The perspectives of NASC service coordinators on the use of self-assessment

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Abstract

Background. Using a supported self-assessment process is thought to empower people with disabilities to be more in control of their lives (Ministry of Health, 2015). This research aimed to investigate the experiences of service coordinators on the use of the supported self-assessment called Understanding You and Your Situation (UYYS).

Method. Interpretive description was the qualitative methodology used in this study. Semi-structured interviews provided qualitative data from 6 participants. The interviews were undertaken to capture the service coordinators' practice and attitudes toward the use of the UYYS. Data analysis applied the Qualitative Analysis Guide of Leuven (QUAGOL).

Findings. Four key concepts were identified on the use of UYYS. These related to: (1) the process of the UYYS, (2) the need for face-to-face interactions, (3) comparison with traditional needs assessment, and (4) assessors' skills. These concepts provided important information in understanding the UYYS process and how it is linked to a funding allocation tool.

Implications. The concepts found in this study can be used to guide other Needs Assessment Service Coordination (NASC) agencies planning to adopt the UYYS.

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> “*Just when the caterpillar thought the world*
> *was over, it became a butterfly*”
> - Proverb

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To God be the glory.

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Chapter 1: Introduction

This research examines the emerging role of supported self-assessment in the context of the New Zealand Disability Strategy 2014 to 2018. The vision of the New Zealand Disability Strategy is to support people with disabilities and their families to live the life they choose (Ministry of Health, 2015). One of the guiding principles of the New Zealand Disability Strategy is to promote individual autonomy and independence by encouraging people to make choices regarding the disability supports that they receive. Over the last few years, the Ministry of Health (MoH) has been transforming New Zealand's disability system to provide people with disabilities and their families' greater choice and control (Ministry of Health, 2015). This has led to a number of projects promoting choice and control, and this study examines one of these projects, i.e. supported self-assessment, which aims to enable people with disabilities to take control of the assessment process.

In 2011, the MOH introduced the 'New Model for Supporting Disabled People'. This was intended as a radical departure from previous practice, the purpose of which was to provide people with disabilities and their families' greater choice and flexibility over their supports by implementing four key components in the disability support system (Ministry of Health, 2015). The components of the New Model include:

1. Choice in Community Living (CiCL) - The CiCL initiative provides opportunity for people with disabilities to choose where they want to live and how they want to be supported (Evalue Research, 2015; Ministry of Health, 2015). It is an alternative to living in residential care and is offered in Waikato, Auckland, Hutt Valley and Canterbury regions.
2. Local area coordination (LAC) - The term LAC refers to a community-based approach in supporting people with disabilities and their families live a good life. Local Area Coordinators (LACs) help strengthen the person's natural supports in the community and provide them information and support in working towards their goals (Evalue Research, 2012).
3. Enhanced individualised funding (EIF) – EIF is a form of self-directed support that enable people with disabilities to have choice and control over how their allocated funded supports are spent to best meet their goals (Ministry of Health, 2013).
4. Supported self-assessment (SSA) – SSA is a process where people with disabilities are given the flexibility of filling out the form themselves at their own pace and in their

own time. They can choose whoever they want to help them write their goals and the impact their disability have on their lives.

The four elements of the New Model were trialled over a three-year demonstration period in three particular regional areas across New Zealand (Ministry of Health, 2015): Auckland, Waikato and Bay of Plenty. The New Model for Supporting Disabled People ended in 2014, and was effectively redeveloped as the ‘Enabling Good Lives Model’ (EGL). Two demonstration projects were initiated in Christchurch and Waikato (Anderson, Janes & Pope, 2017; Were, 2017; Ministry of Health, 2015). The EGL is a partnership between the MOH, the Ministry of Education, Ministry of Social Development and disability organisations and has the intention of transforming the disability support system, so people with disabilities have access to mainstream supports that are flexible and tailored to their needs (Ministry of Health, 2015).

One of the principles of EGL is to empower people with disabilities to be more self-determined through using a supported self-assessment process. A self-assessment form called *Understanding You and Your Situation (UYYS)* was developed and trialled in 2010. Then under the New Model, the objective of the trial was to promote self-determination by getting people to complete the UYYS form by themselves and to think creatively about tailoring their supports to live a good life (Evalue Research, 2012; Were, 2017; The Independent Working Group on Day Options, 2011).

In the Enabling Good Lives model the overall aim is self-determination, so, completing the UYYS is ideally associated with person-centred funding (or Enhanced Individualised funding (EIF)). In the demonstration being carried out by the Enabling Good Lives team in Canterbury, person-centred funding is effectively connected to the SSA. How this works is that after the individual completes the UYYS, Service coordinators calculate the amount of funding based on the person’s unmet disability needs. People with disability then control how this funding is spent or what they use the allocation for (Anderson et al., 2017; Were, 2017).

The Working Group (2011) was formed to develop the principles in the EGL model. This group proposed a move toward individualised and flexible disability supports that enable people to participate in the process (The Independent Working Group on Day Options, 2011). The Working Group (2011) further elucidated the notion of ‘self-directed’ support, to refer to a process of allocating personal budgets, with the intention of empowering people with disabilities to opt for supports suitable to their needs (Working Group on Day Options,2011; Evalue Research, 2015; Slasberg, Beresford, & Schofield, 2012). The EGL model refers to self-directed support as personal budget which is the same terminology used in disability care in the United Kingdom (Ministry of Health, 2015; Harkes, Brown & Horsburgh, 2014). In this study, “personal budget” will be used solely when referring to the process of allocating budget to pay for disability support services (Ministry of Health, 2012; Ministry of Health, 2013).

One of the projects of the original demonstrations of the New Model for Supporting Disabled People was the implementation of the UYYS in the NASC agency. Disability Support Services (DSS), an agency operating under the direction of the (MoH), is responsible for funding disability services to support people with long-term physical, intellectual or sensory needs (Ministry of Health, 2015). People with neurological conditions resulting to permanent disabilities, and children with developmental disabilities receive appropriate supports and services through DSS. Examples of these various supports and services DSS fund are carer relief, respite care, household management assistance, personal care assistance, supported independent living services, and community residential services (Disability Support Services, 2015). In addition, DSS provides funding for home and equipment modification to help people with disabilities become more independent in their everyday activities (Ministry of Health, 2015). DSS holds contracts with over 900 service providers that deliver the supports and services previously stated.

In order to access DSS-funded supports and services, Needs Assessment and Service Coordination (NASC) services identify the person’s eligibility for disability supports through completion of a needs assessment process. There are 16 NASC agencies across New Zealand contracted by the MOH to facilitate needs assessment and coordinate DSS-funded supports and services (Disability Support Services, 2015; Ministry of Health, 2015).

The term *‘traditional needs assessment’* is used in this study to refer to the standardised needs assessment NASC agencies use to determine the person’s unmet disability needs. Traditional needs assessments are conducted face-to-face by a service coordinator using a MoH-approved need assessment form. The completion of needs assessment helps NASC gain better understanding of the person’s abilities and unmet needs that are important for them (Disability Support Services, 2015).

Throughout this paper, the term '*service coordinator'* refers to a person employed by NASC to facilitate needs assessment and coordinate disability support services. The role of the service coordinator is to complete the needs assessment process directly with the person to identify the person's strengths and prioritised needs. Apart from this, the objective of the service coordinator is to complete the needs assessment process and determine the person's eligibility to receive DSS-funded supports by confirming the person's disability through obtained information. Information such as specialist assessment reports help to establish the person's diagnosis of disability (Ministry of Health, 2007). Experience working within a disability sector and a relevant tertiary qualification are the specifications for the service coordinator role, however, few service coordinators are trained health professionals (Ministry of Health, 2007).

The UYYS replaced the traditional needs assessment in the community, although the traditional needs assessment remained the standard assessment for people with disabilities living in residential care (Evalue Research, 2015). However, although the UYYS replaced the traditional needs assessment, the NASC agency had to consider whether it was appropriate for people with disabilities and their families to complete the form by themselves (Evalue Research, 2012).

There were a number of factors to consider when implementing self-assessment, such as literacy levels, English as secondary language and lack of natural supports. Although people with disabilities and families are encouraged to fill out the UYSS themselves, they may ask a NASC service coordinator or a family member to support them to complete the form, particularly those with literacy issues (Evalue Research, 2015). People with disabilities can have face-to-face contact with their NASC service coordinator should they require support to complete the form because of the above mentioned factors (Evalue Research, 2015).

A demonstration site was chosen that had a significant population of Māori and younger people, as well as a mix of people living in urban and rural areas (Evalue Research, 2012). As one of the New Model's four components, the implementation of the SSA started in October 2011 and an evaluation of its effectiveness was reported by Evalue Research a year after its launch (Evalue Research, 2012). The report by Evalue Research (2012; 2015) had very little focus on the UYYS, and in particular did not provide any real evidence on the effectiveness of the UYYS. The evaluative assessment of Evalue Research (2015) on the use of UYYS concludes:

> *"It is not possible to draw any definitive conclusions about the effectiveness of supported self-assessment for disabled people given the small number of participants in our sample who had used the form and the range of their responses"* (p. 51).

There is therefore very little known about the UYYS. However, the use of UYYS is increasingly being proposed as 'best practice' and developments pioneered by the demonstration site could be instrumental in shaping how supported self-assessment tools is rolled out in other regions.

As a service coordinator working for Capital Support NASC, I facilitate needs assessment and coordinate services for people with disabilities within the Wellington region. I become interested in supported self-assessments when this was indicated as one of the recommendations in the external audit report for Capital Support NASC. The use of supported self-assessment might be relevant to occupational therapy but I am deliberately not going to focus on this, because I am employed in a generic role. The external audit report suggested that Capital Support should investigate the use of the SSA as it is currently being used in the demonstration site. Although Evalue Research reports have recognised and minimally evaluated the use of SSA, the role of SSA in NASC remains largely unexamined. Also, there is no previous study that has investigated the role and use of SSA in disability NASC. Therefore, this research aimed to investigate the experiences of service coordinators on the use of self-assessment following its inception in a particular NASC agency seven years ago. This study aimed to answer the research question: *What are the perspectives of NASC Assessors about the use of supported self-assessment?*

This study has two key aims (with sub questions).

- To investigate how and when the SSA is being used.
- To explore the advantages and disadvantages of using the SSA in comparison with the traditional needs assessment.

The findings of this study are intended to provide insights into the process of self-assessment which could potentially be used by NASC service coordinators and lead to a trial of supported self-assessment tool in the wider Wellington region.

Structure of the Study

The overall structure of the study takes the form of six chapters. The introduction has outlined the background of supported self-assessment in the context of the New Zealand Disability Strategy, Enabling Good Lives and the ‘New Model’.

The literature review in Chapter 2 includes a discussion of self-assessment in the context of strength/ deficit-based assessments.

Chapter 3 describes the methodology and method, including the interpretive descriptive approach utilised in the study.

Chapter 4 presents the findings of the research, focusing on the four key themes that emerged from the participant interviews.

Chapter 5 discusses the significant findings and includes the implication of the findings for practice and future research.

Chapter 2: Literature Review

The aim of this chapter is to review the literature on self-assessment. There are two sections in this chapter. In the first, the concept of self-assessment is scrutinised. In section two, the way that self-assessment is used in NZ is examined.

Section 1

The first section contextualises the research by providing background information on self-assessment. Further information regarding the definition of self-assessment and the different ways self-assessment is used in health and clinical situations is provided in this section.

1.1. What is self-assessment?

The definition of self-assessment varies in the literature and there is terminological confusion. Web-based databases were used to search for the meaning of self-assessment and at times a combination of search terms were entered. Since the definition of self-assessment varies among researchers, it is important to clarify how the term is used in social and health care. Grey literature and evaluation reports within the field of social and disability care from Australia, England and New Zealand frequently used the term "*self-assessment*" (Evalue Research, 2012; Australian Federation of Disability Organisations (AFDO), Deafness Forum, People with Disability Australia, and Women with Disabilities Australia, 2011; Tucker, Brand, O'Shea, Abendstern, Clarkson, Hughes, Wenborn & Challis, 2011). Griffiths (2005) defined self-assessment as "*the client's response to an evaluative question about health status or need asked by a practitioner*" (p. 522).

On the other hand, in the academic literature, peer-reviewed articles in health care appear to use several terms that describe self-assessment. For example, '*Self-report'* is used in physical health (Wand et al., 2010; MacDonald, 2010), and this is defined as a method of gathering data where individuals report information about their health condition, feelings or beliefs without direct involvement from a health professional. The term "*patient-reported outcome (PRO)"* is used by Mejdahl, Schougaard, Hjollund, Riiskjær, Thorne and Lomborg (2018) in health care service. Mejdahl et al. (2018) defined PRO as a "*measurement based on a report that comes directly from the patient about the status of their health condition*" (p.1). Both PRO and self-report have generally been developed as quantitative assessments.

It seems that self-assessment tends to be used as a way of more qualitatively capturing the perceptions and attitudes of people with disability (Productivity Commission, 2011). The definition given by Griffiths (2005), above, is the one that seems to more clearly describe what is happening in New Zealand with the UYYS and so this is the term that is used in this literature review.

1.2. Why is self-assessment used?

The term "self-assessment" refers to the ability of the person with disability to report his or her own needs (Productivity Commission, 2011). According to Griffiths (2005), self-assessment is used to consider the person's understanding of his or her own health needs. Self-assessment is therefore a way of encouraging patients to become more actively involved in the management of their own health needs (Mejdahl et al., 2018). In a pilot study of self-assessments in selected sites in the United Kingdom, Glendinning et al. (2008) reported that self-assessments reinforce positive communication between the service user and the health professional and tend to improve patient-professional therapeutic relationship (Mejdahl et al., 2018).Therefore self-assessment is used as a way of empowering individuals to develop an action plan about their own health without the need to rely on health professionals' clinical expertise (Griffiths, 2005; Productivity Commission, 2011)

1.3. Where has self-assessment been used?

There is a range of different ways that self-assessment can be used clinically. For example:

a) One form of Self-assessment can lead the person paying or doing something to help themselves, for example, in learning about equipment that they can self-fund, or to manage their own symptoms. The "Ask SARA tool", used in the United Kingdom, is an example of interactive online self-assessment that provides a personalised report of useful products and equipment for people with disabilities (MacDonald, 2011; Tucker et al., 2011).

b) Another form of self-assessment can be used in situations where there is no strong evidence that there is any strong advantage from a clinician doing the assessment. For example, self-reporting is used in the UK for driving, whereas in many other countries there is medical assessment of fitness to drive (Elgar et al., 2016).

c) Self-assessment can be used instead of a clinician follow-up, and this seems to be increasing. For example, the study undertaken by Mejdahl et al. (2018) describes the use of PRO-based follow-up in three outpatient clinics to determine whether patients could self-manage their symptoms of epilepsy.

d) Self-assessment is also used in research and health care to predict health status and mortality risk. For example, the Global Self-Rated Health (GSRH), (Lee, 2015; Griffiths, 2005).

e) Finally, self-assessment can be used as a tool to inform funding by the health service. For example, in the United Kingdom, the information that comes from the self-assessment is translated to an indicative funding using a funding allocation tool (Glendinning, et al., 2008).

This final use of the term is the way that self-assessment is being used in this study.

1.4. The composition and format of self-assessment

Self-assessment typically consists of self-administered questionnaires with individual responses determined by a four-point Likert scale (Griffiths, 2005; Nakamura-Thomas & Kyougoku, 2013; Mejdahl et al., 2018; MacDonald, 2010). An example of this Likert-type questionnaire is the Occupational Self-Assessment (OSA), a 29-item rating scale that allows the person to report their perspectives of their own occupational competence in everyday activities (Nakamura-Thomas & Kyougoku, 2013).

There are also self-report tools which combine a rating scale and a performance test. For example, The Roland and Morris Disability Questionnaire (RMDQ) is a notable example of a self-report that requires the person with low back pain (LBP) to rate their performance on 24 activities (Wand, Chiffelle, O’Connell, McAuley & DeSouza, 2010) . Following completion of the self-report, the person gets assessed by a therapist using a functional assessment, which is part of the performance test to measure the person’s speed and experience of pain.

In health and disability settings, self-assessment tools are commonly presented in traditional paper-and pencil formats that are either posted out to subjects or sent through electronically (Griffiths, 2005; MacDonald, 2010; Harris, 2006). However, online versions of paper-and – pencil questionnaires have become more widespread and acceptable in this day and age

(Harris, 2006; MacDonald, 2010). Tucker et al. (2011), in their evaluation of self-assessment pilot projects in various local sites in England, mentioned that people receiving occupational therapy services were able to assess their need for community assistive equipment through web-based assessment tools. These studies demonstrated significant advantages of using electronic version of self-assessments. The automated questionnaires provide direct access to services, improve customer experience and reduce patient wait list times (Harris, 2006; Tucker et al., 2011).

Griffiths (2005) and Harris (2006) helpfully suggest 3 practical elements a self-assessment tool should have. Firstly, the person must provide details about one's overall history and health condition (self-report). Secondly, the assessment tool itself should be completed by the person rather than without immediate involvement from the person's family or team of professionals (self-completion). Thirdly, the person is the one who will benefit from completing the self-assessment by increasing their independence and actively participating in the process (Griffiths, 2005; Productivity Commission, 2011).

1.5. When is self-assessment used?

Self-assessment has been used in various health care settings for the purpose of screening for specific medical or health condition (Harris, 2006). As has already been noted, the Global self-rated health functions not only as an indicator of one's overall health status, but also determines whether or not the person requires long-term residential or rest home-level of care (Harris, 2006; Griffiths, 2005).

Apart from screening-related purposes, self-assessment has been used to aid clinicians to differentiate between patients who require urgent medical attention and those who are capable of managing their own symptoms (Mejdahl, 2018). As indicated previously, the data derived from patient's PRO helps health professionals in assessing potential patients with self-management skills. For example, patients who have the capacity to take ownership of their epilepsy and its symptoms, and the ability to self-manage the symptoms in their everyday life (Mejdahl, 2018).

For the purpose of determining eligibility for support, self-assessment has been increasingly used across adult social services (Tucker, 2011). People with disabilities participate in the assessment process by accessing web or telephone services to determine the appropriate daily living equipment and adaptations for them (Tucker, 2011; MacDonald, 2010).

