Research Paper

Individual support planning with people with ID in The Netherlands: Official requirements and stakeholders' expectations ☆

Planification de soutien individualisé pour des personnes avec une déficience intellectuelle aux Pays-Bas : obligations officielles et attentes des parties concernées

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A R T I C L E   I N F O

A B S T R A C T

Introduction. – Individualized support planning (ISP) has become a key aspect of supports for people with ID and is mandated in several countries. Different stakeholders develop policies and expectations regarding ISP. In this study, we report on requirements as found in Dutch official ID policy and on the results of consultations of panels of stakeholders and experts working in the field of ID. It was intended to describe, summarize and discuss these requirements for the purpose of enhancing ISP practices.
Method. – A combination of desk research of policy documents and consultation of two expert panels was performed.
Results. – A variety of criteria on content, procedures, quality and person-centeredness of ISP is being used by different stakeholders. These criteria were described and summarized.

Discussion. – The broad range of inconsistent requirements and sometimes conflicting expectations from different stakeholders hamper a clear conceptualization of ISP and affect the use of ISP in practice.

R É S U M É

Mots clés :
Déficience intellectuelle
Planification individuelle de soutien
Projet de vie
Politique en matière de handicap
Soutien

Objectif. – Description et analyse des critères officiels et des attentes de différents intervenants et parties intéressées concernant la planification individuelle de soutien pour des personnes avec une déficience intellectuelle (DI) aux Pays-Bas. L'analyse vise à comprendre les exigences officielles en relation avec les attentes des parties prenantes, en particulier des clients avec DI et les prestataires professionnels de soutien. Les auteurs cherchent à formuler un dénominateur commun pour la pratique.
Méthode. – Une combinaison de recherche documentaire suivie de débats en deux groupes d'experts est utilisée pour arriver à un ensemble de caractéristiques de bonnes pratiques dans le domaine des plans de soutien.
Résultats. – La synthèse des critères formels avec des attentes des partenaires a résulté en un aperçu de caractéristiques de bonne pratique de planification individuelle de soutien (contenu, processus, utilisation).
Discussion. – Le processus de cette analyse a mis en évidence des inconsistances entre des attentes des parties concernées. Ces inconsistances présentent des obstacles à une conceptualisation claire et à une utilisation de plans de soutien dans la pratique.

1. Introduction

Individualized support plans (ISP) are mandatory in several countries, such as England, the Netherlands, Belgium, Canada and several states of the United States of America (Felce, 2004; Herps, Buntinx, & Curfs, 2013; Robertson et al., 2007). Individualized planning has become an important instrument in providing professional supports for people with intellectual disabilities (ID). The term 'individualized support planning' is used to address a multi-faceted, long-term intervention aimed at supporting persons with intellectual disabilities (Holburn, 2002). It consists of a continuous cycle of identifying desired life experiences, assessing support needs, defining personal objectives and goals, developing required strategies and resources in order to achieving these objectives and goals, monitoring the progress and, finally, evaluating the extent to which personal outcomes have been realized (Buntinx & Schalock, 2010; Schalock et al., 2010; Thompson et al., 2009). Therefore, ISP is regarded as a tool for person-centered supports (e.g. Adams, Beadle-Brown, & Mansell, 2006; Mansell & Beadle-Brown, 2004; Robertson et al., 2005; Schwartz, Holburn, & Jacobson, 2000). Person-centered supports are based on the individual's interests, preferences and strengths; require active involvement of the focus person and people who are important to him/her; supposes that the focus person has meaningful choices; uses, when possible, natural resources; is focused on relationships, inclusion, dignity and respect; offers a range of experiences and opportunities; is collaborative and recurring; and aims at the person's satisfaction with his/her activities and supports (Schwartz et al., 2000).

Different stakeholders in ID policy and practice, such as self-advocacy and parents' associations, Healthcare inspectorates or budget allocation agencies, develop their own understanding and

interpretation of what constitutes a 'good quality ISP' (Charmaz, 2006). Each of these stakeholders cherishes their own beliefs about a good quality ISP and accordingly set and relays their criteria to the field. It has been argued that increasing formal requirements regarding ISP documents enhances the risk that in practice, formally meeting criteria ('ticking boxes') may become more important than using ISP in daily support practices to the benefit of persons with ID (Smull & Lakin, 2002). The aim of the present study is to explore rules and expectations regarding ISP in the Netherlands. So far, in the Netherlands, no overview of different ISP requirements and consequences for not meeting such expectations is yet available. The present authors therefore undertook a desk research to make an inventory of official requirements as found in Dutch ID policy documents and applicable laws (referred to as 'formal requirements') and subsequently consulted panels of professionals working in the field of ID to add their expectations and to discuss the implications that requirements have on ISP in ID practice.

