering from these types of co-morbidity (Gardner, 2002; Chadwick et al., 2003; Schroeder, Reese, Hellings, Loupe & Tessel, 1999), it is striking that very little is known about the prevalence of challenging behaviour in people with profound intellectual and multiple disabilities (PIMD). Nakken and Vlaskamp (2007) define these people as having a profound intellectual disability (estimated intelligence quotient of 25 points or below), profound or severe motor disabilities (manifesting in an inability to move independently) and sensory impairments.

Furthermore, people with PIMD often suffer from various health problems, such as seizure disorders (Codling & MacDonald, 2009), pulmonary and respiratory disorders (Wallis, 2009), bowel and abdominal problems (Crawford, 2009), and are more likely to suffer from pain due, for example, to constipation, pulmonary or respiratory problems, or dental problems (Van der Putten & Vlaskamp, 2011; Watt-Smith, 2009). As a consequence, people with PIMD rely heavily on others (family but also direct support professionals) for all the activities of daily living (Nakken & Vlaskamp, 2007). We would therefore expect challenging behaviour to be a central topic in practice and research on individuals with PIMD. However, although challenging behaviour is a common experience in practice, to our knowledge the topic is rarely discussed and numbers on the prevalence of challenging behaviour within this group remain unknown. The magnitude and impact of challenging behaviour in people with PIMD is therefore currently unclear.

Furthermore, even though an increasing amount of research has been conducted into factors that related to the onset or continuation of challenging behaviour in people with intellectual disabilities in ‘general’ (e.g. Døsén, Gardner, Griffiths, King & Lapointe, 2007; De Winter, Jansen & Evenhuis, 2011; Emerson, 2001), the risk factors associated with the development of challenging behaviour in people with PIMD are not yet known. This lack of knowledge is a cause for concern, because these risk factors could provide insight into the background and development of challenging behaviour in this target group and could also guide the development of interventions to diminish or prevent challenging behaviour in people with PIMD. Staff beliefs/attributions regarding the causes of challenging behaviour could also affect the steps staff take or refrain from taking in relation to people displaying challenging behaviour; as it is assumed that staff behaviour is determined by emotional responses and cognitions (beliefs/attributions) about the challenging behaviour (Hastings, 2002; Hastings & Remington, 1994; Hastings, 2005; Snow, Langdon & Reynolds, 2007). Staff attributions/beliefs about challenging behaviour might not only affect their responses to the challenging behaviour displayed, but might also affect their beliefs about effective intervention strategies as well (Dowey, Toogood, Hastings & Nash, 2007; Hastings, 1997). The steps which staff may or may not take in their work with people with PIMD as a result of these beliefs could determine, at least in part, the emergence and persistence of challenging behaviour (Hastings & Remington, 1994; Hastings, 2002). Since the research carried out so far in this field has not focused on people with PIMD, and given the expected high prevalence of such behaviour, it is important to gain a better understanding of the explanations staff have for challenging behaviour in people with PIMD because this could also offer clues for the reduction or prevention of this behaviour and consequently for developing an intervention designed to reduce or prevent it.
Interventions specifically aimed at reducing or preventing challenging behaviour in people with PIMD are unsurprisingly rare. A recent review study into the effects of the pharmacological, psychotherapeutic and contextual interventions applied to treat challenging behaviour in people with intellectual disabilities shows that there is evidence for the effectiveness of all interventions, used alone or in combination with others [Heyvaert, Maes & Ongena, 2010]. The interventions included in this study were targeted at people with mild to profound intellectual disabilities, but did not focus on people with PIMD specifically. Therefore, it is not yet clear which interventions can best be used to support people with PIMD who display challenging behaviour. This overall lack of knowledge regarding challenging behaviour in people with PIMD is a cause for concern, as challenging behaviour does not only have physical consequences for the person him or herself, but can also have serious consequences on the ability of people with PIMD to establish relationships with the world around them. These relationships are vital to people with PIMD as they allow them to gain experiences and exert control over their own lives [Vlaskamp & Van der Putten, 2009]. More insight into the prevalence and impact of challenging behaviour, possible risk markers related to the onset or continuation of the behaviour, the beliefs/attributions staff have regarding the explanations of challenging behaviour in people with PIMD and how staff deal with challenging behaviour in practice is therefore required. This knowledge must be obtained in order ultimately to develop an intervention tailored to people with PIMD to reduce or prevent challenging behaviour specifically.

This thesis focuses on children and adults with PIMD and their direct support staff and aims to gain insight about the abovementioned gaps in knowledge. Knowledge about the prevalence, frequency and impact of challenging behaviour in people with PIMD was an important and necessary first step. Information on how practice addresses challenging behaviour in people with PIMD was then needed to gain insight into the way in which reduction or prevention of challenging behaviour is part of daily routines. Knowledge about the extent to which known risk factors for challenging behaviour was also applicable to people with PIMD was also needed to give more insight into the background and development of challenging behaviour in this target group. Furthermore, knowledge of the causal explanations staff favour for challenging behaviour in people with PIMD was also important because this could provide insight into whether staff choose to treat challenging behaviour in people with PIMD. Finally, we examined whether staff training might be an important tool to address potentially unhelpful attributions. All this knowledge helps us understand the extent and impact of challenging behaviour within this group so that appropriate interventions to reduce or prevent challenging behaviour can be deployed in practice in future, which is of great importance to the quality of life and support of people with PIMD.

The overall aim of this research project was to develop more knowledge on the prevalence and prevention of challenging behaviour in people with PIMD. Five main research questions were our guides:

1. What is the prevalence, frequency and severity of challenging behaviour in people with PIMD?
2. How do staff address challenging behaviour in people with PIMD in daily practice?
3. Which known risk factors for challenging behaviour are also applicable to people with PIMD?
4. Which explanations are offered by staff for challenging behaviour in people with PIMD?
5. What effects does staff training have on the assessment of challenging behaviour in people with PIMD in terms of severity and the causal explanations of behaviour?

1.1 Outline of the thesis

After this introductory first chapter, Chapter 2 reports on the prevalence, frequency and perceived severity of challenging behaviour in people with PIMD. Challenging behaviour was measured using the Behaviour Problem Inventory [Rojahn et al., 2001]. The Behaviour Problem Inventory is a behaviour problems rating scale used for people with various degrees of intellectual disability of all ages. It is an informant-based scale which addresses three types of challenging behaviour: self-injurious behaviour, stereotypical behaviour and destructive or aggressive behaviour.

Chapter 3 presents a study of how self-injurious, stereotypical, aggressive/destructive behaviour are addressed in daily practice.

Chapter 4 describes risk markers associated with the occurrence of self-injurious, stereotypical, withdrawn and aggressive/destructive behaviour in people with PIMD.

Chapter 5 reports on the causal explanations staff attribute to challenging behaviour in people with PIMD. Direct support professionals were asked to explain challenging behaviour in people with PIMD in accordance with five causal explanatory models of challenging behaviour measured using the Challenging Behaviour Attributions Scale.

Chapter 6 describes an exploratory study on the effects of psycho-education on the assessment of challenging behaviour in people with PIMD in terms of severity and causal explanations of behaviour.

This thesis concludes with Chapter 7, which reflects on the main findings of the five studies. The limitations of the research and the implications for practice and further research are discussed.
1.2 References