1.6. Who performs self-assessment?

Service users are encouraged to actively participate in the process of self-assessment (Griffiths, 2005). From a social care perspective, people with disabilities are regarded as the experts of their lives and more than others, they know how their disability impacts on their daily routine (AFDO, 2011; Productivity Commission, 2011). However, there are obvious difficulties in writing down self-report information. MacDonald (2010) and Griffiths (2005) point out that people who are severely cognitively impaired will find the process of self-assessment challenging. In addition, it does appear that older people have a tendency not to respond to self-administered questionnaires (Harris, 2006; Griffiths, 2005; MacDonald, 2010).

While Glendinning et al. (2008) identified that service users can complete self-assessment themselves, Griffiths (2005) and the Productivity Commission (2011) were more concerned with the accuracy of the self-assessment in the absence of professional input. It has been suggested that professional-driven self-assessments help service users identify the appropriate support to meet the goals indicated in their self-assessments (Productivity Commission, 2011). This view was supported by Griffiths (2005), who stated it was the role of health professionals to review the content of the assessment and determine suitable management or support options for service users.

Much of the literature on self-assessments has emphasised the importance of family members, friends and carers in the process of self-assessment (Griffiths, 2005; Glendinning, 2008; MacDonald, 2010). The inclusion of family members and carers is considered particularly important in supporting older people and people with intellectual disabilities over the course of self-assessment process (Glendinning, 2008; Brooks, Mitchell & Glendinning, 2017). The presence of these people who serve as advocates ensure that the service user’s views are heard and they are part of support planning that comes after the completion of the self-assessment tool (Glendinning, 2008; MacDonald, 2010).

However, concerns are sometimes raised about the impact the views and perceptions of family members and carers may have on the assessment questions about the service user

(MacDonald, 2010; Glendinning, 2008). It has been reported that carers tended to dominate the assessment process supplying information that could be different from those provided by the user of the self-assessment (Glendinning, 2008; Griffiths, 2005). This conflicting information given by both parties could be difficult for the service coordinator to interpret and could have a significant impact on the allocation of disability funding (Glendinning, 2008).

1.7. Potential problems and benefits of self-assessment

One of the strengths of self-assessment is that it cultivates a sense of ownership by encouraging people to take responsibility of their health conditions (Mejdahl et al., 2018). Patients who used the PRO questionnaires indicate that they feel comfortable about making active choices for their lives, which provides them with the opportunity to test their capacity to self-manage their illness (Mejdahl et al., 2018).

Not everyone, however, is unperturbed about being the driver of their self-assessments, and in the case of the PRO follow-up, some patients indicate that they are contented to take the back seat and let health professionals facilitate the PRO questionnaire (Mejdahl et al., 2018). Where this is the case, it can be beneficial to train health professionals in the use of self-report or self-assessment questionnaires (Mejdahl et al., 2018; Tucker et al., 2011; MacDonald, 2010; Elgar et al, 2016).

Boyce et al. (2014) made a similar point in their study of patient-reported outcome measures (PROM) by investigating the attitudes and experiences of health care professionals who use various PROM. The authors suggested that the involvement of health care professionals in the development stages of the PROM could help improve their use of the outcome measure tool.

Elgar (2016) emphasised that education should not only involve health professionals, but also patients. Without appropriate education in the use and content of self-assessment, there is the potential for patients to misunderstand the purpose of a self-report questionnaire. Mejdahl et al. (2018), highlights the barriers to completing the PRO-based questionnaire, and emphasises that patients need to recognise the connection between the self-report questions and their condition. If patients have difficulty in seeing this connection, it can result in them having problems in assessing their own needs and being able to actively participate in the assessment process (Mejdahl et al., 2018). Stuart, Pasco, Jacka, Brenna, Berk & Williams (2014) made a similar point in their study of a self-administered depression symptom scale compared with a

Structured Clinical Interview (DSM-IV (SCID), which is a standardised psychiatric examination. The authors point out that a patient's lack of understanding of the self-assessment method as well as the symptoms of their depression can influence the accuracy of the self-assessment.

Section 2

The second section of this chapter begins by examining how self-assessment is used in New Zealand disability services, and looks at comparing the differences between deficit-based and strengths-based assessments. This section also aims to introduce the process of Understanding You and Your Situation (UYYS) supported self-assessment form, and its comparison with the traditional needs assessment.

2.1. Use of Supported Self-Assessment in New Zealand Disability Services

Across disability settings, self-assessment involves the use of a set of questionnaires that people with disabilities complete to allow a disability service to come up with a plan that is generated by an individual (Griffiths, 2005; Australian Federation of Disability Organisations, 2011). In needs assessments, self-assessment questionnaires have become one of the most common tools used (Finlayson, 2017). This method provides people with disabilities the opportunity to express themselves and create a positive setting to talk about their goals and needs (Glendinning et al., 2008). The needs assessor makes use of the person's language and perspectives when identifying and interpreting information (Finlayson, 2017). Glendinning et al. (2008) see self-assessment as a collaborative effort with the person with disability, families and needs assessor all involved in the process

The Supported Self-Assessment (SSA) was developed and used at one demonstration site for the pilot of the New Model for Supporting People with Disabilities. The SSA is a combination of narrative self-report and multiple choice survey questions (Evalue Research, 2012). Throughout this study, the term "Understanding You and Your Situation" (UYYS) will refer to the SSA used at the demonstration site (see Appendix 1).

Although Evalue Research (2015) have outlined the sections that constitute the UYYS, there appears to be no description of the format of the UYYS available in the literature. Therefore, Table 1 is provided to give an overview of the four sections of the UYYS form (see also appendix 1). The UYYS has 10 pages and includes a combination of narrative, check boxes and Likert-type of questions. While page 1 covers the consent form, pages 2 and 3 consist of demographic questions that the person with disability and their family have to fill in with their details. Page 3 of the assessment form contains a narrative section that prompts the person to provide an overview of their current situation and tell the reader about their life. The succeeding page continues with another narrative question about how disability affects the person’s ability to manage daily practical activities. What follows after the narrative section is a combination of tick boxes and Likert-type questions that prompts the person to indicate when support is required, how many people is needed to support them, and how much assistance the person is getting from their natural supports. The assessment concludes by asking the person with disability and their family to write down any formal supports they currently receive. The information from each section of the UYYS form is scored using a funding allocation tool that generates an indicative amount (Evalue Research, 2015). The indicative funding is moderated by considering factors such as the client’s needs and the level of disability support. The service coordinator and the person with disability discuss the indicative allocation to identify appropriate supports and services (Evalue Research, 2015)

Table 1. Sections of the UYYS form

“Understanding You and Your Situation”	
Section One	Includes information about consent and the individual’s contact details
Section Two	Narrative section: Tells the reader about the person’s story and life events
Section Three	Narrative section: Focuses on the person’s needs and how disability impacts on their everyday life
Section Four	Tick boxes and Likert scales: Talks about formal supports the person currently receives.
The last two pages of the form is where the person with disability or their whanau signs to confirm that everything written on the form is accurate. After the person with disability completes the initial self-assessment, the NASC service facilitator allocated to the person determines the amount of funding required to fund their disability support services.	

2.2. Deficit-based assessment versus strengths-based assessments

Much of the literature on strengths-based assessments has emphasised the importance of gathering information from the viewpoint of the person with disability (Anderson & Heyne, 2013). The assessment becomes a collaborative process between the person and the practitioner, with the health professional helping the person to discover their strengths, goals and interests (Niemiec, Shogren & Wehmeyer, 2017). This is very similar to the intention of the self-assessment process and Evalue Research (2015) describes the main features of the UYYS that makes it a strengths-based assessment. First, the person with disability is the expert on his or her life and does this by taking the initiative of completing the self-assessment. Second, the person and their support people fill in the form at their own pace and in a time that is convenient for them. Then, the person considers the expertise of those around them to obtain a comprehensive assessment.

Anderson & Heyne (2013) carried out a comparison deficit-based and strength-based assessments for therapeutic recreation. Adopting a similar position as Evalue Research (2015) with regard to people taking the lead on completing assessment, Anderson & Heyne (2013) highlighted the importance of empowering people to be in-charge of the assessment process. In addition, the authors take into account the involvement of the person's natural supports in the completion of the assessment, which makes it even more a strengths-based process. Niemec et al. (2017) emphasised the importance of the role of health professionals in promoting strengths-based assessments of natural supports as this could lead to increased understanding of the person's strengths and abilities.

2.3. The UYYS in comparison with different self-assessment tools

The UYYS has a narrative component as well as a portion of check list and Likert-type questions.

The mode of facilitating the UYYS is similar to other self-assessment tools used in various settings around the world. For example, both the UYYS and one of the previously mentioned self-assessments, the OSA, are facilitated face-to-face by a health professional in collaboration with the service user (Evalue Research, 2015; Kielhofner et al., 2010; Nakamura-Thomas & Kyougoku, 2013).

One advantage of facilitated self-assessments is that it exercises shared decision-making when it comes to developing plans and goals (Anderson & Heyne, 2013). By learning about the person's story during the assessment process, the health professional supports the person to explore their aspirations and strengths, and uses these attributes to navigate barriers (Anderson & Heyne, 2013).

In terms of filling out the form, one of the most notable differences between the UYYS and the OSA is that the UYYS provides the option of a hardcopy of the assessment form that can be mailed to the person with disability to fill in themselves (Evalue Research, 2015). The OSA, on the other hand, does not appear to have that "send-by-mail" option and is only filled in with an occupational therapist present. Similarly, with the UYYS, people with disability have the option to request a service facilitator who complete the form with them (Evalue Research, 2015).

Another area where significant differences between the UYYS and other self-assessment tools have been found is the availability of online assessment format. The UYYS form can be sent by email to the person with disability (Evalue, 2015), but this is quite distinct from self-assessment tools which have a web-based interface (MacDonald, 2010). Examples of web-based self-assessments include the Self-Assessment Rapid Access (ASK-SARA) (Spiliotopoulou & Atwal, 2014; MacDonald, 2010). ASK-SARA is web-based self-assessment tool that provides advice on products and equipment for independent living. In contrast to the UYYS, ASK-SARA contains online tick box questions that are answerable by yes or no, and generates a personalised report about equipment use that users can either print or email (Spiliotopoulou & Atwal, 2014).

2.4. Self-assessment in comparison with traditional needs assessment

The standard form used by NASC services throughout most of New Zealand is described here as the "*traditional needs assessment*". This refers to the process used by NASC service facilitators to develop a support plan to meet the person with disability's goals and needs (see Appendix 2). The intention behind the UYYS form is to encourage the person with disability to take the lead by completing the form themselves (Evalue Research, 2015; Evalue Research, 2012). In contrast, the intention of the traditional needs assessment is for a NASC service facilitator to meet with the person with disability in their own home, in order to complete the assessment. Each component is supposed to be completed to a standard required by the Ministry of Health (Ministry of Health, 2011).

There appears to be little research directly comparing the similarities and differences between self-assessment and traditional needs assessment. Similarities and differences between self-assessment and traditional needs assessment are discussed below:

1. *Level of independence and participation*

Evalue Research (2015) found that SSA empowers the person with disability to maximise their independence and participation by completing the assessment form themselves. A similar point has been made by Evalue Research (2012) and Finlayson (2017) who consider self-assessment as a collaborative way of identifying the person's strengths to address disability challenges, rather than putting an emphasis on the person's deficits. However, other researchers who have looked at the UYYS form found the questions too intense to be completed by a person with a disability alone (Evalue Research, 2015).

2. *Assessment Method*

In the study by Evalue Research (2015), one of the NASC assessors described how he/she felt that the method of traditional needs assessment was invasive of one's personal space. Commenting on the traditional needs assessment, Evalue Research (2015) writes:

> "*She talked about how hideous it was using the old form and how negative and draining it was. She said it felt like she was invading the person with disability's space"* (p. 72).

While the intention of the UYYS is to encourage people with disabilities and their families to fill in some or all of the form themselves, half of the respondents who were interviewed by Evalue Research (2015) said they chose to fill in the UYYS form with support from their NASC service coordinators. The view that people prefer direct support from health professionals is supported by Tucker et al. (2010), who reported that older people were more comfortable completing a professional-mediated self-assessment.

3. *Completion Time*

One of the most notable differences between traditional needs assessment and SSA is the time needed to complete the form (Evalue Research, 2015; Evalue Research, 2012; Finlayson, 2017). Traditional needs assessment is usually completed in one face-to-face session that takes one hour to two hours (Ministry of Health, 2011), whereas SSA seems more flexible for it can be completed at a time that suits the person. Respondents of the Evalue Research (2012) study reported that it took them between 45 minutes to 4 hours to complete the UYYS questionnaire. The majority of those who responded said they filled out the form over several days, taking time to carefully digest each section (Evalue Research 2012). As Evalue Research (2012) states: "*The respondent said this process worked because they could think about the questions holistically. They believed information would have been missed out if they had been interviewed"* (p. 22). Having that flexibility of time allows people with disabilities and their family members to think carefully about what to write in the SSA form.

However, having more time can also be overwhelming for some people especially if they are to fill out the form by themselves, which can result in low response rates (Evalue Research, 2012; Finlayson, 2017). Some individuals opted not to complete the UYYS on their own and asked for service coordinators to come to help them fill out the questionnaire. Overall, these studies highlight the importance of providing people with disabilities the flexibility to complete a self-assessment in their own time (Evalue Research, 2012; MacDonald, 2010).

Section 3

The final section of this literature review chapter examines the evaluative studies on the use of self-assessment and how the process of SSA links to the principles of the Enabling Good Lives model.

3.1. Evaluation of Supported Self-Assessment

To date, the use of self-assessment for provision of disability services has not been comprehensively evaluated (MacDonald, 2010). The Productivity Commission (2011) in Australia points out the lack of detailed investigation into the accuracy of self-assessment in disability care. Productivity Commission (2008).indicates that self-assessment alone would not accurately sum up the person's needs. Care managers from the Glendinning (2008) study believed that, along with self-assessment, some degree of facilitation by health professionals is necessary to find out their views as well as to what the individual’s needs are.

Although there are several studies in the literature on the evaluation of self-assessment, most are restricted to people with mental illness and older people (Griffiths, 2005; Stuart et al., 2014). As indicated previously by MacDonald (2010), what is known about self-assessment has largely been derived from studies commissioned by government agencies.

One of the issues about accuracy that emerge from the finding of Evalue Research (2015) and MacDonald (2010), relate specifically to people with disabilities who might potentially either under- or over-assess their needs. The study on the completion of patient reported outcome-based reports identified that lack of confidence assessing their own health condition may have contributed to people’s ability to correctly assess their needs (Mejdahl et al. 2018). This study reported that some patients experienced difficulty assessing their needs because they had no understanding of the symptoms related to their illness.

One factor thought to be influencing how people with disabilities might under and over-assess their needs is the lack of information on how to complete a self-assessment form (MacDonald, 2010). This finding is consistent with that of Glendinning et al. (2008) and Mejdahl et al. (2018) who also found that lack of understanding about the purpose of the self-assessment could result in the carer and the person with disabilities’ having conflicting interpretations of how to complete the self-assessment form. Mejdahl et al. (2018) also found that having a recognised introductory process about the self-assessment tool can help enhance the patient’s understanding of the self-report process and prepare them to their active role of doing the assessment themselves.

Another issue with self-assessment is the inclusion of the carer perspective. Seddon & Robinson (2015), who both explored the current dilemmas in carer assessments, highlighted the need to preserve carers’ perspectives in assessment practice. The authors suggested that future assessment tools must incorporate a narrative platform where carers are separately given the opportunity to reflect on their caring responsibilities.

The Productivity Commission (2011) highlights the importance of service coordinators working collaboratively with people with disabilities to produce a more accurate and reliable self-assessment. However, studies also indicate how difficult it can be to get reliable assessments that are replicable across health professionals. This highlights the potential difficulty of getting reliable self-assessments (Dell-Kuster, Lauper, Koehler, Zwimpfer, Altermtt, Zwimpfer, Zwimpfer, Young, Bucher & Nordmann, 2014). On the other hand, it is also important that self-assessment should be carried out in a way that people with disabilities take the lead in completing their assessments, even when professional support is also needed (Australian Federation of Disability Organisations, Deafness Forum, People with Disability Australia, & Women with Disabilities Australia, 2011).

In a study investigating the role of SSA in developing budgets for individuals, Glendinning et al. (2008) suggested the need for service coordinators to be around. Some people also refuse to to complete the UYSS form and indicate their preference to meet a service coordinator instead (Evalue Research, 2012). MacDonald (2010) sees this as an opportunity for service coordinators to help individuals complete the form and make sure service users do not under-estimate their needs as they fill out the assessment tool. Supporting this view, Griffiths (2005) writes that intention behind the involvement of health professionals in completing self-assessment is to ensure partnership and collaboration with the service user.

Another additional advantage of professional-led assessment is that it prevents family members from taking ownership of the assessment by ensuring that the perspective of the service user “takes centre stage” in the assessment process (Australian Federation of Disability Organisations, Deafness Forum, People with Disability Australia, & Women with Disabilities Australia, 2011; MacDonald, 2011).

A potential disadvantage of the professional facilitation of a self-assessment process is pointed out by MacDonald (2011), who is concerned about the possibility that service coordinators might over-assess the disabled person’s needs in an attempt to deliver the best packages of care for those people with complex needs. MacDonald (2010) suggests that this issue demonstrates the need for staff training and development so they are informed not only of the assessment process but also of the allocation tool involved with translating the person’s needs into an identified budget.

A potential problem with self-assessment is identified by Were (2017). Researchers who were involved in the Waikato demonstration of EGL found that those people who completed the SSA were left feeling in doubt about the outcome of self-assessments (Were, 2017). Nineteen percent of respondents interviewed felt they did not get the right assistance needed to complete the self-assessment process. Were (2017) suggests that one possible way to improve satisfaction is the establishment of better communication with support persons and the delivery of SSA form that is easy for people with disabilities and families to use.

3.2. Enabling Good Lives and Client-centred practice

The self-assessment process is clearly aligned with client-centred practice, and the philosophy underpinning this in New Zealand is articulated in the Enabling Good Lives model. The EGL model has eight core principles as shown in Table 2. One of the most significant principles of the EGL model is client-centeredness (Ministry of Health, 2015). From the EGL perspective, client-centred practice can be broadly defined as the consideration of supports that suit the person with disabilities' needs and goals (Anderson et al., 2017; Ministry of Health, 2015).

