INTEGRATING IN SOCIETY WITH AN INTELLECTUAL DISABILITY

A THESIS ON THE LIVED EXPERIENCES OF SOCIETAL INCLUSION, CONDUCTED ON BEHALF OF SPECTRUM CARE

Author	*Ires Romijn — 3718336*
Auckland	*March 29th, 2023*
Faculty and course	*Fontys HRM and Psychology; Applied Psychology*
First assessor	*C. M. R. Smerecnik*
Second assessor	*T. T. R. Vijgenboom*
Supervisors organisation	*A. M. Barr; P. Rutherford*

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ABSTRACT

Globally, social inclusion of people with an intellectual disability has been a long-standing challenge. From the public stigma, lack of understanding and little societal exposure, to discrimination, maltreatment and abuse, all show to be examples of difficulties this minority group encounters all over the world while integrating in society. Their disability being defined as a neurodevelopmental disorder which arises in childhood, creates intellectual challenges, as well as a combination of challenges in the social, conceptual, and practical areas of life (American Psychiatric Association, 2022). With a dark history of this minority group being subdued to effects of the eugenics movement, with labels like 'idiocy' and 'mental deficiency' being the norm, the relatively recent shift in approach, appears to be a slow process. Through policies, equal rights and social inclusion have been promoted to initiate integration of the minority group. As a result, institutional care was replaced by community integrated living arrangements. In New Zealand specifically, the organisation Spectrum Care played a big part in this process, where the old ways continued for longer. It took huge reformations, with limited resources, which is an ongoing mission to this day. Attempts of stimulating exposure and societal awareness are a relatively young process, with limitations. The current need for improvement shows to be ever pressing, with many contributing factors making this complex. It includes exposure, a shift in attitude, insight and understanding, as well as tools and resources for both parties involved. The crux has been the lack of knowledge in both literature and practice, of the lived experiences from the minority group's perspective. Global, national and local policies have been made with little involvement of people with intellectual disabilities. Little is known about their personal perspective of the process thus far. Hence, the research question came to be "What are the experiences of individuals with an intellectual disability with regards to social inclusion?"

Ten semi-structured interviews were conducted with members of the target group. The Talking Mats tool was used, creating a structure adapted to the disability. This provided space for new information to come to light, as well as a framework that would allow to 'tap in and out' of topics, making it easier to express oneself. Findings were grouped into three overarching themes: the perception of their own social skills, their experiences with immigration thus far and their found barriers to inclusion. This provided new insight into elements, such as their tendency to avoid confrontation, experiences of maltreatment and social exclusion, employment experiences, effects of childhood experiences, level of self-regulation and emotions, their understanding of the able majority and the current level of engagement, autonomy and exposure of the minority group. Empirical findings form the conclusion that the experiences of attempts to integrate in society, are currently mostly ineffectual, with room for growth. They experience it to be a complex process and generally don't feel like the outside world, including the service providers at times, is sufficiently equipped to support their integration. This shows in forms of undesirable reactions to their presence in certain social settings, to a struggle in communicating with staff members regarding making arrangements for steps forward. The shared success stories do show potential, desire for engagement and a willingness to integrate. With new findings for the literary database from the perception of the target group themselves, there does need to be held into account that this data can't be generalised and could be coloured by factors such as social desirability during interviews or an inaccurate view of one's own behaviour. Future research could focus on also gaining the perception of the able majority. Recommendations regarding an intervention are aimed towards improving the following skills, in order to enhance social inclusion: understanding one's own potential; establishing goals to enhance engagement; making autonomous choices regarding future; growing community connections; and protecting and expressing personal interests. With this enlarged understanding of the lived experiences of individuals with an intellectual disability, Spectrum Care can now adjust their support accordingly to improve their aim of social inclusion for this minority group.

INTRODUCTION

Throughout history the views, knowledge and ethical beliefs regarding people with an intellectual disability (ID) have varied immensely. An intellectual disability is defined as: a neurodevelopmental disorder which arises in childhood, creating intellectual challenges and a combination of challenges in the social, conceptual, and practical areas of life (American Psychiatric Association, 2022). Up until more recently than one might imagine, terms like 'imbeciles' and 'mentally defective person' were used to describe individuals that fell under these classes. Early 1900's, the eugenics movement had a big impact on the attitude towards people with disabilities, believing them to be invalid to breed — from which the term 'invalids' originated (Tøssebro et al., 2012). They were separated from society and their families as wardens of the state, often from an early age. In the institutions they resided, they had no belongings of their own, wore grey uniforms, couldn't choose when to eat or drink, couldn't leave, were only exceptionally allowed visits from family but more often none at all and lived in large numbers in dorm rooms (Spectrum Care, 2014).

Then, a new approach within the disability sector gained momentum that focused on human rights and contemporary service delivery. Starting with a longer history of Nordic disability rights activism since the 1960s, the rest of the world slowly caught on (Tøssebro et al., 2012). In 2008, the United Nations convention on human rights of persons with disabilities, set the commitment to this approach of also the New Zealand government in stone. After a long time of nescience regarding this matter from the public as well as specialists, equality for all humans is now secured. It emphasises that any individual, with a disability is entitled to all human rights and fundamental freedoms (Disabled Persons Assembly NZ, 2008). Government agencies are currently following The New Zealand Disability Strategy. It stands by the vision of being a non-disabling society. Defined as 'equal chances to realise goals and aspirations for each and every individual', the goal is for the entirety of New Zealand to cooperate and make this happen (Office for Disability Issues, 2016). Human rights here are the crux of the matter, because as mentioned above, for the longest time people with disabilities were treated with far less dignity, respect and sense of freedom and autonomy (Spectrum Care, 2014).