The study was part of a larger, nation-wide improvement program on ISP practices in the field of ID. This program was initiated by the Dutch Association of Service Providers in the field of ID (VGN) and funded by the Netherlands Organization for Health Research and Development (ZonMw). One of the aims of the program was to develop a set of recommendations for service providers in ID that would be compatible with official requirements, congruent with relevant stakeholders' visions, and could be used as guidelines in practice. In this article, we report on requirements as found in Dutch ID policy and on the results of consultations of panels of stakeholders and experts working in the field of ID. The research questions are: (1) what formal requirements on ISP process and/or content exist; and (2) what are expectations regarding ISP according to stakeholders and experts in the field of ID.

2. Method

2.1. Desk research identifying formal requirements

The study started with a desk research of relevant Dutch Acts and official policy documents to identify requirements that affect the process and/or content of ISP. Official documents in this project were considered Health Care Acts and complementary regulations that have a mandatory impact on ISP and may lead to consequences for service provider organizations in case such requirements would not be met. Included in this study were:

- Health Care Acts: Exceptional Medical Expenses Act (AWBZ), Individual Healthcare Professions Act (Wgbo), Psychiatric Hospitals Compulsory Admission Act (BOPZ);
- current requirements from the Dutch Healthcare Inspectorate with respect to ISP in the field of ID;
- the quality framework for service provision as formulated by the Dutch Association of Service Providers (VGN, 2013);
- regulations stemming from budget allocation agencies (insurance agencies).

For retrieving the requirements in these documents, we read each document and searched with the Dutch equivalents of the terms 'care plan(ning)' and/or 'support plan(ning)' and '(intellectual) disability' and/or 'mental retardation'.

2.2. Consulting stakeholders and experts

Consultations with stakeholders took place in the course of one year. Two panels were set up. Panel A was asked to reflect on the formal requirements, their organization in domains and later, to evaluate the outcomes of Panel B and to decide on the final list of requirements. Panel A consisted of relevant stakeholders at the national policy level. Purposive sampling was used to decide which organizations should participate in this panel and invitations were sent by the researchers to these organizations to participate and to form their delegation in the panel. All invited organizations accepted the invitation. Panel A comprised eleven representatives from: four different self-advocate organizations ($n = 4$), the Dutch Association of Service Providers ($n = 1$), quality management officers from four service provider

organizations (*n* = 4), and legal advisors specialized in Health Law: one legal advisor worked in a service provider organization and the other worked at the Dutch Association of Service Providers (*n* = 2). Panel A was consulted twice: first after the initial desk research to formulate the input document for Panel B and later after consulting Panel B.

Panel B comprised three groups of professionals working in the field of ID. The first group consisted of an existing advisory expert network of legal advisors (*n* = 7) facilitated by the VGN. The second group was an expert network of quality officers working in Dutch service provider organizations (*n* = 10) facilitated by the VGN. The people that participated in this network work at different service provider organizations and differ from the people and organizations that participated in panel A. The first author visited a regular meeting of each of these networks and initiated an open group discussion on what, from their professional point of view, was considered important for ISP. The researcher led the discussion and detailed minutes of the discussion were taken and afterwards checked by the participants. The third group consisted of project leaders (*n* = 28) that were participating in the nation-wide improvement program on working with ISPs in The Netherlands. Project leaders were professionals with a bachelor or masters degree in psychology, special education or health care sciences. These groups were offered a document with the provisional outcome of the desk research and comments of Panel A. They were subsequently asked to answer the question: 'what do you find important to appropriately work with ISP in professional supports of people with ID?' The groups of Panel B were invited to eventually add requirements they considered important in practice. The results of these consultations were finally presented to Panel A in order to produce a list of ISP requirements based on formal requirements, and views of stakeholders and experts in the Dutch field of ID.

The requirements that were found during the desk research and the statements that were made by the people during the consultation phase were categorized by the researchers according to the domains of: content, process, quality and person-centeredness of ISP.