Disability Support Services (DSS) have a strategic plan that includes making disability supports flexible for people to use and encouraging people to exercise increased control and choice over how their personal budgets are used (Anderson et al., 2017; Ministry of Health, 2015; Mitchell, Beresford, Brooks, Moran & Glendinning, 2017). An example of what is meant by personal budget is the allocation of self-directed supports, such as individualised funding, whereby people with disabilities and their families have the freedom to plan how they want to spend their allocated funds (Anderson et al., 2017; Ministry of Health, 2015; Evalue Research, 2012).

Table 2. Principles of the Enabling Good Lives Model (Ministry of Health, 2015)

8 Core Principles	
Self-determination	People live the life they want
Person-Centred	Disability supports that are customised to people's needs
Investing early	Help people with disabilities and their families to strengthen their natural and community support networks.
Ordinary life outcomes	Provide more opportunities to learn, find employment and participate in social and community events
Access to mainstream services	Enable access to mainstream services first before specialist services
Enhancing Mana	The skills, capacities and contributions of people with disabilities and their families are acknowledged and respected.
Easy-to-use	Provide disability supports that are flexible, simple and comfortable to use.
Building relationships	Improve relationships between people with disabilities, their family and the wider community

Summary

The evidence reviewed in the literature seems to suggest a role for self-assessment in the field of disability. The evaluation reports prepared by those who were involved in the EGL demonstration, such as the work of Were (2017) and Anderson et al. (2017), provided important insights on the use of supported self-assessment in the regions of Canterbury and Waikato. These on-going demonstrations of the EGL programme provided strong evidence for the usefulness of the self-assessment process. It can also reveal potential challenges for facilitating and promoting SSA in the regions.

There is a relatively small body of literature that is concerned with self-assessment. Much of the New Zealand literature reviewed focussed on the country's disability system as a whole with self-assessment as part of that extensive process. The topic of self-assessment was seldom the emphasis of evaluation reports commissioned by government agencies. For example, when Evalue Research carried out an evaluative study of UYYS in 2012, a year after its inception in the NASC agency, the investigations on self-assessment did not yield definitive trends due to low number of respondents. While the study captured the experiences of people with disabilities who completed the form, the evaluation report was not able to provide conclusive evidence on the effectiveness of SSA (Evalue Research, 2012; Evalue Research, 2015).

This chapter has used literature from a range of sources to investigate the use of self-assessment in various clinical and social care practice in New Zealand and internationally. Its potential benefits, strengths and problems were identified in the context of disability and health. However, the literature reviewed remain narrow in focus in terms of capturing users' perspectives and experiences of using a self-assessment form. Therefore, the aim of the present research is to gain a better understanding of the process of self-assessment by investigating the perspectives of NASC service coordinators on the use of the SSA. Information gathered in this study will be about how service coordinators use the current SSS form, the barriers and challenges they are facing, and the implications of self-assessment in their practice.

The next chapter describes the methodology used in this study.

Chapter Three: Methodology

Qualitative Research

An interpretive descriptive methodology was chosen as the methodology, because it aims to develop an applied interpretive framework for inquiries that arise within an applied context. In this study I was particularly interested in exploring a question about self-assessment, in response to an auditor's report that suggested it should be implemented in my workplace. The intention was therefore to use a method that would enable some suggestions to be made about what could be learned from the experience of applying self-assessment in one region that could be usefully applied in another region. In this chapter I describe the utilisation of interviews as a method for data collection. In addition, I describe the theoretical positioning of interpretive description, the participant sample, and the data collection and analysis processes. I also discuss the ethical issues associated with the research.

Interpretive Description

The interpretive description approach was first articulated by Thorne (2008) in the mid-90s and has gained momentum since then. Originally intended for a nursing audience, because of the need in nursing to move beyond tradition qualitative methods that are based in the social sciences. The interpretive description approach has now been widely adopted by other disciplines, not only in the field of health, but also in applied science (Thorne, 2008).

The advantage of interpretive description is that it allows occupational therapists to seek the perspectives of sample participants about the phenomenon being explored (Jindal, MacDermid, Rosenbaum, DiRezze & Narayan, 2018; Mejdahl et al., 2018). An example of this was the study carried out by Makepeace & Zwicker (2014) in which interpretive description research was used to understand the views of patients on occupational therapy assessment reports. In addition to exploring the perspectives of patients, occupational therapists have applied the interpretive description methodology to build more knowledge about the assessment process (Makepeace & Zwicker, 2014; Mejdahl et al., 2018; Lam Wai Shun, Bottari, Ogourtsova & Swaine, 2017; Jindal et al., 2018).

Interpretive description methodology offers an effective way of capturing themes and patterns to generate experiential knowledge that informs the researcher more discipline-specific understanding of the phenomenon being studied (Makepeace & Zwicker, 2014; Lam Wai Shun et al., 2017). To generate more information based on the existing knowledge of the phenomenon, data collection in interpretive description involves the use of a range of strategies, including participant observation, in-depth interviews and focus groups (Thorne, 2014; Makepeace & Zwicker, 2014). Interview questions probe for background information related to the aim of the study and consider the relevance of the context that drives the inquiry (Thorne, 2014; Thorne, 2008; & Thorne et al., 2016). In the analysis phase of interpretive description, the qualitative researcher considers all possible meanings and develop codes to produce a meaningful account of the phenomenon being investigated (Lam Wai Shun et al., 2017). Brewer et al. (2014) and Thorne (2014) emphasised the importance of utilising the similarities and differences in insights gained from the participants and how these newly gained perspectives largely influence current practice within the phenomenon.

In this study, an interpretive descriptive approach was chosen to explore how the self-assessment tool was being used in order to make recommendations about whether and how it could be used in my own work context. The preliminary step of the interpretive description approach is to engage in a deep consultation process (occurring naturally within the disciplinary context), and a literature review. Taking a non-prescriptive approach, the advantage of interpretive descriptive approach is that it captures the complexities of the phenomenon (self-assessment) and allowed me, as the researcher, to make use of my interpretive skills as a clinician/service coordinator to understand the action and meaning of the phenomenon being explored. Interpretive description is an approach that can only realistically be applied by a qualitative researcher with a strong grasp on the applied disciplinary lens (Thorne, 2014). Disciplinary lens is defined by Thorne (2014) as a reasoning tool where the researcher relies on their professional knowledge in exploring a phenomena of clinical interest within their own discipline. With my experience in the practice of occupational therapy and role within the disability Needs Assessment and Service Coordination (NASC) as service coordinator, I am well-positioned to conduct a project using an interpretive description approach, with the intention to provide new insights and recommendations to inform practice within applied disciplines of occupational therapy, health and disability.

With regard to self-assessment, I utilised interpretive description’s ‘angle of vision’, which was about making a connection between the behaviours and views of research participants on the use of self-assessment and my own interpretation of those views and behaviours (Thorne, 2008; St. George, 2010). Finally, considering the aim of interpretive descriptive was to use one’s interpretation as baseline for future practical work around self-assessments, the insights gained from the study were used to inform a discussion about the relevance of establishing a self-assessment tool for Capital Support - Needs Assessment and Service Coordination (NASC) in Wellington.

Ethics

Prior to commencing the study, ethical clearance was obtained from Otago Polytechnic Ethics Committee (28 June 2018:775) (see appendix 3). Locality Approval was also sought from the relevant DHB, and this was given in May 2018 (appendix 5).

In addition, this study was culturally supported through consultation with the Office of the Kaitohutohu of Otago Polytechnic (6 June 2018). The ethics consultation was reviewed by Tumuaki: Rakahau Māori/Director of Māori Research. Please refer to appendix 4 for a copy of consultation feedback.

For this study, participants are '*service coordinators'* employed by NASC to facilitate needs assessment and coordinate disability support services. Service coordinators complete the needs assessment process directly with the person with the disability or their main carer to identify the person's strengths and prioritised needs. Service coordinators determine the person's eligibility to receive DSS-funded supports based on the identified disability needs and goals in the needs assessment. Experience working within a disability sector and a relevant tertiary qualification are the specifications for the service coordinator role (Ministry of Health, 2007).

Participants were informed of their right to withdraw from the project at any time. They were also advised of their right to refuse to answer particular questions and to ask to stop the audio recording at any stage during the interview. All transcribed data was anonymous and the participants' names were replaced by pseudonyms.

I considered vulnerabilities for this study including the vulnerability of NASC employees. The topic of self-assessment is a professional and non-contentious issue to discuss with the group in this setting. NASC service facilitators are experienced and have tertiary qualifications. Many of them are also health professionals. There are scheduled team meetings to talk about caseloads and the topic of self-assessment is a natural issue to discuss in this context. Generally, the NASC culture is that service facilitators talk about their work as part of a team in a non-threatening environment. There may be a potential risk that employees may be critical of the NASC process in front of their manager. Service coordinators were interviewed separately to the manager to alleviate this risk.

Recruitment and Participants

Participants were recruited from one NASC agency within the DHB. Prior to recruitment, I visited the NASC office and delivered a 15-minute presentation to five staff about the research project. Attendees of the presentation were provided the opportunity to ask questions about the research project. Some of them voluntarily shared their views about their use of the self-assessment tool. Following the presentation, attendees were given a copy of the participant information sheet (see appendix 6) and consent form (see appendix 7). The information sheet included the purpose of the research project and the rationale of conducting semi-structured interviews in relation to the project. Potential participants were advised of their privacy rights as well as the right to terminate the interview at any point if they wish to. They were advised to either contact me by email or approach me in person if they were interested in participating or if they had any questions about the research presentation. Six people agreed to participate in either a phone or face-to-face semi-structured interview following the presentation.

Sample

The project used purposive sampling of service coordinators working a particular NASC agency that was using the self-assessment form, the *Understanding You and Your Situation* (UYYS). To date, the use of UYYS only applies in one particular NASC agency – which is not named in the body of the findings in order to protect confidentiality of the participants. Service coordinators and the manager were purposively selected to participate in the study following the inclusion criteria: (1) currently employed as service coordinator in the NASC agency; (2) have been using the UYYS form. A sample of 5 service coordinators and the manager agreed to participate in the study. This sample size was 54% of the total number of Support Net Service Coordinators.

All were between 45 and 60 years old (mean age = 52 years), and comprised of five females and one male. Amongst these participants, five identified themselves as New Zealand European and one Māori. Table 3.below presents the demographic information of the participants.

Table 3. Demographic characteristics of the participants

Participants	Age	Gender	Ethnicity	Years of Working experience as NASC Service Coordinator
P-01	62	Male	Māori	13 years
P-02	61	Female	NZ European	12 years
P-03	45	Female	NZ European	14 years
P-04	50	Female	Māori	8 years
P-05	55 - 64	Female	NZ European	10 – 15 years
P-06	51	Female	European	10 years

Data Collection

Data were collected using semi-structured interviews between July and August 2018. Phone interviews were recorded using a mobile application called *Rev 1.0.0.* This mobile application was downloaded on a Samsung Note 8 through *Google Play*. The mobile application was easy to use and played voice recordings. The voice recordings were sent to *Rev.com* transcription services.

The participants were geographically dispersed and it would not have been possible to conduct face-to-face interviews. Therefore, interviews were all conducted by telephone with the exception of one person who was interviewed face-to-face during the visit. The benefit of phone interview is that it reduces both the participant's and researcher's cost, time and resources required for travel (Irvine, Drew, & Sainsbury, 2013). As with data collection, Knox & Burkard (2009) highlighted a number of advantages of using phone interviews. The authors described that phone interviews maintains anonymity which enable interviewees to comfortably disclose more information. By promoting anonymity, authors reported that participants' feel more anonymous allowing them to participate fully (Knox & Burkard, 2009).

Another advantage of phone-interview is that it avoids response bias. In the absence of the interviewer, participants are able to fully respond to questions without being bothered by the facial reactions of the interviewer to their responses (Knox & Burkard, 2009).

Open-ended interview questions were developed based on a preliminary review of published literature such as evaluation reports about the use of UYYS in the NASC community, and following discussion with the academic supervisor. According to Thorne (2008), semi-structured interviews have a wide-spread popularity in qualitative health research. One significant advantage of using the semi-structured interview is that it allows the researcher access to the respondent’s subjective experiences of the phenomenon being studied (Sandelowski, 2000; Thorne, 2008). The purpose of the interview was to gain understanding of the process of self-assessment in the region and capturing the service coordinators’ perspectives and experiences of using the UYYS form in their practice. The average length of each participant interview was 49 minutes. See appendix 8 for semi-structured interview questions.

Data Analysis

Prior to analysing the interview data, the transcripts were checked by re-reading the passages to develop that level of theoretical understanding of the data (Mertens et al., 2017).Transcripts were then shared with the academic supervisor. The decision was made, in consultation with the group of service coordinators, that it was not possible to do member-checking because of the heavy work load of the participants. Upon completion of this research, I will visit the NASC agency to present the findings of the research study to the participants.

Data was analysed using the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterlé, Gastmans, Bryon, & Denier, 2012). The steps of QUAGOL are outlined in Table 4 (p. 28) . As a method of analysis of qualitative interview data, is divided into two parts: (1) a pen-and-paper work where the researchers utilise their imaginative and creative thinking to produce a narrative interview report and identify preliminary concepts, and (2) the actual coding process which may or may not make use of a qualitative software to substantiate those list of concepts and come up with descriptions of the research findings (Dierckx de Casterlé et al., 2012; Mertens et al., 2017).

Table 4. Stages of QUAGOL

STEPS OF QUAGOL
PREPARATION OF CODING PROCESS
1. Thorough reading of interview ---- a holistic understanding of participant's experience
2. Narrative case report ---- a brief abstract of the key storylines of the interview
3. Schematic Cards ----- concrete experiences replaced by CONCEPTS
4. Fitting-test of the schematic cards ---- testing the appropriateness of concepts in dialogue with data
5. Constant Comparison Process --- forward-backward movement between within-case and across-case analysis
ACTUAL CODING PROCESS
6. Draw up a list of concepts ---- a common list of concepts as preliminary codes
7. Coding process —---- linking all relevant fragments to the appropriate codes
8. Analysis of concepts ---- description of concepts, their meaning, dimensions and characteristics
9. Extraction of the essential structure ---- conceptual framework or story-line
10. Description of the results ----- description of essential findings

The sample size (n = 6) in this study was manageable enough to do the actual coding process without the use of a qualitative software. To make adjustments on the list of preliminary concepts developed, I engaged in an iterative forward-backward dynamic to merge comparable concepts. The forward-backward analysis is one of QUAGOL's strengths as it helps researchers to strengthen their developed themes by making comparison with other identified concepts and date from other interviews. In the absence of the qualitative software required for concept analysis, I made use of *peopleware*, which is one of the applied principles of QUAGOL (Mertens et al., 2017). *Peopleware* refers to the use of the individual researcher to analyse the data, acknowledging that this draws on the whole variety of researcher skills, such as the imaginary, creative and interpretive ability to find meaning beyond the meanings of the interview data (Mertens et al., 2017). The analysed data, which includes the narrative interview reports and description of themes, was discussed with the academic supervisor.

Summary

In this chapter, it has been explained that the methodology chosen was interpretive description and data were collected using individual semi-structured interviews. Ethical clearance was obtained and ethical issues which include the right to withdraw, consent form, potential risk were discussed. I then described the method of analysis of qualitative interview data, including the principles and process of QUAGOL. In the next chapter, I will present the principal findings from this research.

Chapter Four: Findings

The fourth chapter presents the findings of the research, focusing on the four key themes that emerged from the responses of the interview participants.

Concepts

Following the principles of QUAGOL data analysis, four important concepts emerged from the participant's experiences and outlook regarding the use of the Understanding You and Your Situation (UYYS) self-assessment form. Table 5 presents an overview of each core concept and associated sub-concept. First suggested by Dierckx de Casterle et al. (2012) who used the word *"concept"* to refer to reviewed codes gathered from the interview data, this term will be used throughout this paper. A brief description of each core concept is presented along with significant findings and insights in response to the research question. Relevant quotes from the interview transcripts are used to support the storyline in relation to the concept being presented.

Table 5. Core Concepts and its sub-concepts

Core Concepts	**Sub-Concepts**
Concept 1. The process of UYYS	Enabling Good Lives (EGL) model Providing choice and control A default narrative assessment Re-designing the assessment tool
Concept 2. The need for face-to-face interactions	People under- and over-estimating needs Literacy levels of people with disabilities and families Getting the forms back Maintaining contact and providing reassurance
Concept 3. Comparison with traditional needs assessment	Capturing relevant information Flexibility of completion Assessing people with high and complex needs
Concept 4. Needs Assessors' skills	Facilitation skills Culturally inclusive Having the rights-based approach

Concept 1. The process of UYYS.

1.1. Enable choice and control

For participants, the core philosophy of UYYS is to give people and their families more control and power over how and when assessment is done. Despite having a set of questions, people are encouraged to write their own story in a form that tells more about themselves.

One participant welcomed the opportunity for people with disabilities and families to take control of the self-assessment process themselves. This view was echoed by another participant who commented*:*

> *The UYYS exercises client choice and control in terms of you know, them being in charge of the information, how much information they share, what information they share, in their own time. (P-04)*

Some participants who are familiar with the Enabling Good Lives (EGL) model confirmed the philosophy of UYYS as fitting with the principles of EGL. As one participant put it:

> *Yeah, I think it's more consistent with the Enabling Good Lives principles perhaps than what there's been in the past, because it does potentially put people in the centre of the process and gives people control over how and when and what will be written in that assessment. (P-01)*

1.2. Deficit-based features of the UYYS

Despite the form’s enabling characteristics, some participants felt that the UYYS operates on a deficit-model. For participants, the claim that the UYYS is a deficit-model arises from the need to identify the person’s weaknesses in order to allocate the appropriate supports for them. Talking about this issue a participant said:

> *We operate on a deficit model. We allocate something on the basis of the things the person can't do. When we go out to see people we don't sit there, I mean, we do to a degree, talking about the things they've achieved and the things they can do. But we default anyway to the need is. And I've yet to see an assessment form that doesn't I'm afraid. (P-02)*

Other responses to the question as to whether the UYYS only intended to capture people's strengths included:

> *We wouldn't be doing it if we were looking at just strengths, all the great things that people can do. How do we know what they need help with?(P-03)*

Although some participants recognised the need to operate on a deficit-based approach, one of them emphasised the importance of having that balance between capturing what the person's strengths are, and at the same time understand what their disability needs are. Another participant argued that the deficit model is not only evident on the use of UYYS, but it is also embodied in other assessments used in the disability NASC.