Spectrum Care is a New Zealand based organisation that strives towards supporting and identifying the unique potential in people with an ID. They support people with these disabilities, by helping them and their families to realise this potential. Their vision is that every person with a disability deserves a life of choice, freedom and independence. Spectrum Care's mission is to help maximise the potential of those people (Spectrum Care, 2021c). To understand the depth of Spectrum Care's mission, their journey must be understood. Spectrum Care first started in 1994, when the closure of a mental hospital in Auckland created a need for housing and support of people with disabilities. This resulted in the start of a new organisation that continued these services. Since, it has been an ongoing journey to deinstitutionalise and support the people from within communities of their own choice. Much of this was new territory, as this deviated significantly from the then present-day practice. By joining forces with several organisations, they continuously were, and are still, striving towards improvement of government policies and appropriate resources regarding these peoples' rights. The attitude of the community, as well as staff and parents varied heavily during this process as it was going through huge reformations — going from institutions to homes for the individuals, supported on benefits. Hence, its goal to keep progressing towards a humane and equal chance at life for people with disabilities is an ever-pressing need (J. Walters, personal communication, September 5, 2022).

Since the shift in approach towards people with a disability, the main value is integration in society. However, in this journey they encountered bumps on the road. Assuming these

individuals will integrate well after a life of segregation and special treatment has proven to be optimistic, without the right support. There appears to be a multifactorial cause, with an overload of interpretation from outsiders who do not have a lived experience of these challenges themselves. In literature, as well as in practice there is a lack of data and understanding from the perspective and personal experiences of the target group (Abbott & Mcconkey, 2006; P. Rutherford, personal communication, September 13, 2022). In addition to this, there appears to be a shortfall of skills essential to disability support, as up to this day there has been a lack of focus on sufficient education in disability support in New Zealand. The funding to pay equipped staff is below average, compared to other Western countries. Therefore, individuals with a degree in this field of work tend to get better paid jobs elsewhere (Office for Disability Issues, 2016; P. Rutherford, personal communication, September 13, 2022).

Since the beginning of this journey, decisions have been made (perhaps with best intentions) on behalf of people with ID, with little understanding of the actual experience of the individuals themselves (Myers et al., 1998). Spectrum Care wants to gain a broader understanding of their perspectives, to find out what accommodates both them and the able majority to level and connect more with each other. So far it has shown in their experiences, time and time again, that integration fails due to a lack of the ability to partake in these environments, mainly on account of the social domain of the adaptive behaviour, in settings of employment and building a network. The mainstream environments are not experienced enough to suitingly take on the presence of these individuals, and they themselves are not subdued enough to these new settings without the right tools or experience. Recent surveys show that people with ID in New Zealand are feeling somewhat satisfied with their lives (Spectrum Care, 2022)[1], but as there is still a proven contrast between the quality of life, mainly socially, of the able majority and the minority group with ID, there is still an urgent need for improvement. An example is the significantly higher percentage of 46% from individuals with a disability reporting feeling lonely most/all of the time in 2020. There is also a significant gap between the social interaction (having face to face contact with friends, at least once a week) of these people, opposed to non-disabled people (General Social Survey, 2018).

The real need for improvement from Spectrum Care's perspective, is mainly felt in two areas. The first area is in employment placements of people they support with employers. They have often shown not to last, with one of the factors being insufficient modelling and preparation regarding social- and communication skills. An example is an adolescent with ID, employed by a lawn mower company. If he misses the social boundaries or etiquette to kindly ask the customer for a cup of tea at their place, but were to demand one before continuing his work, this could lead to mutual discomfort and potentially termination of the placement (P. Rutherford, personal communication, September 13, 2022). The second area a need for improvement is felt, would be where some individuals miss the social cues or concepts of boundaries to grasp when they are being taken advantage of. This occurs in varying forms, from not being able to say no to others in the dynamic of a group and becoming overworked or unhappy with the outcome to inviting people that came across on the street over for a sleepover and waking up with their television stolen (J. Toomey, personal communication, September 28, 2022). Currently, it is not part of the staff's tasks to address or improve these occurrences and to set the right boundaries, in order for them to navigate more fluently in mainstream environments. Nowadays Spectrum Care supports its people through a range of services, varying from community residential services to supported independent living, planned break services, carer support and rehabilitation services (Spectrum Care, 2021b). As of yet, structurally there is little offered in terms of social skills. For instance, in the aspiration centre where the individuals come to try out certain aspirations (t-shirt making, video editing, etc), the staff will generally have the primary goal of working with those particular

[1] Origin source from the intranet (not publicly available) of Spectrum Care

tools. Currently the social skill aspect of the people Spectrum Care supports is stated to be an uncomfortable space for many of the staff and it has not yet been expected to have difficult conversations with this group (P. Rutherford, personal communication, September 27, 2022).

Spectrum Care has previously made an effort to approach this, while going through a full system transformation. However, as this emerged in times of the Covid-19 pandemic and lockdowns, staff that handled this appeared overstretched and it was found to not get the maximum value out of the project. There's a possibility for some of Spectrum Care's staff to be stuck in a pattern, due to the majority of their experience in this field stemming from old ways. Others might be scared to fail or do the wrong thing and then be held responsible. Spectrum Care has thus far not had the opportunity to start a research project on this before due to being under-resourced. This is why now, with a fresh start and an outsider's perspective, they have asked for a look into these matters in order to gain a better understanding of the points of view of the people with ID in New Zealand (J. Walters, personal communication, September 5, 2022).