3. Results

The requirements as found in the desk research and in the consultations are summarized in Table 1. Identification numbers are used to tag the source of the criterion: '1' when that the requirement was found in Health Care Acts; '2' for Healthcare Inspectorate requirement; '3' for a requirement from the Dutch Quality Framework of service providers 2013 (VGN); '4' for a requirement from Dutch Insurance companies; and '5' to tag the outcomes of the consultation of the panels.

3.1. Formal requirements

3.1.1. Health Care Acts

The rights of people with ID who are clients of professional service providers are protected through several acts. A central aspect in these acts is the focus on the right to self-determination (Herps, Buntinx, & Curfs, 2010; Frederiks & Dörenberg, 2012). This right is reflected in various acts that refer to ISP. The 'Besluit Zorgplanbespreking AWBZ-zorg' (2009) mandates the use of ISP with the aim of enhancing person-centeredness. It states that there should be an ongoing dialogue between professional support workers and people with ID regarding their supports and that the results of that dialogue should be incorporated in the ISP document as mutual agreements regarding the provision of supports. If the person with ID is not thought to be 'mentally competent' to decide on (parts of) the ISP, this dialogue is between the paid support worker and the legal representative of the person with ID. The Individual Healthcare Professions Act (Wgbo) states that a personal file should be kept for each individual. The ISP is regarded to be part of this file. The Psychiatric Hospitals Compulsory Admission Act (BOPZ) is applicable whenever a person is admitted to a residential service for persons with ID against his or her will, if they do not agree with the provided care and/or if the person is unable to give or withhold consent for admission. In these cases, a professional 'treatment plan' is to be put in place, describing the treatment and how the 'danger' the person poses to himself or to others is being reduced or eliminated (Herps et al., 2010).

Table 1

Overview of ISP requirements as formulated in official policy sources and stakeholders and experts in the field of ID.

Domain	Requirements
Content: what should be addressed in an ISP document?	Support goals related to quality of life, and the agreements that are made to achieve these (1,3,5) Resources and strategies (1,5) Needs and wants of the individual (1,5) Overview of medication (2,3) Restrictive interventions[a] (2,3) Conclusions of diagnosis, strengths and weaknesses (2) Risk analysis and prevention of risks (2,3) Agreement with the ISP from clients/representatives (preferably in the form of a signature) (2,3,4) If the topic of sexuality is part of the ISP (3) The ISP should mention which professionals are responsible for the ISP (1)
Process: what are procedural requirements?	Involvement of the person with ID and/or their legal representative in ISP development (1,2,5) The ISP-cycle follows a Plan-Do-Check-Act-cycle (2,5) Agreed by client and/or representative (1,2,3,4,5) A first ISP document should be written within the first six weeks of support delivery (1,3) Yearly review of the ISP (1,2,3,4) Involvement of a multidisciplinary teams (2)
Quality: requirements regarding organizational ISP-policy	Each organization should have a policy document regarding ISP (3, 4) This policy document should be reviewed on a regular basis (3) Organizations need to protect the privacy of clients (5) Every organization describes who is responsible for the procedures (5) ISP is part of the client's file and makes references to other (personal) information and professional (treatment) plans (1,5) Having a vision on ISP and develop the ISP procedures and format accordingly (5)
Person-centeredness	ISP related documents should be understandable/in clear language (1,5) Active involvement of the person with ID[b] in all ISP components (1,2,3,5) The annual review meeting should be based on equality between the individual, their representatives and professionals (5) The person with ID[b] is informed about the development and evaluation of ISP policy (5) The individual with ID is in control (choices in content and process, resources) (1,3,5) The person with ID[b] have access to their personal file and to their ISP document (1) The individual has a copy of their ISP (5) The individual is seen in the context of his/her social network (5)

[a] What interventions are used, the reasons for using these interventions, perspectives of clients, representatives and involved professionals regarding the use of these interventions.

[b] And/or their legal representatives.

3.1.2. Requirements by the Healthcare Inspectorate

The Healthcare Inspectorate pays announced and unannounced visits to locations of service providers. A quick-scan is used to assess risks with respect to safety, restrictive interventions, ISP and quality of staff and organization. During these site visits, the inspectorate talks with clients, staff and managers and inspects samples of ISP documents and files. The items with respect to ISP are summarized in Table 1 (tagged 2). Based on the results of the quick scan, the Healthcare Inspectorate decides if the location meets their criteria and if not, what measures need to be taken. Measures vary from improving specific items to getting placed under guardianship of the Healthcare Inspectorate.