> *I don't think it's specifically the self-assessment form. Whether it's the old form or the self-assessment, they are still trying to identify what the disability needs of the person are. (P-03)*

One participant acknowledged the challenges of using a deficit-based assessment tool.

> *Of course we also appreciate the assessment in itself. It's looking at the deficits and that's just a bit tough because it's the gaps that we therefore fill. (P-06)*

A recurrent theme in the interviews was how participants and persons with disabilities make use of the UYYS form from the point of referral to coordination of services and supports.

1.3. UYYS as the default assessment

Participants mentioned that the UYYS is the default assessment used by NASC for people who are not in residential care. The region being studied still uses the traditional needs assessment for people living in residential care facilities. For new referrals, what is now known is that the standard approach is to go out, meet the person face-to-face and complete the UYYS assessment with the person or their family member. For reassessments, participants explained the practice of completing three-yearly assessments using the UYYS form:

The **first step** in the process is to post a standard letter to the person with disability with the UYYS form attached. When the self-assessment form had its launch, Ministry of Health developed an information sheet which remains current and is also enclosed in the letter. The form is posted out four weeks before needs assessments are due. There is an element of flexibility in terms of how the standard letter is sent to people and this is to ensure that people are being supported. As one participant said:

> *Sometimes we kind of tweak that and sort of personalize it a little bit. We're really, really flexible about how it's done. Some people get their standard letter, some people get a phone call and then get the letter. Some people will get the form and then ring us and we can talk about. (P-02)*

Another participant reported that people can request an early assessment if and when there is a significant decline in their condition. A face-to-face assessment is considered when a person’s situation changes or a new referral comes from another NASC agency. Additionally, service coordinators facilitate face-to-face assessment if the person chooses not to fill out the UYYS form by themselves.

The **second part** of the process is for service coordinators to review the content of the assessment once the completed form comes back. If more information is required, they either phone the client or meet with them face-to-face to obtain more information.

Following clarification of information, the **final step** is for service coordinators to calculate a budget from the information using a funding allocation tool. One participant referred to the UYYS and funding allocation tool as a pair. There is now more choice and control about funding and this goes hand in hand with the philosophy of the UYYS. She stated:

> *You can't consider the UYYS without considering the funding allocation. Certainly funding allocation has lived through much greater choice flexibility and control**.** (P-02)*

Although NASC allocate the budget, the participant emphasised the importance of providing persons with disabilities the choice and flexibility over how they want their allocated budgets to be used.

> *If someone wants to put their entire budget into 110 days of carer support, then that's their choice to do that. And we don't have any "Oh no, you can't that's way too much carer support, you're not getting that." That's their choice to do that with the budget. (P-02)*

Narrative-based assessment. In addition to being a default assessment, the UYYS form contains narrative-based sections where people tell their stories in their own words. According to participants, people with disabilities and their families have options for completing the *My Story* component of the assessment. They can choose how much information they want to put in the form. As one participant noted:

> *That becomes their choice as to whether they do use all of that information or not. For some families, they will, and for some families, they won't. (P-04)*

Some participants viewed the narrative-based process as valuable for people with disabilities. For example, one participant said:

> *To have some information, a chance to put some more information and make it a bit more real I think is important. (P-06)*

This view was reiterated by another participant who stated that narrative-based assessments lead people to areas of the form where useful information can be told, rather than filling in a question-and-answer format.

1.4. Re-designing the assessment tool

Issues related to re-formatting the UYYS tool were particularly prominent in the interview data. Participants identified specific components of the UYYS form that could potentially be formatted. The *My Story* page is a narrative section of the UYYS where people write about their current situation. For one participant, the *My Story* page generally provides considerable information about the person’s life, and people are therefore encouraged to complete this section as much as they can. It seemed that people find this narrative section easier to complete than the tick boxes which people find quite confusing. One of the participants highlighted that every person and their family members have a completely different interpretation of the questions asked in the tick boxes.

> *Often what I encourage people to do with that is to either have a think about or write the My Story page, because what people find difficult is the boxes. Which boxes to check, often. Because for a lot of people they don't have the breadth of the information and skill that we have, so they might be worried that they're going to underestimate or overestimate the need for their disabled family member's need. (P-02)*

> *The subheadings where they have to tick where they think ... yeah, I think that's quite confusing. And , 9 times out of 10, they tend to just go to the last box, so I think that's largely to do with how those questions are being asked. It's quite confusing. (P-04)*

Another participant, when asked about the *My Story* page, said that some people find the narrative section to be intrusive. They feel they have to give away more than they want to. This leads to a minimalist version of their story. It is still a story, and one that says something about their stance.

> *I've had one assessment come back to say that: "I live on my own. I'm happy with that and everything else is my business". (P-03)*

This comment highlighted the need for service coordinators to review the information they received and go through their responses with them through face-to-face contact or by phone. One participant noted that some people with disabilities only began providing more information when they reached the particular section of the UYYS that was applicable to what their need was. It may be the case that the form asks for a lot of information that does not appear to be directly pertinent to the person. They will refuse to give information that they feel does not directly bear on their case.

> *That was sort of the tone right through the assessment until it got to "This woman has only household management support" and so until it got to that section she elaborated a little bit more on what she needed. (P-03)*

Besides the *My Story* page, the *My Needs* part of the UYYS was also one of those components where there was on-going discussion among participants. The *My Needs* page is the third section of the UYYS form that informs how disability affects the person's life. Apart from ticking the boxes that fit the person's situation, there is a narrative component entitled "Being in Charge of my Life". One participant was particularly critical of the *My Needs* section of form. Talking about this section, the participant commented:

> *I think the part underneath the title of the section, for example, "Being in charge of my life." The part that tells you what information we need, needs to be better. It has to stand out more somehow. I don't know if this will be bullet pointed to address all these points, but that's the section that people are not seeing sometimes. (P-05)*

Another participant made reference to the "*Enabling my life*" domain which is also part of Section Three. It was reported that people with disabilities found it difficult to complete this component of the UYYS too. Commenting on this domain, the participant said:

> *It's only 3 lines, but it's actually covering a huge part of their life. It talks about caring for dependents and school. Do you work? Do you access your community for cultural and spiritual activities? You know, seven or eight different things that they've got to try and answer under one domain. (P-04)*

There were some suggestions that sections could be re-worded to make the questions clearer for people with disabilities and families to understand better. One participant argued that the words under the domain "*Safety, risk and vulnerability*" needed to more comprehensible.

> *People still have a lot of trouble picking which spot they or their child fits into. I think that should all be re-worded. The rest of them are reasonably okay.*
> *(P-05)*

Given that NASC has yet to develop a self-assessment tool that is easy for blind people to use, there is value in doing face-to-face assessment alongside clients. One participant said:

> *There always has to be space for face-to-face or else they have to have someone at home who fills it in for them because we don't offer it in a format that works for blind people and there's plenty to talk about doing that, but doesn't mean it'll happen, does it? (P-02)*

Providing clients an electronic version of the UYYS form is another option of filling out information.

> *We can email an electronic version to them and they can type into it. If some people choose to do that and we may get a 50-page assessment that comes back instead of a 15-page one, which just depends how much information they decide they want to put in it. But if we don't do it that way then they will just write it on extra paper and attach it. (P-03)*

Although some people have had the opportunity to complete the form electronically, there is still room for improvement to make the tool easily navigable for clients.

> *We have had some people complete it online, but that needs more development so that it's better adapted and it's easier. (P-01)*

Overall, despite a number of sections that need re-formatting, the majority of participants felt that the current self-assessment tool offers an effective way of eliciting information from clients and families. As one participant put it:

> *I think that what we have at the moment is probably the best version we've ever had. (P-03)*

Concept 2. The need for face-to-face interactions

Here, participants discussed the challenges of facilitating the assessment for and with their clients. Apart from their own experiences, participants' accounts indicated that clients also encountered different challenges in completing the self-assessment form. I present two separate categories with relevant sub-themes to clearly identify the challenges faced by participants resulting from those barriers experienced by clients and their families.

2.1. Challenges for Service Coordinators (Participants)

Under and over-estimating needs. Concerns were expressed about the possibility for clients to become disadvantaged if they fill out the form themselves. One of the issues that emerged was clients tend to under- or over-estimate their needs when completing the UYYS form. One participant highlighted the risk of leaving out valuable information related to their disabilities:

> *If they've got 18 hours of support a week, and then filled out with all the good stuff in their life. They don't tell us they need support to adjust the water temperature, to wash myself in the shower, to put clothes on and help with dressing. If they leave all that out, there's a risk of not getting enough support. (P-05)*

Another participant experienced people who tend to under-estimate their needs. The participant indicated that clients perceived themselves as fine and their level of need was less than what was actually needed. The participant suggested checking the given information with the person's natural supports, a family member for example, to make sure that facts are verified.

> *We have to walk the line and that's what we do. It's lucky some clients have families who have much better insights and are in agreement with me. (P-06)*

While the majority of participants demonstrated their experiences of working with people who underestimate their needs, there were some participants who encountered people over-estimating their needs when filling in the form. One participant argued that people do not have that breadth of awareness when filling in the assessment form, which leads to ticking the wrong boxes. Another participant suggested the importance of facilitating face-to-face follow-up to help validate the needs of the person.

> *We have the ability to decide whether we want to send it out as a self-assessment or whether we want to go into a face-to-face. So, you know, with those ones I would be more inclined to go into a face-to-face so that you can sort of see them in their own environment and see exactly what their needs are. (P-03)*

Not only did clients have a tendency to under and over-estimate their needs, but one participant recounted the time she completely under-estimated the person's disability.

> *I can hand on heart say I completely underestimated the level of need for that family. Then when I met with her, and I don't even know if it was three years later, I felt absolutely terrible that I had completely underestimated the kind of impact of the disability. (P-02)*

Getting the forms back and the quality of information. Participants expressed different experiences concerning receiving completed self-assessment forms on time. The amount and quality of information received was also posed as one of the challenges faced by participants.

As previously stated in the process of self-assessment, the UYYS form gets sent out a month before any service support expires, but the letter indicates that the self-assessment form must be returned within ten days.

For one participant, making a phone call to clients is one way of checking how they are getting on with filling in the form.

> *I would give my clients one to two weeks, and then ring them up and say, "Hey, how's it going? Did you get it? Did you start it? You feeling okay about filling it in?" (P-05)*

Meeting the service Key Performance Indicators (KPIs) also persuades service coordinators to get the forms back promptly from their clients. As another participant said, "*"We have KPIs to meet…One of the issues is how quickly the forms come back". (P-06)*

The amount and quality of information obtained presents challenges as well. According to one participant, the calibre of information received by service coordinators varies among clients. For example, signed self-assessments have been found to have minimal information.

> *Forms might come back and all they've done is tick the boxes and not actually written anything in it. (P-03)*

In some cases, clients have written out each section of the assessment form as *"no change*". In addition, there have been assessments with details that places heavy emphasises on the person's areas of strengths, but not on the areas they need support with. Some participants related the amount and quality of information to the person's understanding of questions being asked. Moreover, most clients were overwhelmed by the scale of the form. One participant noted:

> *I think for a lot of people, that's a big form with a lot of words and then a lot of gaps where they're meant to write their own words. And I think that's overwhelming for some people. (P-02)*

Once the self-assessment forms were obtained, the role of service coordinators was to look for any gaps in the information.

> *We do walk alongside the person and ask for additional questions. It is those gaps we ask additional questions. (P-06)*

2.2. Challenges for Clients and Families

*Literacy***.** The majority of participants identified literacy level of the person as another barrier in completing the UYYS. The amount of information provided depends on the person's writing ability. One participant reported that people who have low literacy levels found it difficult writing a lot more information in their assessment.

> *The way the assessments come back and what is written in them often shows different. It can be quite minimal in the information that they put out. (P-03)*

Among some participants there was an assumption that only highly literate clients and families can complete the form. However, one of the participants argued even people who were less confident with their writing proficiencies could send the forms back with good information.

> *There are people who are less confident, less skilled at writing and spelling, who have sent the forms back. The spelling might not be great, but the information is good. (P-05)*

> *Some people don't worry about that, they just go for it. Other people, they just know they can't spell or they know they don't quite understand, and so, they'll just ring and ask. (P-05)*

The level of English of clients, for whom English is their second language, can also prevent them from completing the form themselves and find the process too daunting for them to complete. One participant said:

> *For someone whose English is a second language filling in the form can be a barrier. I absolutely think it is our job to work individually with people to have their needs addressed.*

Experiencing anxiety. Some participants worked with families who found the UYYS too long to complete. The whole process could make some family members feel frightened to fill in the form, in case they got it wrong.

> *Parents of children with disabilities are already experiencing high anxieties themselves so when they see the form it adds to their everyday work load therefore they express that they cannot do it. (P-05)*

> *They feel too anxious to do it. What we've done is make their life harder. That's a risk and that's why I don't ask the Admin to send it through to Mothers that I know have high anxiety because they told me last time. (P-05)*

Despite the challenges of completing the UYYS form, clients were encouraged to fill it out to the best of their ability. Service coordinators ensure that the client voice is heard by encouraging them to fill in the form as much as they can or like, but the assessment is moderated by the assessors. For example, one participant said: *"What I said to them is do as much or as little as you like, but sign the forms, send them back, then we'll just finish it off over the phone. So that's fine too". (P-02)*

2.3. Value of Face-to-face Support

The theme of face-to-face recurred throughout the transcribed data. When asked about the value of face-to-face, the participants were unanimous in the view that meeting up with clients and their families assists in the identification of the person's unmet disability needs. Talking about the benefit of face-to-face a participant said:

> *I would be more inclined to go into a face-to-face so that you can sort of see them in their own environment and see exactly how they move around as opposed to sending the UYYS out because then it gives you more of a gauge of what their actual need is. (P-03)*

Inclusion. Having that one-on-one interaction with service coordinators provides clients the opportunity to engage in a safe, non-threatening forum.

> *They value that opportunity to meet with us. (P-02)*
>
> *Meeting with them means that they can communicate with us verbally, than being able to describe their stories on paper". (P-04)*

One participant felt that people were missing out on opportunities to start making connections and become part of the wider community network. The participant stressed that the UYYS form was meant to be completed alongside the person, not in isolation.

> *I absolutely think it is our job to work individually with people. Big way of doing that is we do it with people. We do the assessment alongside them. They never do it in isolation. (P-06)*

According to a number of participants, face-to-face was considered important especially when undertaking assessments with people who are blind and/or hearing-impaired. Talking about working with people who are blind, one participant reported:

> *There always has to be space for face-to-face or else they have to have someone at home who fills it in for them because we don't offer it in a format that works for blind people. (P-02)*

Clients can complete the UYYS themselves or receive assistance from their service coordinators. Describing the purpose of the UYYS as a self-assessment, one participant clarified:

> *We abbreviate it to self-assessment and it was never self-assessment.*
> *It was always supported. (P-02)*

Another participant highlighted the importance of accessing interpreting services to enable greater participation of deaf people.

> *The person has got an interpreter with her. Someone to help explain the process. (P-06)*

Maintaining contact. With face-to-face, one participant reported that people valued the time service coordinators were able to spend with them.

> *They value that opportunity to meet with us. The vast majority of people actually value the time we're able to spend with them. (P-02)*

Concept 3. Comparison with Traditional Needs Assessment

As mentioned in the previous theme (Concept 1), service coordinators maintain the use of traditional needs assessment in assessing clients living in residential settings. People who are placed in residential care have high and complex needs. Following completion of a traditional needs assessment, service coordinators make use of allocation tools specific to residential care to determine the appropriate funding level to support the clients and their needs.

Some of the participants considered the possibility for the UYYS form to be used for and with people in residential care. One of the participants alluded to the notion that clients with physical disabilities who do not have intellectual disabilities are more likely to fill out the self-assessment form. However, not to be discounted are clients with intellectual disabilities who can complete the form with support from the service coordinator.

> *It's obviously more challenging for people with an intellectual disability who wouldn't be able to do that, but that doesn't mean to say that someone couldn't sit alongside them quite closely and do that with them. (P-01)*

In terms of support, some participants argued the traditional needs assessments undertaken in residential care are completed with no family input as key informants were mostly the staff. Therefore, the traditional needs assessment might be the only one that guards against the inflation of needs the residential staff might. In the case of the UYYS, the funding allocation system generates the funding and the service coordinator allocates the funding. Commenting on the role of residential staff, one participant asked:

> *Are they going to identify objectively or are they going to identify that clients need more support than what they actually do?(P-02)*

Other participants, however, who have used the UYYS, found that clients and families were more involved in the process of completing the self-assessment. One participant noted:

> *The self-assessment moves the NASC assessor away from controlling that process and giving more control to the client or their family really. (P-01)*

The traditional needs assessment must contain detailed information to get residential funding approved. In order to determine the appropriate residential placement level for clients, service coordinators were required to provide detailed information on their traditional needs assessments. As one participant said:

> *People in residential… they have high needs. You really have to catch a lot of information to get that high funding approved, and if you miss out a lot of stuff, you might struggle to get that approved. (P-05)*

Another participant commented that the sections of the traditional needs assessment favourably prompts the service coordinator to capture more information on a specific area of need.

> *If a person has a physical disability there's a whole section on mobility. They have this whole section on education. It was a very good assessment. (P-05)*

However, a number of participants agreed that the use of UYYS in non-residential settings would not yield specific information in terms of the person’s skills for each self-care task, for example. Despite the absence of specific information, one participant commented this did not impact on their funding allocations. It is possible that the funding allocation tool being used alongside the UYYS does not require in-depth information about the person’s level of independence to determine the appropriate funding.

> *Whether a person can wipe their own bottom or, you know ... cook their own toast or whatever. We're probably not going to get that information on UYYS. We might, but actually the UYYS is a much bigger picture than that. I don't think it's impacting on the allocations we make by not knowing that stuff.*
> *(P-02)*

Furthermore, some participants remarked that the flexibility of the UYYS tool helped them to adhere to what was relevant in terms of capturing information. For example, one participant said:

> *In many situations, just having brief information is fine and perfectly adequate. There is a balance between the quantity of the person's own personal information and how much service coordinators really need to know. (P-06)*

One participant noted that, between the traditional needs assessment and the UYYS, there were ways of keeping in touch with clients and families to obtain relevant information. One of the participants remarked about the flexibility of using the conceptual structure of either of the two assessment tools if this helps in the thorough completion of a needs assessment.