Spectrum Care reports the desire to work towards the following behaviour change among this minority group: 1) An improved ability to act on unwritten social norms around communication, including non-verbal cues (e.g. posture, eye-contact); 2) Adapting to behavioural expectations in public settings (e.g. community centres, malls, employment spaces); 3) Building and maintaining relationships (e.g. sharing and respecting mutual expectations, boundaries, safekeeping). Their aim is to work towards this increase in behaviours that are socially acceptable, to contribute towards the goal integration. In order to support the minority group in developing these skills and demonstrating this behaviour, there is a need to gain a perspective of the minority group's own experience in relation to their social skills (P. Rutherford, personal communication, September 27, 2022). According to the DSM-5 (American Psychiatric Association, 2022), people with ID tend to struggle with an awareness of others' thoughts, feelings, and experiences (e.g. egocentrism), empathy, interpersonal communication skills, friendship abilities, risk awareness, and social judgement. More in depth information about the characteristics and specifics of the disability and its effects can be found in the theoretical framework. As of yet, there exists little insight in how these struggles are perceived from the minority group's own point of view.

Therefore, for this research the following focal point has arisen. There exists a hinder in approach, caused by an evident lack of literature in the existing knowledge base on the personal experiences and viewpoints of this target group (both internationally as well as in-company). This creates the need to gain an understanding of the target group's perspective and challenges regarding social inclusion. Hence, the questions presented below have arisen.

a. Practice question

What can Spectrum Care do to support young people with a mild intellectual disability, in order for them to experience social inclusion?

b. Research question

What are the experiences of young adults with mild intellectual disability with regards to social inclusion?

c. Overarching goal

To find out what the social barriers are for people with a mild intellectual disability to participate in society, so Spectrum Care can adjust their practice accordingly and effectively assist these people in building their social skills. This, to increase succeeding in the integration process of the people they support into their environments, to be more efficient as an organisation with knowledge from the target group's perspective and to improve their services as a leading role in the disability sector of New Zealand.

THEORETICAL FRAMEWORK

Here, the concepts important to the graduation assignment are laid out. It delves further into what literary knowledge is already established and lays the foundation for empirical research.

I. INTELLECTUAL DISABILITY CRITERIA

In order for the perception of individuals with a mild intellectual disability to be understood, regarding the social barriers of participation in mainstream environments, it is important to delve further into the definition that was mentioned earlier in the introduction, of an intellectual disability. The DSM-5 states three criteria in order to be diagnosed with ID:

1. Deficits in intellectual functioning — "reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience" — in line with findings from clinical evaluation and individualised standard IQ testing (American Psychiatric Association, 2013, p. 33);
2. Deficits in adaptive functioning that substantially obstruct matching up to sociocultural and developmental standards for the person's level of independence and capacity to reach their social responsibility; and
3. The continuation of these deficits in the time period of their childhood (National Academies of Sciences, Engineering, and Medicine, 2015).

In the context of this research this indicates what the relevant themes are to explore, in order to establish an understanding of the experiences of the target group with regards to social participation. Besides this, it gives an indication of the intellectual capacities of the target group, which provides insight into what a suitable level, intensity and duration of research methods would be. What is also relevant here, are the specifics of the specific 'mild severity' bracket the target group falls under.

II. SOCIAL BARRIERS AND SOCIAL INCLUSION

These concepts go hand in hand with each other. As mentioned in the introduction, inclusion is one of the main pillars, laid out in the New Zealand government policy for subsequent service allocation for people with ID (Office for Disability Issues, 2016). In the disability field particularly, social inclusion is defined as a substantial participation in community activities and a wider social network. Although in a broader scope of society it also encompasses other dimensions, like being a consumer of goods and services or partaking in activities like employment or raising children, that are socially and economically valued (Burchardt, Le Grand & Piachaud, 2002). There is a vast amount of evidence of social exclusion of individuals with disabilities in general (Oliver and Barnes, 1998), in addition to those specifically with ID (Myers, Ager, Kerr & Myles, 1998). Social barriers stand in connection with the circumstances people are born in, develop, learn, work and grow in (e.g. the social determinants of health) which induce a lower level of functioning of people with a disability. Clear examples of these social barriers are found to be the following: 1) Disabled individuals hold significant lower chances of employment. In 2018 in the United States, 35.5% of disabled individuals, aged between 18 - 64, were employed, opposed to a 76.5% of individuals with no disability that were employed (Houtenville & Boege, 2019). This is more than double; 2) individuals with disabilities, aged 18 years and up seem less likely to complete high school, compared to peers without a disability. In the United States was found that in 2019, this differed by 22.3% (Centres for Disease Control and Prevention, 2019) and; 3) an international meta-analyses showed that youngsters with a disability seem nearly four times more likely to suffer from violence at the hands of others, opposed to children without disabilities

(Jones et al., 2012). This feeds into the higher prevalence of social anxiety (SAD) among individuals with ID, of an estimated 38 - 50% (Einfeld, Ellis & Emerson, 2011). In most cases SAD arises in the adolescent stage of life and is characterised by a continuous fear of performance- or social situations (American Psychiatric Association, 2013).