3.1.3. The official quality framework as set by the Association of service providers

In 2013, the Dutch Association of service providers implemented a quality framework (VGN, 2013). This framework is based on a vision document (VGN, 2007, 2013) in which 'self-determination' and 'quality of life' are the leading concepts. ISP is regarded to be one of four preconditions for delivering quality supports. The other three preconditions are safety; quality of staff and organization; and consistency in care and supports. Every member organization of the Dutch Association of Service Providers is required to report on these preconditions through standardized surveys on a yearly basis. Table 1 (tag 3) mentions indicators in this surveys regarding ISP that were part of the mandatory data set in 2013.

3.1.4. Nation-wide regulations stemming from budget allocation agencies

Service provider organizations receive their budgets through insurance companies. Budgets are approved provided that the organization meets specific criteria. Regarding ISP, insurance companies require that the service provider organization documents the ISP process and that every person with ID or his/her representative signs their ISP. As part of their quality policy, regional offices of these insurance companies can set extra criteria as incentives for extra budget. These criteria differ per region and per year. Organizations that work in more regions have to deal with requirements from different insurance companies. ISP related criteria of insurance companies are shown in Table 1 (tag 4). Not meeting criteria set by budget allocation services, can lead to missing funding.

3.2. Consultation of stakeholders and experts

The discussions in the panels finally led to a confirmation of the importance of some of the formal requirements (see Table 1, tag 5). For example, the AWBZ states that the ISP should describe the goals and agreements between a person with ID and a service provider organization. This requirement was found important by all stakeholders that were involved in this study.

The consultation also added extra requirements regarding ISP. For example, stakeholders discussed that the increasing use of digitalized files and ISP documents raised issues of client privacy (who has access to the individuals' files) and that it presents an important quality aspect.

4. Discussion

The study identified nation-wide requirements regarding the content of ISP documents, the procedures regarding ISP, the policy that service provider organizations need to install for ISP within their organization, the requirements related to person-centeredness and the function that ISP has according to different stakeholders. The results seem to confirm the statement of Charmaz (2006) that different stakeholders develop their own understanding of what constitutes 'good ISP'. The variety of requirements and different perspectives with respect to ISP quality can have several implications in ID practice.

First, the amount of and variety within the criteria can lead to confusion about the principles, methods and desired outcomes of ISP (Schwartz et al., 2000, p. 236). Workers in the field of ID face the challenge of balancing the criteria in workable ISP procedures. This results in a tendency to include a vast amount of information in the ISP, resulting in ISP documents ranging up to fifty pages and more (Herps, Buntinx, Schalock, Van Breukelen, & Curfs, 2016). This increases the staff's workload, bureaucracy and reduces the likelihood of using the ISP in practice (Stancliffe, Hayden, & Lakin, 1999).

Second, even though the legal justification for mandating ISP is based on 'enhancing person-centeredness', few formal requirements address this aspect. These requirements leave little room for tailoring the content of ISP documents and procedures in developing and implementing ISP. Standardized forms and processes are implemented leaving little room for flexibility and person-centered approaches to planning (Mansell & Beadle-Brown, 2004; Kinsella, 2000; Schalock et al., 2008; Cambridge & Carnaby, 2005; Adams et al., 2006; Stancliffe et al., 1999).

Third, setting criteria and consequences for not meeting the criteria, is no guarantee that the intention or goal behind those criteria is met (Cook & Odom, 2013; Smull & Lakin, 2002). For example, one criterion is that the person with ID and/or his representative are involved in the process of developing

and reviewing their ISP. A study of Herps et al. (2013) demonstrated that even though people with ID are often present at ISP review meetings, they do not feel involved because they do not fully grasp the meaning of the meeting or a non-person-centered approach is used during these meetings. It is important that a written ISP document that ticks all the boxes is not the outcome, but rather that the implementation of the goals and agreements that are set in the ISP document have effectively led to the enhancement of the person's quality of life.

As the present study was part of a larger, nation-wide program, concessions had to be made regarding the selection of participating organizations and people, and regarding the analyses of the outcomes. The present study had a pragmatic approach and although it resulted in a description of the current formal criteria and expectations of stakeholders, an interesting next step would be to develop solutions for the issues raised here, involving both policy and practice. Therefore, the results of the present study highlight some key issues in ISP in policy and practice and can be regarded as a first step in improving ISP policy and practice in The Netherlands.

Disclosure of interest

The authors declare that they have no competing interest.

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