> *I think that within both, there are means of being able to follow that chock full of information. I'm switching between the traditional and the UYYS assessment quite a lot. But I think in doing it, where there are deficits for me in using the UYYS my residential hat will often kick in and so I will certainly seek out any information that I think is missing from the UYYS. (P-04)*

Concept 4. Assessors' Skills

This theme arose in discussions of how important it was to be sensitive in facilitating a partly narrative-based assessment like the UYYS tool. A common view amongst participants was that the skills of the service coordinator were essential in eliciting relevant information from clients. Participants related the completion of the self-assessment tool to a person narrating their story. In order to help clients recount their stories, service coordinators must have the ability to assist the person to provide a detailed narrative of their lives

> *Their ability to draw information out, to put people in a comfortable place where they can tell their story. So I think, really, a good assessor is someone who can help a person tell their story. (P-02)*

> *Sometimes, what's not being said is probably the information that's needing to be discussed with the families. The ability to anticipate the story, and being able to extract that with the carers is in a way that is meaningful. (P-04)*
>
> *I think partly it's the knack to read between the lines. To be able to pull out what information is in the assessment that we really need and to be able to identify where the shortfalls may be or where the gaps may be for people.*
> *(P-03)*

Facilitation Skills. For some participants, service coordinators must have sound facilitation skills in order to draw out information from their clients.

> *It's sort of a facilitator type of role where you talk to them about: "Could it be this; or could it be that?" (P-03)*
>
> *They have to have good facilitation skills, be able to bring out the information that they need from people. (P-01)*

Besides facilitation skills, one participant mentioned other skills a service coordinator should possess, such as good listening and writing skills.

> *That willingness to sit down, have a cup of tea, ask a few leading questions and then listen. (P-02)*

Rights-focussed approach. In relation to the service coordinators' backgrounds, some felt that gaining knowledge relevant to human rights is more important than understanding a person's disability. As one participant commented:

> *I've always said that you don't need to know much about disability to do this work but what you do need to know about is human rights. And come from that position of equity and fairness. And so, you see, the work we do is a rights-based role, So, I think that that's really important. (P-02)*

Other participants, however, considered having knowledge about disability fosters greater understanding of the person's disability needs.

> *It's about their ability to understand the disability and ask the right questions. Got to have good understanding of the disability sector and of disability. They need to be able to, I guess, translate what people are saying into a way that's going to be meaningful for them around what the disability needs are. (P-01)*

Similarly, one participant asserted that knowledge derived from other branches of learning also assists in the interpretation of client information.

> *So having some knowledge, whether it’s clinical, medical or whether it's around a specific disability and what the impact of that could be, certainly helps in being able to identify what somebody might need. I found that my clinical background certainly helps as well, especially with clients who have complex needs. (P-03)*

Summary

Four primary concepts were identified from the interviews: 1) the process of the UYYS, 2) the need for face-to-face interactions, 3) comparison with traditional needs assessment, and 4) service coordinators’ skills.

Together these four concepts provide important insights into the use of the UYYS. The findings presented the perspectives of participants in relation to their use of the UYSS tool and their experiences of using the form with clients and their families.

The chapter that follows provides an interpretation of the key themes that emerged from the study, including the findings which showed that the UYYS is perceived to function from a deficit-based model and has domains that need further review.

Chapter 5: Discussion

Using an interpretive description approach, the study delved into the different experiences of service coordinators who provided us their narrative account of the process, as well as the guiding principles, of the self-assessment tool.

Having looked at the four concepts described in the previous chapter, this section will discuss the key findings that emerged from the themes. As mentioned in the literature review, there has been little published information exploring the current process of the UYYS, other than the evaluation reports completed by Evalue Research (2012, 2015).

The research question in this study sought to uncover the experiences and perceptions of service coordinators on the use of the Understanding You and Your Situation (UYYS), a supported self-assessment (SSA) tool currently used at one demonstration site.

This chapter will draw on the findings to examine the value of face-to-face contact as a facilitated process. Here, we will identify the skills essential for service coordinators to have to undertake supported self-assessment. Here, discussion will take place about the need for organisational shift to successfully integrate the SSA process. The study's implications and recommendations for practice are also reported in this chapter.

Operating on a deficit-based model

The majority of the participants of the study see the UYYS as a deficit- based assessment tool. In particular, participants reported that they allocate disability support services following identification of the person's deficits. Despite the tool's ability to capture the person's strengths through the 'My Story' page, one participant described that service coordinators would move toward exploring what the needs are from a deficit perspective. It seemed that for the service coordinators in this study, knowing what the person's deficits are helped them gain a better understanding of services that could be appropriately offered to clients and their families.

This finding is contrary to previous studies of Evalue Research (2012) which have suggested that the UYYS is a strengths-based tool. Evalue Research showed an interview summary of clients and families' experiences of using the UYYS form, however there was no explanation offered of how the UYYS was thought to operate on a strengths-based model, other than indicating that Needs Assessment and Service Coordination (NASC) staff thought of the UYYS in a strength-based manner.

The above finding that the UYYS uses a deficit approach is consistent with the data obtained in the report by MacDonald (2010). In her study, MacDonald (2010) undertook telephone interviews with NASC managers from different NASC agencies that utilised some principles of self-assessment. Respondents from a NASC service located in the North Island, the only agency that developed a self-assessment process, felt that their assessment tool focuses on clients’ deficits rather than goals. In order for a self-assessment tool to become more strengths-based, the respondents of MacDonald’s (2010) study suggested using a more goal-oriented approach so service coordinators could come up with a plan to eliminate barriers that prevent the person from achieving their goals. This finding also draw my attention to the importance of considering building the person’s strengths. The strengths-based assessment used by Niemiec et al. (2017) for people with intellectual disabilities focussed on identifying the person’s character strengths and positive attitudes to traverse disability barriers and build on their self-determination.

The view that the UYYS operates on a deficit approach may be explained by the fact that disability support services (e.g. NASC), assumes and supports a deficit-based model and process. The Enabling Good Lives (EGL) model was established to shift the focus towards a more strengths-based approach, and this model may play an essential role in the development of self-assessment tools that are more strengths-based and goal-oriented. MacDonald (2010) suggested that self-assessment tools should be developed in a manner that is holistic, integrating all aspects of a client’s life and needs. It can thus be suggested that self-assessment questionnaires could put an emphasis on the person’s strengths and goals, and not just on their deficits. In strengths-based assessment, there tends to be an increased emphasis on the importance of supporting the person to build on the person’s life stories and empowering the person to discover their uniqueness as an individual (Anderson & Heyne, 2013). One participant in this study acknowledged the importance of having that balance of information: knowing what your client’s strengths and deficits are. Despite the UYYS’s deficit-based elements, another participant of this study in particular described that the current version of the form is probably the best version they ever had for it offers an efficient way of drawing out information from people with disabilities and their natural supports.

As discussed above, the perception that the UYYS uses a deficit-based approach may be further explained by the fact that the UYYS is linked to a funding allocation tool. Without considering the client's deficits, the funding allocation tool is unlikely to generate a personal budget that can be used by the client in different ways to live a life they want (Anderson et al., 2017; Were, 2017).

Yet, for one service coordinator in this study, if there is one process that uses a strengths-based model, it is the funding allocation tool participants use to determine a personal budget for their clients. As reported by Were (2017), the majority of participants in the Enabling Good Lives (EGL) demonstration project in Waikato highlighted positive experiences using a comparable funding allocation tool that fit with a supported self-assessment used for the study. The funding allocation used for the Waikato demonstration was different from the funding allocation tool used by the sample location of this research study. The funding allocation process in the Waikato demonstration was managed by a funding committee composed of the EGL Team (Were, 2017). Participants in Were's (2017) study felt they had greater flexibility of spending their allocated funding and could express their desires to their assigned support person on how to best manage their budget plan

It is important to bear in mind that the perception of UYYS as a deficit approach is based on the views of service coordinators as participants of this study, and do not represent the responses of clients and families. The deficit-based approach seems to be fundamental to the needs assessment process from the perspective of the participants. These findings draw my attention to the importance of considering clients as participants of future studies to gain a better understanding of their experiences using the UYYS tool and the indication that it operates on a deficit-based approach.

> *"…….we've also got to understand what their disability needs are and by definition, that's a deficit based approach really" (P-01)*

> *"……the fact of the matter is that we operate on a deficit model. We allocate something on the basis of the things you can't do" (P-02)*

“Supported self-assessment”, not “self-assessment”

> *“We abbreviate it to self-assessment and it was never self-assessment.*
> *It was always supported”. (P-02)*

This quote from one of the participants clarifies exactly how the UYYS should be called. Clients can complete the SSA themselves or receive assistance from their service coordinators. As was mentioned in the introduction section of this chapter, this study set out to determine the process of the UYYS tool and that includes how the form is completed. For new referrals, what is now known about the use of the UYYS is that the allocated service coordinator meets the new client in person to complete the UYYS form. On the other hand, those clients due for three-yearly re-assessments receive a standard letter from NASC with the UYYS form by post. Clients are given the flexibility of completing the form by themselves, in their own time and pace. If people are unable to complete the narrative assessment for a number of reasons, they always have the option to fill out the form alongside their service coordinator. For three-yearly reassessments, the referral coordinator of the particular NASC agency determines whether the person has the capacity to complete the form by themselves or requires a face-to-face reassessment with their service coordinator who supports them to fill in the form. Complexity of needs, English language ability, literacy and cognitive skills are taken into account. Although the referral coordinator knows the background of the majority of existing clients due for three-yearly assessments, the referral coordinator rings the person and gives them an option of to complete the UYYS or meet their service coordinator face-to-face. It would be interesting for a future study to find out how many people actually fill in their UYYS forms by themselves and how many of them leave everything up to the NASC assessor.

Face-to-face contact is a true representation of what the word “supported” in supported self-assessment means. The result of this study shows that service coordinators see the value in face-to-face contact with their clients. In addition to supporting people to complete the UYYS form, face-to-face element serves as a validity check. This is what is likely to stop fraud and mistakes in a self-assessment situation. However, this study also pinpointed the value of providing people with disabilities and their family the privacy they deserve. The initial study by Evalue Research (2012) reported that some families are happy to complete the form over a number of days and put their perspectives forward without having to meet a service coordinator.

Perhaps one of the most important findings is that face-to-face is a required facilitated process for people who are blind, deaf, or have low vision. Since the current UYYS tool is not being offered in a format that is accessible for blind/low vision people, the majority of participants in this study cited the need for these people to receive face-to-face contact from their service coordinators. Without face-to-face contact, it is possible that people with disabilities miss out on opportunities to link with existing services (Evalue Research, 2012).

One participant highlighted that the UYYS was intended to be completed alongside a service coordinator and not for clients to fill out in isolation. This finding is in accord with those of MacDonald (2010) who indicated that clients could lose the opportunity to continue one-to-one interaction with a health care professional, therefore she stressed the importance of supporting people complete their self-report questionnaires. This seems similar to the findings in (Mejdahl et al., 2018) where health professionals were very concerned about the loss of connection with clients where there was self-report only.

Although there was no mention of the importance to support people who are blind and deaf in the reviewed literature, MacDonald (2010) noted the elderly, in particular, as one of those vulnerable people who needed support to identify the goals they wish to achieve. There is, therefore, a greater need for *supported* self-assessment to ensure people with disabilities are not disadvantaged by doing the assessment process in isolation. In addition to new referrals, there is a strong recommendation that face-to-face contact should be undoubtedly made available during supported self- assessment to those people who are highly vulnerable and have complex needs.

The present finding raises the possibility that additional one-to-one input can come from different people, other than service coordinators. Face-to-face support can come from carers, family members or advocates (Brooks, Mitchell, & Glendinning, 2017). While Anderson & Heyne (2013) acknowledged the positive role these carers and family members play in attaining a comprehensive strengths-based assessment of the person, Glendinning (2008) and Griffiths (2005) were more concerned that confusion could be the result of the person's and their natural support's opposing responses. Glendinning (2008) and MacDonald (2010) suggested the formulation of a carers' assessment separate from the main needs assessment of the service user to isolate carer's aspirations and views from those of the person being assessed.

Assessors’ Skills

Effective Facilitation Skills

Another important finding that emerged from the analysis is the importance of service coordinators’ skills and knowledge in implementing the UYYS. In order to elicit relevant information from clients, the majority of participants hold the view that service coordinators should have sound facilitation skills. Given that the UYYS contains narrative components, service coordinators should have the ability to interpret the person’s stories and pull out the relevant information that pinpoints the disability needs of the person. The use of facilitated self-assessment is about negotiating the ‘truth’ of the assessment. What it squarely does is ensure that the client voice is heard, while the overall assessment is moderated by a professional. In the end, the professional is required to make a gatekeeping judgment about the words and claims that are being made, and so face-to-face meetings become a means of validation of the information.

Niemiec et al. (2017) also recommended that practitioners should apply the practice of “*strengths-spotting*” when using strengths-based practice. The term “strengths-spotting” has been used to describe the careful observation of the person’s strengths within narrative component of the practitioner’s face-to-face interaction with the person.

Rights-focussed approach

One of the participants acknowledged that the role of service coordinators is a rights-based role, therefore it revealed the need for service coordinators to know more about the rights of people with disabilities. The task of using a rights-focussed approach involves not only understanding the person with disabilities’ rights and social inclusion, but also to promote and implement disability supports (Anderson et al., 2017). According to Mladenov (2016), access to disability support can be achieved through flexible, available disability assessments where people with disabilities can actively participate. The establishment of supported self-assessments, such as the UYYS, is an example of liberalising disability assessments to make it more person-driven. Although person-centred disability assessments is just one way of promoting disability supports, service coordinators can do more by implementing social inclusion and fair treatment by helping people with disabilities widen their community networks and natural supports, as well as fair access to the benefit system and disability funding (Mladenov, 2016).

The need for service coordinators to have sound knowledge and skills draw my attention to the importance of considering staff training and development. Macdonald (2010) recommended involving service coordinators in the development and implementation of a SSA tool, for example, as one of those changes within the disability sector's assessment process. Further staff training regarding facilitating narrative-based assessments, developing communication skills and styles required for assessments and being able to interpret the person's communication. Like MacDonald, Were (2017) maintained the need for practitioners to get involved in on-going training and become more increasingly aware of the EGL principles.

The use of SSA in residential care

It could be hypothesised that service coordinators are intent on using the traditional needs assessment for residential clients because of their high and complex needs. Given the fact that people in residential care have significant cognitive and health issues, it may be felt that this might preclude them from driving and being involved with the self-assessment tool. This gives rise to extensive traditional needs assessment process driven primarily by service coordinators (Ottman et al., 2014). It would be interesting for staff to attempt to use both, and to compare and contrast how effective each is in fulfilling the purpose of the assessment.

In a study by Ottoman et al. (2014) on client self-assessment in community care, the majority of patients gave positive feedback on the impact of supported self-assessment completed with assistance from care managers. Ottoman et al. (2014) suggested that client self-assessment should be seen as a co-assessment process where there is considerable involvement from health professionals. In residential care, carers mostly participate in the needs assessment process in behalf of residential clients who are unable to because of their limited cognitive It looks to me like you should have a complete section in the discussion about the use of SSA in the residential care section. Social justice would suggest that this group should also have all the benefits of the EGL approachability and low literacy.

There is some evidence to suggest that practitioners have reservations about carers' contribution in the assessment process and there is even doubt about the carer's willingness to care (Seddon & Robinson, 2015; Brooks, Mitchell & Glendinning, 2017). There is even doubt about the carers' willingness to care. These on-going practice issues will have implications within the residential setting should a supported self-assessment be introduced. By taking a strengths-based approach, carer perspectives are acknowledged and reflected in the assessment process and the importance of building health professional-carer relationship (Seddon & Robinson, 2015; Ministry of Health, 2015). Seddon & Robinson (2015) suggested that future assessment tools must incorporate a narrative platform where carers are given the opportunity to reflect on their caring responsibilities.

Organisational shift (Recommendations)

Macdonald (2010) and the Australia Federation of Disability Organisations, Deafness Forum, People with Disability Australia and Women with Disabilities Australia (2011) acknowledged that cultural or organisational shift is required to allow the process of SSA to thrive within the disability system and become a creative method of identifying people's needs and providing disability supports. The participants were doing a good job. However, there were elements that they found difficult – like taking a strength-based approach. It seems obvious that this may be because of cultural issues within the organisation. The SSA seems to require a complete culture shift. At the moment this is not evident in the stories of the participants. Therefore, I recommend a culture change and these are some of the ways that culture change may be advanced in a NASC organisation:

a) The development of a SSA must encourage the importance of establishing meaningful interaction with the carers and provide them a separate section in the SSA to tell their own narratives (Seddon & Robinson, 2015; MacDonald, 2010).

b) The delivery of strengths-based practice training must embed the principles of a social care model, the need to have high fidelity to the EGL model, for example, where SSA focuses on the person's life experiences and the abilities of the person with disability and their natural supports are acknowledged and appreciated (Ministry of Health, 2015; Glendinning, 2008).

It is likely that the SSA will need to continue to be developed and this should ideally include the voices of consumers. One way of doing this would be to establish a forum where the implementation of the EGL could be discussed in general, and the SSA in particular.

c) Principles of deficit model are embedded in needs assessments used in disability NASC. Because of this, opportunities for the person with disability to regain their functioning and skills are not steadily assessed (Productivity Commission, 2011). A significant shift in the assessment process is needed to evaluate whether the person might gain from re-building their functional skills (Productivity Commission, 2011; O'Brien & Sullivan, 2005).

Further Research

Further research is needed to fully understand the implications of the funding allocation tool (FAT) which ties together with the UYYS. FAT is a resource allocation system that produces a personal budget based on the information from the UYYS (Evalue Research, 2015; Were, 2017). The allocation of personal budget is an example of self-directed support aimed to provide people with disabilities greater choice and flexibility in terms of purchasing supports that they need (Were, 2017; Evalue Research, 2015; Harkes, Brown & Horsburgh, 2012; O'Brien & Sullivan, 2005). My experience of allocating individualised funding (IF) supports following completion of a traditional needs assessment, is one way of empowering people with disabilities and their families to have greater choice and control. This example of self-directed support enables people with disabilities to choose their support persons and plan how best to use their funded hours of support (Ministry of Health, 2012). Self-directed support would be a fruitful area for further work. Although recent work by the EGL demonstration in Waikato included setting up of personal budget for each person with disability included in the study (Were, 2017), further work is required to establish the efficiency of funding allocation tools and its direct link with supported self-assessments. In future investigations, it might look in detail at the relationship between what is put into the UYYS and the actual allocation.