III. SOCIAL PERCEPTION OF PEOPLE WITH INTELLECTUAL DISABILITY

To gain a broader insight in the current status of the target group's path to inclusion, it is important to understand the characteristics of intellectual disability. It is characterised by issues regarding overall cognitive abilities, which have an effect on adaptive functioning in three domains. Regarding the social domain, it is found that an individual with a mild intellectual disability could be perceived as less mature in social environments, in comparison to others within the same age group. What this could entail are their forms of communicating, conducting a conversation, and use of language. This person could experience difficulty in understanding social cues of others and struggle to regulate their own behaviour. What could be a point of concern is the individual's risk perception and judgement in social situations. At last, they may be more gullible in comparison to peers and this could leave them more susceptible to manipulation (PsychBite, 2022). All these could form potential barriers to social inclusion. What literature lacks currently is the perception of the target group themselves, which creates a need for new research.

The social domain is relevant to delve into further as it provides insight into the particular topics that could be questioned later on. The other two domains are left out as they are readily covered by Spectrum Care's support team as their approach thus far has mainly been focused on the first (conceptual) and third (practical) domain (Spectrum Care, 2021a). The social domain covers the themes of interpersonal communication skills, empathy and social judgement of a person, in addition to the ability to make and uphold friendships and capacities alike (American Psychiatric Association, 2022). The social domain also zooms into the reactions of an individual in a social environment (e.g. with family, friends, and romantic relationships). Aspects that are involved are the individual's feelings, awareness of others' thoughts, and experiences (e.g. egocentrism), risk awareness, interpersonal communication skills, empathy, friendship abilities, and social judgement (American Psychiatric Association, 2013). These form the basis of the themes that play a role in the dissimilarity between those with ID or without and thus will be the areas most relevant to dive into, in order to gain a broader understanding of perceived barriers to social inclusion. This domain is used to base the further operationalisation of the research on, therefore the following paragraphs elaborate what these themes entail according to literature.

III.I Feelings

The first aspect involved in the adaptive functioning of the social domain, is the affective component (i.e. the feelings of the individual). Subcategories in which individuals with ID can differentiate from non-disabled individuals are the following: their self-control regarding the sensation of anger, regulating their behaviour and their cognitive flexibility within doing so, the expression of their feelings in general, grasping or understanding their own feelings (i.e. knowing what initiates certain emotions) and their level of assertiveness and decision making (American Psychiatric Association, 2013). Especially the lack of behavioural regulation skills could potentially form a barrier, as in overall mainstream environments there exists a risk of others misinterpreting this behaviour as hostile or uncivilised (Aro et al., 2012). Therefore, finding out what the perspective of the person themselves on this is would be relevant, as there is no data to be found on their own grasp of this potential counterproductive behaviour.

III.II Awareness of others' thoughts and experiences

Another aspect from the social domain is how the target group perceives others around them. Subcategories that form this particular area are their sense of humour (or that of others), capability of taking on a positive attitude to influence a situation, the level understanding of how oneself is perceived, the act of active listening and their perception and respecting of personal space (PsychBite, 2022; American Psychiatric Association, 2013). Overall, in literature there is little evidence of the barriers to social inclusion, as perceived by individuals with ID themselves. This leaves a gap, open for exploration, in order to truly be able to conclude as to what extent current people with (mild) intellectual disabilities struggle with the awareness of other individuals' thoughts and experiences (Abbott, & Mcconkey, 2006).

III.III Risk awareness and social judgement

These aspects from the social domain within the adaptive behaviour of individuals with ID are grouped together due to their overlap. This area is mapped out over the following subcategories: The 'gullible' trait the target group appears to possess, the heightened degree to which they are susceptible to manipulation, the potential exploitation by others they are at risk of, the possible victimization, false confessions, and risk for physical and sexual abuse. These categories are paired with a heightened leniency towards impulsivity, the overall stigma and prejudice of others they are exposed to and the discrimination this can cause. All these traits come back in an examination of the validity and reliability of the 'Social Skill Scale', a tool used as an index of social competence (Anme et al., 2013). This, in combination with the definition of these terms as by the DSM-5 (American Psychiatric Association, 2013).

III.IV Interpersonal communication skills

These skills form the basis of one's social skills (Anme et al., 2013) and therefore make this aspect, involved in the adaptive functioning of the social domain, crucial in understanding social barriers for individuals with ID. The subcategories these are divided in, are: the verbal communication of the target group (i.e. expressing desire, tone and volume of voice), making eye contact during communication, the social confidence (i.e. daring to participate, asking for help or assistance), the ability or tendency to initiate contact with others, the extent to which the target group cooperates in social settings (i.e. attending to instructions, accepting other people's ideas), the ability to stay on the same topic in a conversation, giving and receiving feedback and the portrayal of their manners (i.e. asking for things politely, wait for one's turn, greeting others). The level of skill obtained by each individual will vary widely due to a combination of character, as well as experience and upbringing. Therefore it is unlikely individuals with ID will be comparable in this particular dimension (National Academies of Sciences, Engineering and Medicine, 2015; American Psychiatric Association, 2013).

III.V Empathy

This last aspect of the adaptive functioning within the social domain is one the target group is most likely to be born with (or a lack thereof) and is therefore harder to be trained or understood (PsychBite, 2022). This is particularly interesting to research as this would indicate a lower level of understanding of the effects of their behaviour and thus their skills to integrate in a mainstream society. If this can be measured, it shall provide clarity towards the goal of this research. It consists of a natural interest in other people's feelings when showing either positive or negative emotions. It also includes their capacity of conflict resolution, acceptance of others and their differences from themselves, ability to show interest in others and complimenting them (Anme et al., 2013; American Psychiatric Association, 2013). Now that there is a broader

understanding of intellectual disability within this particular context, it's important to lay out what the social barriers would be in this particular context.

IV. POTENTIAL BARRIERS TO SOCIAL INCLUSION

A potential barrier of this process is for one the risk of discreditation of pivotal differences between individuals with and without intellectual disability, that comes along with this group now submerging into society. Doing so could imply an expectation of these differences to cease from impeding. Striving towards equality and inclusion as per the current governmental strategies has the potential to undermine the original drivers of what started the institutionalisation, for example the current lack of experience of the public with how to navigate in an inclusive society alongside individuals with ID, as well as lack of skills of citizens to enhance cohabitating within communities. An undesirable outcome would be for it to result in an aversion towards this group (Morin, Valois, Crocker & Robitaille, 2019). These citizens will equally be integrating in a new, more inclusive society, without there currently having been enough incentive or form of stimulation, beside the limited exposure thus far, to do so. This has globally shown to be a slow process, whereas the physical relocating and subduing of these individuals into their new environment is a fast process, at risk of being precarious or overwhelming (Altermark, 2016).

This brings us to the second barrier of the potential (irreversible) harm it could do to this group by prematurely executing the attempt of integration. There's a likelihood of this group being exposed to unwanted negative reactions of hostility, indifference or dislike by their surrounding environment. A sense of estrangement could be triggered by a lack of social approval or self-assurance, as well as behavioural and emotional disorders (Morin et al., 2019). An example is the finding since the shift from institutionalisation to social inclusion, that one in four mildly intellectually disabled young adults that have grown up within their communities, showed emotional dysfunctions: distorted moods, disproportionally defensive attitudes or an increased anxiety level due to exposure to social exclusion by the community, underachieving in social activities or school and continuous risk of failure. It has shown to result in a tainted self-perception, motivation loss for achievement, a fear of failure and negative changes in self-perception (Verdonschot, De Witte, Reichrath, Buntinx & Curfs, 2009). To gain insight in the truly lived experiences of this target group thus far, it is essential to include these aspects into further conduct of this research.

A third potential undesired consequence is the confrontation of incongruity in employers hiring individuals with ID, that wish to participate through employment. Employing this group accompanies a higher social investment, a decrease in efficiency, occupational health and safety complications, as does it often require adaptation of the workplace. However, working acquires a vital significance for integration of individuals with ID, as it fuels independence and overcomes personal and financial limitations. It makes them a consumer and a fully-fledged member of society, which is key to social inclusion as this creates opportunity to find a network (professionally, socially and romantically). Employment would tackle the stigma of 'being a second rate citizen' and stimulates independence, satisfaction, self-development, -appreciation and coping with difficulties. At last it helps satisfy major mental needs: recognition, respect, appreciation, safety, a sense of belonging and significance. Employment for this group shows to be the best form of support, therapy, and a path to social integration. Reality shows though that employers still carry a stereotype of people with ID. The attitude found was that they're often seen as inconvenient, inefficient, and non-competitive in contrast to other employees. Furthermore, there is an added impediment by the lack of governmental structure in gaining subsidy and compensation for the added investment. Perhaps most prominently, the insignificance in the current system between wages and retaining social benefits demotivates the individuals to step outside their comfort zone. Regulations and administrative strategies

don't serve to tackle discrimination, as it outs itself in multiple, covert ways. It can show through attributing negative characteristics to this group, devaluing them, or a decrease in empathy for their mental state or struggles (Oliver & Barnes, 1998; Morin et al., 2019). The experiences of the target group under Spectrum Care's support would need to be examined to understand the current effects and extent of hinder from this.

V. EXISTING APPROACHES

Social models of intellectual disability lean towards a focus on the contribution of specialist services to the social exclusion that individuals with ID experience, that was especially noticeable during the age of long-stay hospitals (before the fairly recent deinstitutionalisation). While trying to approach this, it was realised that physical presence within a certain 'mainstream' community does not guarantee an increase in social inclusion. Joining local activities and using local facilities as a measure on its own does also not directly lead to meaningful social contacts with others, in particular not with non-disabled individuals (Ager et al., 2001).

Regarding this target group, gathering an idea of social inclusion perceived by these individuals themselves, can also bring along challenges. An example is establishing the validity of the information subtraction can be an ambiguity, in combination with the social barriers that stand in the way of this process. Not much research has been done about these perceived barriers and their solutions, from the perspective of the individuals with ID themselves. Some research has found four main barriers amongst individuals with ID, in supported living or shared group homes: deficiency of needed knowledge and skills; the influence of staff; location of home; and other community features like lack of amenities and attitudes. Advocacy regarding this has proven to be an essential pillar in decreasing the social isolation of such marginalised groups (Abbott & Mcconkey, 2006).

There have been a number of methods implemented to obtain insight in the perspective of the target groups themselves, one of them being the advocacy survey, conducted by the advocacy team on Spectrum Care (2022). The advocacy team consists of a group of individuals with a mild intellectual disability that themselves receive support from Spectrum Care, but are also employed by the organisation to assist in providing information to others who are supported by Spectrum Care. They help smoothen their journey, by educating them on their rights, familiarising them with the processes within support of Spectrum Care and they conduct the 'my life survey'. The angle of this survey is to gain insight in the experiences of individuals under the care of Spectrum Care, lowering the barriers of speaking freely, without fear of consequences.