NASC has yet to adopt the UYYS for use in residential care. The findings from this study suggest it is possible that the UYYS does not accurately capture information of the person's needs on a wide scale as compared with traditional needs assessment. The continued use of the traditional assessment for residential placement suggests some of the weakness of how the UYYS is approached in this setting, therefore, I do not see the UYYS being carried out in residential care at the present time. Further research could usefully explore the similarities and differences between self-assessments and traditional needs assessments especially in those regions where SSA is being introduced as part of the EGL demonstration.

Further work is required to explore the viability of self-assessment in residential care in relation to use of various funding streams. In my experience assessing people with disabilities in residential services, different resource allocation tools are used and the level of funding could be modified by completing a traditional needs assessment, which identifies the change in the person's needs. Although the UYYS ties with a specific funding allocation tool use for non-residential people, it raises some questions regarding the UYYS's practical adaptability to other funding allocation tools, particularly those used in residential care (Evalue Research, 2015).

Limitations of research

Although the current study is based on a small sample of participants, the findings certainly add to our understanding of the use of the UYYS assessment tool. Hearing the perspectives and experiences of service coordinators and NASC manager on the use of UYYS offers some insights into how a self-administered questionnaire is used by people with disabilities with support from their service coordinators.

One limitations may be the fact that interviews were undertaken over the phone. While phone interviews were favoured because of the geographic location of participants, face-to-face interviews could usefully explore how non-verbal cues such as emotions and body language influence the interview (Irvine, Drew, & Sainsbury, 2013). The authors indicated that non-verbal cues can have an effect on the quality of information gathered during the interview. These contextual details are often considered to be important in interpretive description, however, what I did was to visit the sample location and give a presentation so I know more about the culture of the place.

The most important limitation lies in the fact that the study did not include people with disabilities as participants, however, this is a pilot study and the findings provide important information about the perspectives of NASC assessors who have been using the UYYS for seven years. The interpretive descriptive approach would ideally draw on multiple perspectives (Thorne, 2014; Thorne, 2008). I was limited by the size of the study and by ethical issues about accessing clients.

A sample of people with disabilities would provide more perspectives related to understanding the phenomenon which is the use of the UYYS form. Involvement of people with disabilities would change the formulation of research questions, and explore different angles related to their experiences and textual analysis of using the UYYS. Questions such as *"how do you describe your experience completing the UYYS form yourself?"* and "*what is the value of filling out a self-assessment questionnaire?*" With regard to this study, people with disabilities who have had the experience completing the UYYS with and without support from service coordinators could be considered (perspective). As with face-to-face assessment, although the study has demonstrated that service coordinators facilitate face-to-face assessment if the person with disability chooses not to fill in the UYYS themselves, we do not have the data to show how many people actually fill in their UYYS forms by themselves before the service coordinator's visit. It would be interesting for a future study to determine the extent to which people fill in their UYYS form or leave everything up to their service coordinators to complete.

The main strength of this study is that it represents an in-depth investigation of the use of supported self-assessment, the UYYS, by a researching service coordinator. Prior to this study, little was known about the characteristics of the UYSS, and supported self-assessment had not been researched by a health professional working in NASC who has strong grasp on the disciplinary lens. Another strength of this study is the high proportion of participants who are Māori. I was able to capture their perspectives on the use of the UYYS in the context of improving Māori health and social well-being.

Implications of research on practice

The findings of this study have a number of important recommendations for future practice and in particular for how the SSA might be implemented in Capital Support NASC.

First**,** this study supports the recommendation that face-to-face contact during SSA should be made available to those people who are highly vulnerable and have complex needs. SSA is intended to be completed alongside the person and not in isolation. The person's complexity of needs, English language ability, literacy and cognitive levels should all be taken into account. In addition, it is important to note that main carers and family members may lack the confidence to assess the health condition of the person, and that the opportunity to rather have a face-to-face contact should be made available.

Second, it would be helpful if service coordinators had specific training regarding facilitating narrative-based assessments, developing communication skills and styles required for assessments and developing the skill to interpret a person's communication and stories. The SSA is consist of a narrative section where people tell their stories in their own words. The findings from this research indicated that people with disabilities and families find the narrative component of the SSA a "comfortable place" where they can write their own stories. It is important that service coordinators know how to critically evaluate and interpret the person's stories and bring out more information that they need from the person.

Next**,** strategies are needed to shift the current NASC organisational culture to a strengths-based practice. The findings draw our attention to the importance of fidelity to the principles of the EGL model where the abilities of the person with disability are respected and accepted. The development of person-centred, strengths-based SSA can provide opportunities for people with disabilities to improve their overall functioning and gain self-determination (Ministry of Health, 2015).

This study has been one of the first attempts to thoroughly examine the use of supported self-assessment within the area of disability from the perspective of the assessor. The findings here add to a growing body of literature on self-assessments in the field of health and disability. I suggest bringing the results of the research back to the study site needs to be done. This process is likely to elicit another round of feedback from staff and their clients, which is likely to be important in terms of what I need to know to integrate SSA into Capital Support.

Summary

This chapter has explored the research findings from the interviews of service coordinators in relation to their perspectives on the use of the UYYS. The implications for practice were discussed particularly in relation to integrating the principles of the EGL model and strengths-based practice into the process and use of supported self-assessment in disability services. The implications for occupational therapy were also presented, especially the promotion of choice and control in self-assessment practice as a way of enabling people with disabilities. The final chapter of this research summarises the study and provides a final comment on future directions.

Chapter 6: Conclusion

This project explored how service coordinators use supported self-assessment (SSA). Returning to the research question posed at the beginning of the study, the process of using the SSA form, *Understanding You and Your Situation* (UYYS) has clearly been identified. The investigation of the UYYS undertaken here, has extended not only our knowledge of the UYYS assessment tool itself, but also of SSA in the context of disability in New Zealand. Previous studies have only focussed on small-scale evaluations of the UYYS, while peer-reviewed literature addressing SSA reveals a range of other terms being used. This study set out to clarify the terms used interchangeably with self-assessment in the health and disability context, and categorise the ways self-assessments are used clinically.

Interpretive description was the qualitative methodology applied in this study. Positioning myself as a qualitative researcher supplied with general knowledge and disciplinary reasoning that comes from my background as an occupational therapist and NASC service coordinator allowed me to uncover the context of the phenomenon that was supported self-assessment. By using semi-structured interviewing as source of my data, not only was I able to gather common themes and patterns on SSA, but gained a comprehensive understanding of participants' practice and attitudes toward the use of self-assessment.

This study has identified four key concepts. These are: (1) process of the UYYS, (2) the need for face-to-face interactions, (3) comparison with traditional needs assessment, and (4) assessors' skills. These concepts establish the UYYS as the default assessment, which replaced the traditional needs assessment for this particular NASC agency. Traditional needs assessments are currently used for clients in residential care. Although the UYYS encourages the person with disability to fill out the form themselves, the findings and discussion highlighted the risk of people missing out on essential disability support funding or being disadvantaged if they complete the assessment in isolation. As with other self-assessments, the person can fill out the assessment on their own. It is, however, how the self-assessment is used that makes a difference. In order for us to minimise the risk of people being disadvantaged, the collaborative and supportive elements should be embedded in the process of self-assessment. A process that enables the person to form a collaborative effort with someone who knows the system and will guide them throughout the course of the assessment.

In response to the external audit's recommendation to explore the option of supported self-assessment for Capital Support, it is evidently clear from the findings that SSA has great value. However, the real benefit of supported self-assessment is the connection with the EGL approach, with its emphasis on strengths-based practice. The UYYS is a prototype SSA, and further work is needed to engineer a model of SSA for Capital Support. Ideally, this would incorporate the principles of the Enabling Good Lives (EGL) model.

The development of the SSA needs to go hand in hand with an exploration of the development of funding allocation tools. From the findings, it was found out that it is by way of the funding allocation that people with disabilities experience and exercise greater choice and control over how they want their personal budgets to be spent, therefore, the tool itself is a great example of strengths-based practice. A natural progression of this study is to analyse the current funding allocation tool developed by the NASC agency being studied, and explore the possibility of replicating a similar funding allocation tool for Capital Support.

The challenge now is to drive change within the organisation. The culture of Capital Support is that service coordinators are the 'experts' in facilitating needs assessments. It is difficult to change, but necessary. Unless service coordinators embrace the fundamentals of strengths-based approach that is in line with the EGL principles, SSA will be ineffective. Ensuring cultural change, education and training on the benefits of strengths-based practice should be a priority for the organisation.

I intend to submit an executive summary report drawing my recommendations and action plan in terms of implementing SSA.

This project provided me an important opportunity to make a contribution to research on the use of supported self-assessment in the field of disability. It is my hope that this project offers a fresh perspective on supported self-assessment in the context of NASC and will bring a potential change on how we undertake needs assessments in Capital Support.

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Appendices

Appendix 1. The UYYS Form

NHI: Name:

Understanding you and your situation
Te mohiotanga ki tou ake oranga

The aim of this form is to understand you and your life. The Ministry of Health through Disability Support Services may provide funding to support you with disability related daily living needs. However some of these needs might be better supported by other services and this form can also help Support Net assist you to access additional supports through accessing community resources and Local Area Coordinators.

You can complete this form by yourself, or with as much support as you need from other people such as family members, friends or your supports.
If you need help to complete this form or have any questions, please contact us at Support Net on 07 571 0093 or 0800 262 477

Consent

It is important that you read and sign this consent section. Without this we can't continue the process of helping you.

- The purpose of this form is to identify your abilities, goals, resources and disability support needs.
- The supply of information is voluntary.
- If you choose not to share relevant information, your disability support needs may not be identified and support options may not be available.
- You have the right to see and correct any personal information kept about yourself.

I agree to:

- Support Net accessing medical reports which clarify my disability and/or my health issues and the release of these reports to Support Net (if required).
- Support Net using my information to identify ways of meeting my disability support needs, through support planning and coordination.
- Relevant information being shared with the Ministry of Health, Health Professionals and/or my Service Provider to support my safety and well-being.
- Relevant information being sent as part of a referral to other agencies who may be able to assist me.
- My information being stored by Support Net.

X___________________________________

(Your signature)

Date (Print your name)

If there is a person or agency who you do not want to receive information about you, write their details here:

Name of the person who is completing/signing or scribing if it is not the disabled person (i.e. recording or answering on their behalf):

Relationship to the disabled person:

NHI: Name:

My details - Oku tini hanga

Section One

Please fill in the details below:

(Please note that if the information is used for statistics or research, you will not be identified)

Your Full Name:

Address: **Date of Birth:**

)

Phone No: **Mobile**: **Gender:** ☐ Male ☐ Female

Email Address:

Do you have a Community Services Card? ☐ No ☐ Yes Number 00000

Expiry Date

Ethnicity – select as many as are applicable

☐ New Zealand European/Pakeha
☐ Maori
☐ Samoan
☐ Cook Island Maori
☐ Tongan
☐ Niuean
☐ Chinese
☐ Indian

☐ Other (please specify)

For Maori (optional)

☐ Iwi ☐ Hapu

What language do you use most for everyday communication?'

Do you require an interpreter when you need to communicate in English? (including 'Signing') ☐ Yes ☐ No

Residential Status ☐ NZ Citizen/resident ☐ Non-resident

Disability/ Health Details: **Please select the option below that <u>best</u> represents where you usually live**

☐ Own/family home
☐ Community residential home (ID/PD)
☐ rest home/continuing care hospital
☐ boarding
☐ rental accommodation

☐ other (specify)

Are you living alone? ☐ Yes ☐ No

If not, what is your relationship to others in your household?

☐ Spouse/partner ☐ Parent ☐ Son/daughter ☐ Sister/brother
☐ Grandparent ☐ Grandchild ☐ Flatmate

☐ Other, please specify

Do you have any dependent children? ☐ Yes ☐ No If yes, number

If yes, are you their sole caregiver? ☐ Yes ☐ No

NHI: Name:

Preferred contact – Ko wai tuatahi
(e.g.) parent, legal guardian, residential Manager
Surname
First Name(s)
Address
Phone No. ( )
Relationship to you

Alternative contact – Ko wai tuarua
(not same address)
Surname
First Name(s)
Address
Phone No. ( )
Relationship to you

Your legal representative (self, parent, Spouse, EPOA, PPPR guardian, CYFS)

Correspondence to:

Section Two

Your goals and ambitions

What do you hope for? Describe the goals and ambitions you'd like to share with us. These might be short or long term goals.

You can use bullet points and write as much or little as you like, or attach a plan already completed

Short term goals/ambitions (within the next 6 - 12 months)**:**

(e.g. Day to day living, maintain health, fitness, relationships, safety)

Long term goals/ambitions (within the next 1 - 3 years)**:**

(e.g. To work, independent living, life after school, relationships, safety)

My Story - **Oku korero**

This section is a place to write about your current situation and what you want out of life. We will ask you about your disability needs in the next section – but in this part we want you to tell us about you and your life in your own words.

We will talk this over with you, so don't worry about getting this perfect – just tell us your story in your own words

Getting to know you

Please tell us a little bit about you. This might include significant life-changing events. Tell us about the activities you enjoy doing and about the people who are important to you, who you live with, your friends and family/whānau, and where you live.

You can use bullet points and write as much or little as you like. If you run out of paper, please attach another piece to this form.

NHI: Name:

My Needs - Oku hiahiatanga

Section Three

This section is about how your disability affects your life. When filling out this section, think about what your needs are, whether or not you currently receive help from any person or organisation in meeting them.

Being in Charge of my Life

Huakinga toku wairua oranga

This part is about how you make yourself understood and communicate with family and friends, your choices both big and small including who you live with, your relationships, managing your finances and health.

Part A: Tell us about this

Part B: Please select/tick the option that best fits your situation:

		My situation
A.	**I am able to make, communicate and carry out <u>all</u> of my choices decisions and relationships.** My disability does not impact on the choices and decisions I can make, or on how I make those decisions.	
B.	**I am able to make, communicate and carry out <u>some</u> choices decisions.** I can make most day-to-day decisions, but my disability limits some of the choices & decisions I am able to make. I need some help / support to maintain and develop relationships	
C.	**I <u>need assistance all</u> of the time to make, communicate and/or carry out my choices and decisions** I am also unable to actively participate in relationships that are important to me without significant help and support	

Part C: Informal/Natural Support for having control and organising your life
How much support does your family/friends or other people provide to support your needs associated with your communication and decision - making? Please select/tick the option that best fits your situation:

		My situation
A.	I have **no informal supports or I don't need any supports** for my disability needs in this area.	
B.	I have **some support** from family / friends to meet my disability needs in this area.	
C.	I have **full support** from family / friends to meet my disability needs in this area.	

NHI: Name:

Enabling My Life
Whakamanahia toku oranga

This part is about your opportunities to work, to learn and participate in activities such as – sports, leisure and or social. This might be things like – caring for children / dependants, attend school / studies, having a job, accessing your community and cultural / spiritual activities

Part A: Please describe how your disability impacts on your opportunities to do the things that are important to you:

Part B:

Please select/tick the option that best fits your situation:

		My situation
A.	**I can carry out <u>all</u> of the roles educational / work / social and responsibilities that are important to me or that I choose to do.** My disability does not affect my ability to undertake the roles that are important to me.	
B.	**I need assistance <u>some</u> of the time to carry out the roles educational / work / social and responsibilities that are important to me or that I choose to do**.	
C.	**I am <u>unable to carry out</u> the roles and responsibilities that are important to me or that I choose to do without significant help and support.**	

Part C: Informal/Natural Support (for roles and responsibilities)

How much support does your family/friends or other persons provide to support your needs associated with your responsibilities and social activities? Please select/tick the option that best fits your situation:

		My situation
A.	I have **no informal supports or I don't need any supports** for my disability needs in this area.	
B.	I have **some support** from family / friends to meet my disability needs in this area.	
C.	I have **full support from** family / friends to meet my disability needs in this area.	

NHI: Name:

Managing myself and being independent

Whakapakiri ake i ahau

This section is about how your disability affects your ability to manage yourself or be independent. It is about managing your daily routine – personal hygiene, eating and drinking, showering, dressing, toileting and continence, menstruation care, taking medication, getting in and out of bed, and mobilising moving around your home. It is also about being able to communicate your needs if your require help.

This section also includes important daily practical activities such as preparing meals, shopping, cleaning, doing the laundry, changing beds, managing finances and reading and dealing with correspondence.

Part A: Please describe how your disability limits your ability to manage yourself or be independent:

Part B: Please select/tick the option that best fits your situation:

	My situation
A. **I have <u>no current concerns</u> about looking after myself and taking care of my daily routines and activities.**	
B. **I manage some day-to-day tasks myself, but I <u>need help/encouragement</u>, or take longer to do, daily routine activities due to my disability**	
C. **I <u>need help/encouragement with most</u> day-to-day tasks due to my disability** AND/OR **I may sometimes have difficulty communicating my needs.**	
D. **I can verbally communicate my needs but I am <u>fully dependent on a carer</u> (family member, friend or paid carer) to help me mobilise and manage all of my daily routine activities.**	
E. **I am <u>fully dependent on a carer</u> (family member, friend or paid carer) and assistance to help me mobilise and manage all of my daily routine activities and I am <u>dependent on assistance to communicate</u> my needs.**	

If you answered C, D, or E above, please indicate when you need support (day and/or night) and how many people you may need to support you at these times. Please select/tick an option for either day or night, or both:

	A	**B**	**C**	**D**
	No one	**One Person**	**Mostly one person, sometimes another is required**	**Two people**
During the day, I require support from:				
During the night, I require **sleeping** support (i.e. someone sleeping, but available if needed) from:				
During the night, I require **awake** support (i.e. someone has to be awake all night) from:				

NHI: Name:

Part C: Informal/Natural Support for managing yourself and being independent

How much support does your family/friends or other persons provide to support your needs associated with your disability? Please select/tick the option that best fits your situation:

	My situation
A. I have **no informal supports or I don't need any supports** for my disability needs in this area.	
B. They can provide **some support** to meet my disability needs in this area.	
C. They can provide **full support** to meet my disability needs in this area.	

Safety, risk and vulnerability

Nga mahi tupatotanga

This section is about how your disability affects safety.