Interventions in the area of lowering social barriers to participate in society for individuals with a mild intellectual disability, vary between methodological procedures, to hands-on training packages or toolboxes for the target group, to group sessions in form of intervisions or training of the staff to stimulate these processes. One example is the cognitive social learning method of Goldstein, implemented in a training for youth with a mild intellectual disability: the Cosis (2021) social skill training. With help of practical experience, adjustments have been made and a method has gradually been developed. Base of the training: Clients learn best from good examples. There are situations to be played out, set up in such a way that each scenario is close to the clients' perception of the world. The training consists of three parts: Sharing skills, non-verbal emotional expressions and a trainer's manual. It involves skills such as meeting others, listening, asking something, having a chat, discussing, giving one's own opinion, saying no, criticising, receiving criticism, congratulating, giving compliments, condolences / wishing good luck, expressing disappointment, expressing sadness and expressing anger.

Methodological procedures for the development of and social abilities in people with ID, pay special attention to the creation and implementation of those procedures — aimed at improving

all three types of adaptive skills. Adaptability is a complex construct which includes the individual's ability to recognize social expectations and to align his behaviour with those expectations. To make this possible, there is the following condition: a personal readiness and initiative to adopt social and conceptual knowledge, primarily in the domains responsible for functional communication and satisfaction of daily life needs, applications in daily life activities (Aro et al., 2012).

Kennedy (2001) believes that the key goals of the method of access to the education of individuals with ID should be, in combination with and in addition to adopting academic knowledge, aimed at developing their adaptive skills. He finds that strategies for children and young people with ID should have more of a focus towards the stimulation and improvement of skills and readiness for mutual cooperation and interdependence with the typical environment, instead of independence. This, as well as the creation of an environment that would allow the peers of the typical population to assume the roles of dominant leaders in these social interventions, instead of traditionally engaged special educators (Kennedy, 2001).

METHOD

I. RESEARCH DESIGN

Due to a number of reasons, a qualitative method of data collection was used — starting with semi-structured interviews with use of a tool to enhance the practicality tailored to the target group. First reason being, that in order to find an effective method to support social inclusion, the encountered social barriers need to be mapped out. This can be done with an explorative method, and qualitative research allows a gain of insight into topics about which there is still little knowledge from the target group's perspective. In addition, the target group would have been too small for quantitative research. This choice lines up with the main goal to gain a bigger understanding of the concepts, thoughts and experiences perceived by the target group themselves. It allows the individuals to share their own views and provides valuable new insights in the field, as thus far there's been little literature available from the perspective of the individuals with ID themselves (Landelijk KennisNetwerk Gehandicaptenzorg, 2004; Cohen, Manion & Morrison, 2017). The research is inductive, as new qualitative data was collected. It started with a theoretical framework, which means the research also partly contains a deductive element (Saunders, Lewis & Thornhill, 2016). Clear agreements were made here about privacy and consequences, further elaborated in the chapter 'Ethical approach'.

II. PROCEDURE

For the semi-structured interviews, a topic list with pre-determined categories surrounding the adaptive behaviour regarding the social domain was formed (appendix 'III. Topic list'). Its content is based on the themes described in chapter three of the theoretical framework, as they play the most prominent role in the dissimilarity between those with ID or without and allow to gain a broader understanding of perceived barriers to social inclusion. Following these steps as a clear method, themes and categories could later be found and compared in the interpretation phase (Baarda et al., 2001). Per participant the same themes were discussed. How these themes are addressed can vary from person to person, as the participant's answer forms the basis of what follows. This is how detailed, underlying thoughts and motives surface (Baarda et al., 2001). In addition to this, due to the characteristics of their disability, there is the potential of the interview becoming too intensive or time consuming for the participants and thus not being able to cover all themes. It will be new to them to be questioned about such topics, which is why the choice in themes is to be tailored to the individual as the interview proceeds. Important is that their input is received with a non-judgmental attitude. This decreases the risk of a socially desirable answer. The participants were not persuaded in a certain direction, with risk of the results having a distorted outcome.

II.I Tools

To increase the effectiveness of communication, the 'TalkingMats' tool is implemented during the interviews. This, as the target group can experience significant difficulty in ensuring their voice is heard. TalkingMats is a tool based on extensive research, designed by Speech and Language Therapists and consists of three symbols: a topic (e.g. feelings), answer options (e.g. being aware when I get sad) and a three-point Likert scale (e.g. good at, ok at, find it tricky). Below it, there is space to display the answers given by the participant. It contributes to a better understanding and supports expression, as it helps express their views by stimulating both the quantity and quality of information communicated (Murphy & Cameron, 2008). Training around the implementation of the TalkingMats method was provided by the clinical team. The details of

the interview protocols, including the application of the TalkingMats and the created content will be added in the appendices under ‘interview protocols’.

The tool in itself leans more towards a structured interview, as the questions are closed-ended, providing limited options to answer, in the form of a Likert scale (Baarda et al., 2021). However, this is chosen to provide a more clear sense of overview for the target group, while the emphasis for the researcher will be on collecting qualitative, open-ended data. With asking open questions, diving deeper into each initial answer to the particular TalkingMat theme, the participant’s thoughts, feelings and beliefs about that particular topic will be explored and potentially even delving deeper into personal or sometimes sensitive issues (Kallio et al., 2016).

III. PARTICIPANTS AND RECRUITMENT

Ten participants were recruited out of the target group. The target group consists of the mildly disabled people supported by Spectrum Care. The mild facet consists of those for who have the most realisable and suitable potential to socially partake in mainstream environments (e.g. employment, social clubs, peer groups, romantic relationships). These individuals have a basic skill level of communication to function in daily life, but need assistance in refining those skills in order to participate in society more effectively (P. Rutherford, personal communication, September 27, 2022; American Psychiatric Association, 2022). As Spectrum Care’s relevant services around this are largely provided throughout the stage in their life in which the individuals will be shaping their future and finding aspirations or moving out into supported or independent living, the age range of the target group is teenagers to middle-aged adults. At the time of the research, the target group under support by Spectrum Care consisted of 48 individuals total.

The route for determining the research group was taken as follows. It was decided whether all those individuals from the target group were questioned or whether a sample would be drawn. Given the size of the then-current target group, this was to be a random sample. The aim of the number of people to be consulted was around ten participants, depending on when the saturation point of the field research would be reached. This showed, after the processing of data and finding themes and topics from the interviews. In terms of stratification of the target group, the main focus was on an age between 15 and 30 years — in line with the original aim of the organisation to focus on people in the transition phase from teenagehood to adulthood. Given the mild variant of the intellectual disability, all participants were able to speak independently. This facilitated the moral implication of whether or not to correctly interpret the information provided by the participant, which is further discussed in the chapter 'Ethical approach'.

Regarding the recruitment method of the interviews, the participants were approached initially through their personal support worker. The support workers were briefed by the researcher, accompanied by the research supervisor. All individuals within the target group were approached this way. Global information regarding the research. That way the researcher had already built some form of a rapport with the individuals, which is in accordance with the protocol of Spectrum Care, as well as methods proven to be successful from the Dutch National Knowledge Network in Disability Care (2004). This, to accommodate the need of familiarising them with the idea from a trusted party (Landelijk KennisNetwerk Gehandicaptenzorg, 2004). Afterwards, the participants were called by the researcher for an introduction and to gain a sense of trust between the two parties. Some more information about the research was shared and where there was an interest to participate, the primary caregiver was informed and asked for an interest to participate. Where both agreed, an email was sent out with the made agreements. As there were more than ten recruited individuals interested, the method of purposive sampling (Baarda et al., 2021) was used, where typical cases were consciously selected by means of a targeted sample.

These were the individuals who — according to the data provided from former research within the organisation — had thus far been least involved in surveys, research and interviews and so were least influenced by earlier experiences. This, to tackle the concern Spectrum Care has that it will often be the same participants that are wanting to share their voice, and the same others that will opt out. Therefore, with this approach there is a more inclusive sound, also from individuals that would usually not be the first to speak up (Baarda et al., 2021). If there had not been a significant difference between the individuals, the scenario would have been chosen to do a single random sample in order to maintain representativeness within the target group (Saunders, Lewis & Thornhill, 2016). Despite this not being the first priority, the sample still consisted of a diverse variety in age, sex, background, ethnicity and work-/social experience.

III. MATERIAL AND MEASURING INSTRUMENTS

The audio of the interviews was recorded, where permission was given. The interviews were conducted face-to-face, as more feelers of the researcher could be used during a physical appointment and the target group could have been extra susceptible to influences if it were to be conducted online. The interviews were conducted at the head office of Spectrum Care. At the homes of the individuals, an opted possibility originally, there was the risk it could not be secured that there would be no distraction, or influence in perception by the environment or other people besides the attendants present. Every interview was transcribed, after which the participants' answers were coded to focus on particular themes (Saldana, 2021). Statements were marked and given a code. Statements with the same code were formed into one category. The categories were placed next to each other to discover relationships and coherence. This data was compared with the themes that emerged from the literature. The conclusions of the research are incorporated in a research report (Saunders et al., 2016). The intervention can be designed on the basis of the insights that arose from this.

IV. DEMARCATION

Beside the above-mentioned characteristics of the target group, it was important that the concepts and subjects to be used were limited to the social domain within the adaptive functioning of the individuals within the target group. More in-depth information can be found in paragraph ‘preliminary definitions’ as to what this entails. The reasoning behind separating these behaviours from the other two domains (the practical and conceptual), is because the demerit in skills from these areas tend to overlap, but have a different origin. Before the interviews took place there was a clear demarcation within the topic list, with themes that are and are not relevant to go into. The interpersonal communication skills that will be questioned, will be related to the transition phase of the individuals between teenagehood and adulthood (e.g. social skills relevant to finding, obtaining and maintaining a job, friendly or romantic relationships, a social network and participating in other forms of mainstream environments). Considering that there is an abundance of diverse approaches to be found in literature, intended for the development of different types of conceptual and social knowledge and skills, it is decided to present a limited number of those whose implementation is relatively simple and effective in terms of outcomes.