This might include circumstances where, because of your disability, you (or the people around you) are placed in unsafe or risky situations; when people worry about your safety; or when you are vulnerable to other people being unsafe towards you. It is also about recognising when you become unsafe and taking necessary action.

Part A: Please describe how your disability limits your ability to keep yourself or others safe from harm:

Part B: Please select/tick the option that best fits your situation:

	My situation
A. **I have <u>no current problems or concerns</u> with my safety.** Any vulnerability or risk to my safety, or to those around me is well managed	
B. **Because of my disability, I <u>sometimes</u> place myself or people around me in an unsafe situation**. I may sometimes be vulnerable or at risk from other's actions or inactions, or I may sometimes do things that can hurt or endanger myself or others. People are sometimes concerned for my safety	
C. **Because of my disability, <u>most of the time</u> I place myself or people around me in an unsafe situation.** I may be very vulnerable or at risk from other's actions or inactions, or I may do things that can hurt or endanger myself or others. People are quite concerned for my safety	
D. **Because of my disability, I <u>require constant supervision</u> all of the time, otherwise I place myself or people around me in an unsafe situation.** I may be extremely vulnerable or at risk from other's actions or inactions, or I may constantly become distressed, unpredictable and/or do things that could hurt or endanger myself or others. People are very concerned for my safety.	

If you answered C or D, please indicate when you need support (day and/or night) and how many people you may need to support you at these times. Please select/tick an option for either day or night, or both:

	A	B	C	D
	No one	**One Person**	**Mostly one person, sometimes another is required**	**Two people**
During the day, I require support from:				
During the night, I require **sleeping** support (i.e. someone sleeping, but available if needed) from:				
During the night, I require **awake** support (i.e. someone has to be awake all night) from:				

NHI: Name:

Part C: Informal/Natural Support for behaviour, safety and risk

How much support does your family/friends or other persons provide to support your needs associated with your disability? Please select/tick the option that best fits your situation:

	My situation
A. I have **no informal supports or I don't need any supports** for my disability needs in this area.	
B. They can provide **some support** to meet my disability needs in this area.	
C. They can provide **full support** to meet my disability needs in this area.	

Please provide any further information or examples about your needs which you feel may be relevant to safety, risk and vulnerability.

My Formal Supports - **Oku pou awhina**

Section Four

This section is about the formal supports you currently receive to help you manage your disability and live your life which are not paid for by Disability Support Services (DSS). This includes services and supports from other agencies or organisations, as well as any equipment, vehicle or housing modifications you currently have which help you manage your disability.
In the space below, please list any formal supports you currently receiving from other agencies, services or related supports which are not paid for by Disability Support Services (DSS). These supports may include services provided by other organisations such as:

- Other government agencies including Work and Income New Zealand, ACC, or the Ministry of Education.
- Other DHB or Ministry of Health funded long term support and/or rehabilitation services which are not part of DSS.
- Non-funding related services and supports provided by Non Government Organisations.

Please list any other Formal Supports you are currently receiving

In the space below, please list any equipment and housing or vehicle adaptions/modifications you **currently** have which support your disability needs. These may include:

- Wheelchairs, shower stools, walking frames and sticks, mobility canes
- Communication devices (for speaking and/or writing) and hearing aids
- Visual/vibrating smoke detectors
- Installation of handrails and ramps and shower modifications in your house
- Car/van modifications such as hand controls or wheelchair hoists

Please list any Equipment, Housing or Vehicle modifications you currently have:

Once we have received this form, we may contact you about the supports you list here. This is to ensure you are receiving all the supports you are eligible for, and ensure your DSS-funded supports align with these other formal supports.

NHI: Name:

Full-time Carer/Parent information - Nga korero pou awhina

This part of the form is for your full-time carer (this is often a family member or

Consent for information

1. I understand that the supply of information is voluntary. However, if I do not supply the information, I understand that my needs may not be identified and assessed correctly which could result in the support I need not being made available.

2. I authorise information given by me in this form to be collected, stored and used to help with my outcomes and supports. This information may be used to assist with and to understand and improve health services. *Please note that if information is used for statistics or research you will not be identified.*

3. I understand that I have the right to see and correct any personal information kept about me

4. If there is a person or agency who you do not want to receive information about you, write the details here:

Full-time Carer's signature ______________________________________Date:

Fulltime Carer's name **Date of Birth**

Fulltime Carer's address

Contact Number ( )_

Relationship to client

Fulltime Carer Health and Wellbeing
Think about your health and well-being, relationships, family life, work demands.
Tell us how it is for you?

Please indicate, by selecting/ticking ONE of the options below, How does providing support affect your life?

	Full-Time Carer's view
A. **It causes me no impact in my daily life.**	
B. **It causes some impact and has some effect on my daily life.**	
C. **It causes significant impact and has a significant effect on my daily life.**	
D. **It has a critical impact on my daily life and affects my health and well-being.**	

Sign off - Te mutunga

Once you have completed this form, please sign below and send the form to your Support Net representative

NHI: Name:

Sign off/agreement

1. I agree that this form has been completed to the best of my knowledge and ability and represents as accurately as possible ☐ **Yes** ☐ **No**
my situation, needs and supports

2. I understand that my Support Net representative may contact me ☐ **Yes** ☐ **No**
   if they have any questions about this form and my situation.

3. I understand that my Support Net representative may make modifications to my answers in this form, *but these changes will only be made after* ☐ **Yes** ☐ **No**
   they are discussed with me, and I give my explicit verbal or written consent.

I wish to make the following comments

X____________________________________ Date

Your signature/Representative's signature

Thank you for telling us about you and your situation.

When you reach this point, please send this form back to your Support Net representative. You can contact them on 07 571 0093 or 0800 262 447 if you need help or instructions.

When we receive the form, we may talk with you about your responses to check we understand everything you've written.

Appendix 2. Traditional Needs Assessment

Support assessment

Capital Support
“Links for Living”

Type of Assessment: ☐Initial ☐Reassessment ☐Annual review ☐Other ________

Date Assessment Completed: ______________________________

Assessor’s Name: ______________________________

Person’s details

Surname:	____________	Title: ____	☐ Male ☐ Female
First Name/s:	____________	Date of Birth:	____________
NHI	____________	Phone:	____________
Address:	____________	Mobile:	____________
	____________	Email:	____________
Ethnicity	____________	Iwi:	____________

Diagnosis/Disability/Health & Wellbeing:

Disability: ______________________________

Health: ______________________________

Client contacts:

Preferred/Primary contact: ______________________________

Person’s legal representative: ______________________________

Correspondence to: ______________________________

Client’s first language: ______________________________

Other services:

GP	____________	Phone Number:	____________
CS Card:	____________	Expiry Date:	____________

ACC claimant: **☐Yes** **☐No**

Health Passport: ☐Info received ☐Passport completed ☐ Chosen not to use

Assessment:

Events Leading to Assessment/Referral: ____________________

Service Coordination to be sent to referrer? ☐**Yes** ☐**No**

Place of Assessment: ____________________

Office use only - File: ☒**Yes** ☐ **No**

consent for information

- I authorise information given by me in this assessment to be collected, stored, used by or disclosed to people who will use it to help with my assessment, health and support services or who may use that information to assist with understanding and improving health services[1]
(examples are the needs assessor, the service coordinator, the agency carrying out Needs Assessment and Service Coordination, relevant support agencies, contracted providers, the District Health Board, the Ministry of Health, my General Practitioner, my family, my next of kin or care giver).
- Please name any person or agency you do not want to receive or supply information about you or your family. [Person to specify]____________________
- I understand that I have the right to see and correct any personal information kept about me.
- I understand that the supply of information is voluntary. However if I do not supply the information, I understand that it may mean that my needs will not be identified and assessed correctly, which may result in the support services I need not being made available.

____________________ __________

Persons/representatives signature Date

____

Persons/representatives name

Next of kin alternative contact

Surname:		Surname:	
First name:		First Names:	
Address:		Address:	
Phone No:		Phone No:	
Mobile:		Mobile:	
Email:		Email:	
Relationship to Person:		Relationship to Person:	

Those present/those consulted/reports used

____

____

____

☐Previous NA ☐Referral ☐Specialist reports (list) ____________________

Family/whanau information

Who does the person have a relationship with, describe extended family, where are family members living, describe roles of the people in the home, do they contribute to supporting the person, what equipment is required to support access within the family/whanau circle ? Are there people other than family who are important in the person's life?

Background

Past interventions by any support services, schools attended, peer relationships, other relationships, any traumas experienced, other significant events (positive and negative), describe any change impactors?

Present living situation

Usual Place of Residence	Relationship to others in the household
☐ Own/Family home	☐ Spouse/partner
☐ Rental Accommodation	☐ Father/Mother
☐ Community residential home	☐ Son/Daughter
☐ Rest home/continuing care	☐ Brother/Sister
☐ Unit in a retirement village	☐ Grandparent
☐ Prison	☐ Grandchild
☐ No fixed abode	☐ Flatmate
☐ other ____________________	☐ other ____________________

Current situation	
Physical environment	
Others in the home	

Current support networks

Formal	
Informal *e.g. Family, Friends, Church group, neighbour, chemist for delivery*	

Educational/vocational/voluntary

What support if any is required for participation, consider equipment and physical support?

Current situation	
Support	
School	
Employment	
Voluntary	

Recreational/social

Activities groups the person is involved in, who assists if required detail any equipment that is needed, how do they get to the event? Do parents have transport? What prevents participation if anything, e.g. fatigue of the carer?

Interests	
Social networks	
Support	

Spiritual

Any blocks to participation? Meets own needs, how, detail assistance needed? Any aspect of life that is held dear.

Cultural

Does the person have opportunity to learn about their culture, the culture of their family, the culture of New Zealand?

Communication

Expressive Verbal	
Receptive Verbal	
Non Verbal	
Reading/Writing	
Technology	
Support	
Behaviour	

Sensory function

Vision		**Hearing**	
Can see well enough with or without glasses	☐	No hearing deficit	☐
Reduced vision, but can read large print/watch TV	☐	Hears well with aids	☐
Very poor vision, may need guidance/assistance at times	☐	Hearing deficit	☐
Blind or nearly blind	☐	Severe deafness	☐

Has a sensory assessment been completed? Is it currently in use? Do they require sensory assist aids? How do they manage cleaning and maintenance? Who is responsible to ensure tasks are completed? Who changes batteries in aids?

Vision	
Hearing	
Touch	
Taste/Smell	
Hypersensitivity	
Support Agencies	

Work and income support

☐ Supported Living Payment ☐ Community Services ☐ Living Alone ☐ High user card

☐ Disability Allowance ☐ Travel subsidy ☐ Accommodation Benefit ☐ New Zealand Super

ACC Weekly Compensation: ____________________

Any other benefits received: ____________________

Mobility

	Ind.	**Sup.**	**Ass.**		**Ind.**	**Sup.**	**Ass.**
1. Mobility inside	☐	☐	☐	**5.** Transfers	☐	☐	☐
2. Mobility outside	☐	☐	☐	**6.** Ability to get up after fall	☐	☐	☐
3. Mobility in the community	☐	☐	☐	**7.**Falls risk? *(frequency)*	**Yes** ☐		☐ **No**
4. Transport	☐	☐	☐				

If the person uses any tool to assist mobility state what is required. Has the home or mode of transport been modified? Are they able to travel without a support person? How is equipment maintained, cleaned? Can the person arrange this?

Inside	
Outside	
Community	
Transport	
Transfers	

Ability to get up after fall	
Falls risk	

Participation household management

	Ind.	Sup.	Ass.		Ind	Sup.	Ass.
1. Shopping	☐	☐	☐	**6.** Finances	☐	☐	☐
2. Meal preparation	☐	☐	☐	**7.** Garden / Lawn	☐	☐	☐
3. Housework	☐	☐	☐	**8.** Home safety	☐	☐	☐
4. Laundry	☐	☐	☐	**9.** Home security	☐	☐	☐
5. Heating	☐	☐	☐				

Can a person collate what is required to purchase? To what level? Can they prepare food to any level? What? What house work can a person do? To what degree? Does the person know what money does? Do they operate their own bank account? Have they a legal advocate? Is the person able to identify risks and vulnerabilities in relation to own safety and security? Are they able to physically secure the home? Leave in an emergency?

Shopping	
Meal Prep	
Housework	
Laundry	
Heating	
Finances	
Garden/lawns	
Safety	
Security	

Personal care

	Ind.	Sup.	Ass.		Ind.	Sup.	Ass.
1. Bed mobility	☐	☐	☐	**9.** Continence bowel	☐	☐	☐
2. Bathing/showering	☐	☐	☐	**10.** Medication	☐	☐	☐
3. Dressing/undressing	☐	☐	☐	**11.** Eating	☐	☐	☐
4. Grooming	☐	☐	☐	**12.** Drinking	☐	☐	☐

5. Dental Care ☐ ☐ ☐

6. Foot Care ☐ ☐ ☐

7. Toileting ☐ ☐ ☐

8. Continence bladder ☐ ☐ ☐

13. Health Management ☐ ☐ ☐

14. Sleeping Patterns ☐ ☐ ☐

15. Menstrual Management ☐ ☐ ☐

Detail any tools required to facilitate the completion of personal cares, detail the degree of supervision assistance required in all of the above areas, how does a person get to the doctor? Can they go alone? Do they remember what is said? How do they get their medication? Can they self-administer? Is the person aware of any risks associated with their medication? e.g. Insulin What happens when there is a side effect??

Bed mobility	
Bathing/Showering	
Dressing	
Grooming	
Dental Care	
Foot Care	
Toileting	
Bladder Continence	
Bowel Continence	
Medication	
Eating	
Drinking	
Health Management	
Sleeping patterns	
Menstrual Mgmt	

Memory behaviour cognition

1. Memory	2. Orientation	3. Behaviour
☐ No noticeable memory deficit ☐ Mild loss of memory of recent events ☐ Fluctuating memory loss ☐ Moderate loss ☐ Severe loss of memory for recent events ☐ Severe loss of memory for both recent and remote events	☐ No evident difficulties finding way about ☐ To familiar surroundings ☐ Sometimes mistakes surroundings ☐ Frequently mistakes surroundings ☐ Totally confused as to surroundings	☐ Observes accepts social standards ☐ Some behaviour is unusual but does not offend ☐ Sometimes behaviour causes others actual distress or discomfort ☐ Behaviour often causes others actual distress or discomfort
What increase to negative behaviour? What has been tried in response to this behaviour? Were strategies able to be implemented? What worked? Why? What didn't? What prevented success? What is the impact on care providers (Natural/funded)? How many agencies/services are involved? Describe functions? Frequency of engagement? Who do services engage with? Was the intent of engagement achieved? Describe gaps? Would the person benefit from a Strengthening Families forum or a Social Worker? Do carers think they are receiving adequate support? If no what needs improving? Is culture a barrier? Has there been a recent medical, dental check to rule out health impactors? Is there a need for the GP to refer to MH services? Is the current package being used? If not why? Also consider: attention/concentration/planning/orientation to time & day		

Memory	
Orientation	
Behaviour	

---

4. Delusions/Hallucinations	5. Motivation	6. Wandering
☐ None ☐ Mild/occasional ☐ Moderate/frequent ☐ Severe (complete loss of contact with reality)	☐ Well motivated ☐ Motivated but can be unsafe ☐ Needs encouragement ☐ Unmotivated	☐ No wandering ☐ Occasional and brief bouts of wandering ☐ Persistent wandering - inside ☐ Persistent wandering - outside ☐ Unsafe wandering

Delusions/Hallucin.	
Motivation	
Wandering	

---

7. Insight	8. Anxiety	9. Night Behaviour
☐ Good	☐ No anxiety	☐ Settled
☐ Some insight	☐ Understandable anxiety	☐ Sometimes unsettled
☐ Little insight	☐ Moderate	☐ Disturbed/wandering
☐ Totally lacks insight	☐ Incapacitated by anxiety	

Insight	
Anxiety	
Night behaviour	

10. Supervision	11. Mood	12. Specialist Care/Treatment
☐ Independent ☐ Daily prompts ☐ Some for safety ☐ Cannot be left alone ☐ Length of time person can be safely left alone?	☐ Usual H L ☐ ☐ At times but recovers ☐ ☐ For long periods - not treated ☐ ☐ Receiving treatment	☐ Needed ☐ Pending ☐ Receiving *This is not intended to capture allied health services e.g. physiotherapist, occupational therapist.*

Supervision	
Mood	
Specialist Care	

Person goals

What does a person want to achieve this coming year? Where do they see themselves this year? Next year?

Parent/primary carer support information

consent for information

- I authorise information given by me in this assessment to be collected, stored, used by or disclosed to people who will use it to help with my assessment, health and support services or who may use that information to assist with understanding and improving health services[1]
  (examples are the needs assessor, the service coordinator, the agency carrying out Needs Assessment and Service Coordination, relevant support agencies, contracted providers, the District Health Board, the Ministry of Health, my General Practitioner, my family, my next of kin or care giver).
- Please name any person or agency you do not want to receive or supply information about you or the person for whom you are providing care. [Person to specify]________________________
- I understand that I have the right to see and correct any personal information kept about me.
- I understand that the supply of information is voluntary. However if I do not supply the information, I understand that it may mean that the needs of the person for whom I am providing care and my own needs will not be identified and assessed correctly, which may result in the support services we need not being made available.

____

____

Caregiver’s signature

Date

Carers Name: ______________________ Relationship to person: _____________________ DOB: _

Health/well-being of carer:	
Carer’s current commitments:	
Carer’s current concerns:	
What support has been of benefit?	
What would assist you further?	
What are the current natural supports for the carer?	
Additional information:	

Notes/other information

All identified support requirements

Assistance required for activities of daily living as a result of disability related needs. Include needs that are being supported and how needs are met. Identify needs that are not disability related and how they are/will be met. May include the following and not limited to:

- Education/Vocational
- Recreational/Social
- Memory/Behaviour
- Personal Care
- Household management
- Financial
- Communication
- Sensory function
- Natural Support
- Spiritual/Cultural
- Mobility
- Other services

Person Priority	**Identified Needs**	**By Whom**	**Urgency**

Completing the assessment

Person/Representative

I have read and discussed this assessment (and the review procedure) with the Assessment Facilitator.

1.	**I agree:**		
	With the content of the assessment	☐ Yes	☐ No
	With the identified needs	☐ Yes	☐ No
	If you disagree, do you want a review of the:		
	Assessment	☐ Yes	☐ No
	Identified needs	☐ Yes	☐ No

2. I understand that this assessment will be used to identify and assess my disability and support needs.

Home-Based Support

1. I understand that I may have to pay for my home-based support if section 69FA of the Social Security Act 1964 applies to me.
2. I understand that I also have the option of applying to the relevant government agency to determine whether I am eligible for government funding of my home-based support costs.

69FA of the Social Security Act 1964 applies to you if you:

a) have been assessed as requiring home-based support; AND
b) are not a child; AND
c) are not entitled to a community services card

Residential Care

1. I understand that I may have to pay for all or part of my residential care if I fall in to the relevant age category and section 69FA of the Social Security Act applies to me.
2. I understand that I also have the option of applying to the relevant government agency to determine whether I am eligible for government funding of my residential care costs.

69FA of the Social Security Act 1964 applies to you if you are:

a) aged 65 years or more; OR
b) aged 50 to 64 years and been assessed as close in interest to people aged 65 years or more and are unmarried with no dependent children; AND
c) Have been assessed as requiring residential care indefinitely

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Persons/Representatives signature Date

Service Facilitator

I have discussed this assessment; the identified needs and review procedure with the person/representative.

Service Facilitators signature

Appendix 3. Ethics Approval Letter

OTAGO
POLYTECHNIC
Te Kura Matatini ki Otago

28 June 2018
Mark Esteves
68A Gemstone Drive
Birchville Upper Hutt

Dear Mark

Re: Application for Ethics Consent

Reference Number: 775
Application Title: *The perspectives of NASC assessors on the use of Supported Self-Assessment (SSA)*

Thank you for your application for ethics approval for this research project. This letter is to confirm approval for the project.

We wish you well with your work and remind you that at the conclusion of your research to send a brief report with findings and/or conclusions to the Ethics Committee.

All correspondence regarding this application should include the reference number assigned to it.

Regards

ondence regarding this a
mphrey

Richard Humphrey
Co-Chair, Otago Polytechnic Research Ethics Committee

Otago Polytechnic
Forth Street
Private Bag 1910
Dunedin 9054
Freephone 0800 762 786 Email: info@op.ac.nz
Phone +64 3 477 3014 www.op.ac.nz

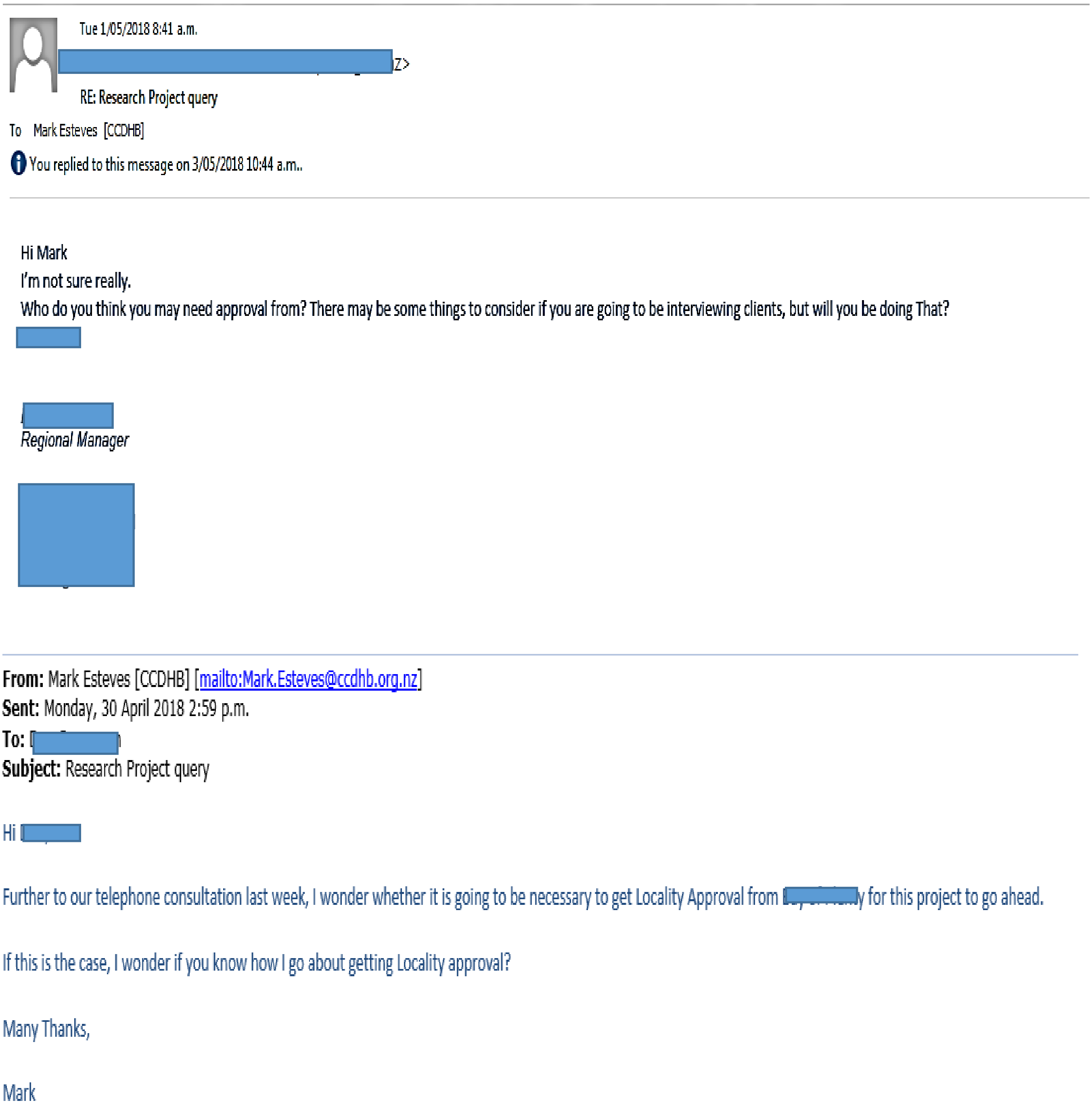
Appendix 4. Office of the Kaitohutohu Māori Ethics Consultation

Whāia te pae tawhiti kia tata. Whāia to pae kiā maua
Pursue the distant horizons so that they may become your reality

Office of the Kaitohutohu Māori Ethics Consultation Feedback
Date: 6 June 2018
Researcher name: Mark Esteves
Department: Occupational Therapy
Project title: The perspectives of NASC assessors on the use of Supported Self-Assessment (SSA).

INDIGENOUS INNOVATION: Contributing to Māori Economic Growth	
TAIAO: Achieving Environmental Sustainability through Iwi & Hapū Relationships with the Whenua & Moana	
MĀTAURAKA MĀORI: Exploring Indigenous Knowledge	
HAUORA / ORANGA: Improving Health & Social Wellbeing	Māori health and access to support services is a priority area for Māori and the Government. Self-assessment reports may be an empowering process for people who possess the literacy skills to develop a support plan, but as the applicant has identified, there is little research on this process. Māori have lower literacy levels than non-Māori, which may be a barrier for Māori to complete the self-assessment tool. This could result in non-compliance by Māori and potentially a loss of access to entitled services. A secondary aim is to explore the advantages and disadvantages of self-assessment in comparison with traditional needs assessment. The applicant aims to gather and interpret data from service facilitators through focus groups and semi-structured interviews. It would be interesting to explore whether the service facilitators identified any cultural disparities. This could be achieved by reviewing the self-assessment process to see if it is a good fit for Māori, the quantity and quality of self-assessments, and review the quality of support plans for Māori when compared with the status quo process.
TO LIVE AS MĀORI: Kaitiaki to Ensure Māori Culture and Language Flourish	The applicant has correctly identified the importance of whānau support to help with this new process. The applicant could explore with service facilitators the role of whānau support within the self-assessment process (if the client wants this) and whether Māori prefer a kanohi ki kanohi face to face approach. The applicant may like to consider what additional support could be offered for Māori with low literacy levels.

Appendix 5. Locality Approval



Tue 1/05/2018 8:41 a.m.
[redacted]
RE: Research Project query
To Mark Esteves [CCDHB]
You replied to this message on 3/05/2018 10:44 a.m..

Hi Mark
I'm not sure really.
Who do you think you may need approval from? There may be some things to consider if you are going to be interviewing clients, but will you be doing That?
[redacted]

[redacted]
Regional Manager

[redacted]

From: Mark Esteves [CCDHB] [mailto:Mark.Esteves@ccdhb.org.nz]
Sent: Monday, 30 April 2018 2:59 p.m.
To: [redacted]
Subject: Research Project query

Hi [redacted]

Further to our telephone consultation last week, I wonder whether it is going to be necessary to get Locality Approval from [redacted] for this project to go ahead.

If this is the case, I wonder if you know how I go about getting Locality approval?

Many Thanks,

Mark

Appendix 6. Participant Information Sheet

Participant Information Sheet

Project title: Perspectives of Needs Assessment and Service Coordination (NASC) service facilitators on the use of Supported Self-Assessment

Researcher: Mark Esteves
School of Occupational Therapy
Otago Polytechnic
Dunedin

Contact Number: 021479773
Contact Email: mark.esteves@ccdhb.org.nz

The information sheet and consent forms are attached.
Participants are informed in this way:

General Introduction

I am Mark Esteves. I am a Masters student in the School of Occupational Therapy at Otago Polytechnic in Dunedin. As part of this degree I am undertaking a research project for completion of Master of Occupational Therapy (MOccTher).

What is the aim of the project?

The purpose of the project is to investigate the experiences of NASC assessors on the use of self-assessment following its inception in the [redacted] seven years ago. The information gathered will help us determine the process of self-assessment in the region and gather ideas to develop a framework for Wellington NASC to meet the external audit requirement.

What will my participation involve?

Should you agree to take part in this project you will then be asked to contribute to in the data collection process by attending a confidential face-to-face interview. There will be a range of questions to guide the interview. The interview will take 60-90 minutes, will be audio taped, transcribed and analysed by the researcher. You may decline to answer a question if it makes you feel uncomfortable or for any reason. After the tape is transcribed, you will be asked to read a summary of your interview, returning it to me with any corrections, or amendments you wish to have made.

How will confidentiality and/or anonymity be protected?

During transcription of semi-structured interviews all participants' real names will be replaced by pseudonyms. All raw data with personal information about the participants will be stored securely during the study and destroyed at the end of the study.

Within any published articles no reference will be made to identifiable information. While I will be asking for participants to draw on their clinical experiences of the use of SSA tool, no client names or identifying information should be used.

What data or information will be collected and how will it be used?

Results of this project may be published but any data included will in no way be linked to any specific participant without prior consent. The primary use of this research will be in the production of a Masters Project.

You may request a copy of the results of the project. The final Masters project will also be available through the Bill Robertson Library.

The information from the Project will be used in general presentations at conferences and as part of a workshop, staff forum and seminar. It may also be published as an academic article.

Data Storage

The data collected will be securely stored in such a way that only the researcher and supervisor will have access to it. The electronic data will be password protected*,* while hard copies will be stored in a locked cabinet*.* At the end of the project any personal information will be destroyed and any raw data on which the results are based will be retained in secure storage for a period of five years, after which it will be destroyed.

Can participants change their minds and withdraw from the project?

You can decline to participate without any disadvantage to yourself of any kind. If you choose to participate, you may withdraw from the project at any time, without giving reasons for your withdrawal. You can also withdraw any information that has already been supplied until the stage agreed on the consent form. You can also refuse to answer any particular question, and ask for the audio/video to be turned off at any stage.

What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact

Either, Mark Esteves, 021479773,

or Dr. Mary Butler, 03 4796073,

Any additional information given or conditions agreed to will be noted on the consent form**.**

Appendix 7. Interview Participant Consent Form

Consent Form

Project title
Perspectives of Needs Assessment and Service Coordination (NASC) service facilitators on the use of Supported Self-Assessment.

I have read the information sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:
☐ My participation in the project is entirely voluntary, and that this signed consent form will provide evidence of agreed participation.
☐ The study will involve semi-structured interviews. The semi-structured interview will be conducted by telephone and take 60-90 minutes Specific date and time will be negotiated between me and the researcher. I agree to the interview being audio-taped and notes to be taken.
☐ I am free to withdraw up to the point of data analysis, at this point, in would be difficult to separate specific information from the body of data. Withdrawal before this point can occur without giving reasons and without any disadvantage.

☐ The data (including video tapes or audio tapes) will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for five years after which it will be destroyed. If it is to be kept longer than five years my permission will be sought.

☐ The results of the project may be published or used at a presentation in an academic conferences but my anonymity / confidentiality will be preserved.
I agree to take part in this project under the conditions set out in the Information Sheet. I would like a summary of the research findings. ☐

…………………………………………………………
(name of participant)
……………………………………………………………………………………………
(signature of participant) (date)
……………………………………………………………………………………………
(signature of researcher) (date)
This project has been reviewed and approved by the Otago Polytechnic Ethics.

Appendix 8. Semi-structured interview questions

Semi-structured interview questions to service facilitators

Demographic Information
What is your role in the Service?

Philosophy

1. What do you think is achieved by the narrative self-assessment?
2. What do you think is the core philosophy underpinning narrative self-assessments?

Getting things

3. How does service facilitators use the current SSA form (UYYS)? Could you tell me the process from referral to service coordination?
4. What kind of information do clients give when they fill in this form by themselves?
5. What happens when a service user declined using the self-assessment form?
6. Is there a possibility that people are disadvantaged if they do not fill in a form alongside someone who is an expert in the system?
7. Does the narrative self-assessment lead to requests that are significantly different from those arrived at through the traditional form?

   If so, why is this? If not, why is this?

Compared to Traditional Needs Assessment

8. **[redacted] uses the traditional needs assessment form for residential clients**.
   What is the difference in terms of quality of information being captured by the UYYS form compared with the traditional needs assessment form?
9. What are the advantages and disadvantages in comparison with the traditional needs assessment?

SSA as a strengths-based, person-centred tool

10. How does Support Net maintain the use of UYYS as a strengths-based approach?

11. In what ways do the self-assessment form promote client choice and control?

12. Does the use of UYYS exercise client choice and control? If so, what parameters are used to make sure choice and control are regulated?

13. Is it more meaningful to do an assessment using a narrative-based approach?

14. How does narrative self-assessment fit with the principles of the new model/enabling good lives?

Potential challenges of using the UYYS

15. Is the UYYS form usable or effective?

16. What does the service facilitator do when clients struggle with completing the form themselves?

17. What are potential barriers clients are experiencing/facing in terms of completing the form? How do you address these barriers as a service?

18. **If people underestimating their needs was not mentioned as a barrier, ask this question:**
    What do you do as a service coordinator when a service user under-estimates their needs when filling out the UYYS form?

    Follow-up/Probing: Could you give an example of a time you experienced this?

19. **If this was not mentioned as one of the barriers, ask this question**:
    In the study done by Evalue research in 2015, they suggested that the UYYS Form does not appear to work well for those who are less confident and articulate. What do you think of this finding?

    Follow-up/Probing: As a service coordinator, have you come across people who struggled to use the form because they are inarticulate?

20. . With self-assessment, there is a transfer of power from service coordinator to the client when it comes to taking in charge of completing the form.
    I would like to know whether you have had experience difficulty transferring your power over to your clients.
    What stand out in your mind about that?

21. **Earlier, I asked you about the challenges service users experience in completing the UYYS form. Now, I would like to ask….**

    What current challenges service coordinators like you are experiencing when it comes to using the UYYS form?

Evaluation/Re-design of UYYS

22. From your perspective, what component/s of the UYYS form needs re-designing and why?

23. Is there a possibility for the UYYS form to be used by people with disabilities in residential care given the potential challenges of filling the form?

24. How do you see the UYYS form being completed online by people with disabilities and their whanau?

25. What else is needed to be done to make the UYYS more effective?

26. What positive comments do you hear from people about the use of UYYS?

Cultural Implications

27. What is the role of whanau support in UYYS (if clients choose to have their family around to support them)?

28. Do you see the UYYS form fit for people with disabilities whose background is Māori?

Appendix 9. Narrative Interview Reports – QUAGOL Stage 2

QUAGOL Stage 2: Narrative Interview Report – Participant 1

Participant 1 sees the self-assessment tool, UYYS, as an opportunity for clients and their families to do their assessments in their own time and with the people that they want around them. For Participant 1, the core philosophy of the UYYS (self-assessment) is to give people and their families more control and power over how and when assessment is done (**Control and Choice).** Despite having set of questions that are asked, people are encouraged to write/put their own story in the form that tells them more about themselves. It's having that sense of flexibility. Narrative assessment

Self-assessment (UYYS) is more consistent with the Enabling Good Lives principles because it puts people in the centre of the assessment process. For Participant 1, there is a power shift whereas NASC assessor moves away from controlling the process and gives more control to the client or their family. It's about putting them in the position of power.
Participant 1 states that self-assessment is not for everyone. Each person sees it differently: "*Some people really enjoy the opportunity of doing self-assessment. Other people don't find it empowering, they find it quite a burden*". (**Challenges)**

. Service coordinators will calculate a budget from the information and coordinate services from.

Participant 1says the amount of information provided depends on the person's writing skills and other factors. **(Literacy)** Some people provide minimal information by just ticking the boxes while some people enjoy the assessment process and will write a lot of information. (**Content of Information)**

. (**Underestimating needs**) If someone is doing an assessment and they tell us something, NASC service coordinator may or may not go back to ask for clarification therefore not getting enough information. In this case, the person could possibly be disadvantaged.

For Participant 1, both UYYS and traditional needs assessment both capture the information that is required. It will all up to the skills of the assessor how he or she obtains the relevant information. The needs assessor needs to have the following skills to bring out the information that they need from people:

- Good listening skills
- Good facilitation skills
- Sound writing skills
- Understanding of disability and disability sectors
- Able to interpret people's stories to identify what their disability needs are. (**Assessors Skills)**

Appendix 10. Preliminary Concepts – QUAGOL Stage 6

CONCEPTS

Choice - Control
Enabling
Flexibility

Principles of users / SSA
According to S-Coordinator

Narratives
Effectiveness
Re-design
Default Assessment
Process
Free-Flowing
Potential for Rea[illegible]al
Social Model
Ideal Form

ompa-
ison
= TNA

SCs describe [illegible]model
as [illegible]
In Comparison to
Traditional

Power Shift
Empowerment

Literacy
writing skills
challenges
Anxiety
self-doubt
Disempowered
Barriers

Barriers

challenges