V. DATA ANALYSIS

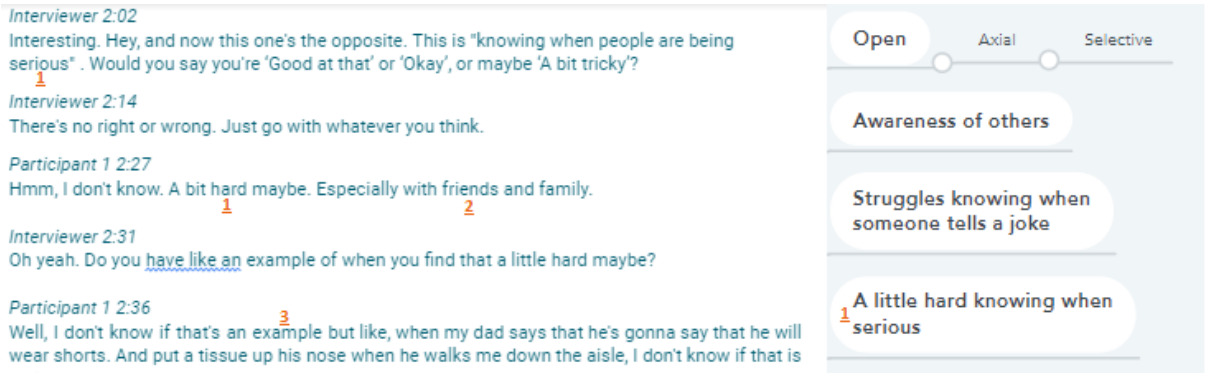
All interviews were first transcribed, then coded in three stages, according to the coding manual for qualitative researchers (Saldana, 2021). Then the data was bundled into a code tree, creating a taxonomy, providing a clear overview of relevant themes and its elements from the findings of the empirical data collection. These are found in the first appendix of the analysis plan.

V.I Transcribing

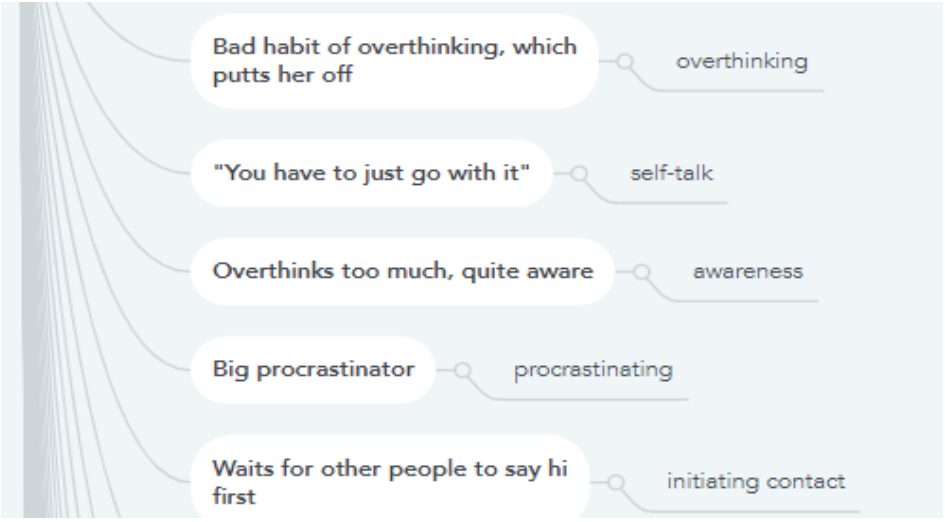
The recordings were transcribed using the app 'Otter' (2018), which automatically distinguishes the different voices, as well as writes out their verbal communication. The next step was to manually go over the recordings (both audio and video, where permission was given) to alter or add to the transcript, making sure it would be accurate and complete (Saldana, 2021). An example is found in the first appendix, paragraph I.I.

V.II Coding and taxonomy

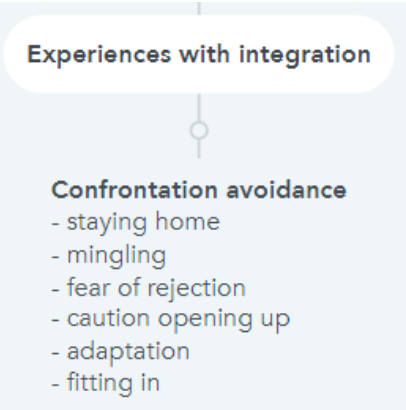
After transcribing the interviews, open codes were added. This was done by connecting characteristic pieces of text to a code. All codes formed the basis of the code tree (taxonomy), created in an online program 'MindMeister' (2023). This was kept alongside the transcripts, as can be seen in the example below. Following the 'in vivo' method (Saldana, 2021) the codes were formed using as much of the original words used as possible, in a rather extensively written out manner. This was to ensure clarity of context, as well as the traceability for later in the process, as the codes were in this form not directly connected in one program. An example is the two pieces of transcript marked with a "1", being coded as "a little hard knowing when serious". These are still in the original words of the interviewee and allow for the context to be clear.



Step two was to add axial codes, where a distinction is made between the different codes: the main and sub-codes. These codes were shaped in more of a form of described experiences (Saldana, 2021), in the second row of the taxonomy. These were constructed with use of less, more summarising terms. An example is shown below, where the first open code is shortened to solely the readily stated word in the code "overthinking", but also the last open code where a synonym " initiating contact" was given to use a more concise term.



Fragments with the same codes were later linked together. This was done by moving separate codes and clustering them together. These clusters together formed a category. This category was given an umbrella term, also called the axial code. An example of how this was done, can be found in paragraph I.III of the first appendix.



Hereafter the stage of selective coding was applied. During selective coding, the codes relevant to answering the research question are sought out and ordered. First was figured out what the core variable was that included all of the data, for example the "experiences" shown in the figure on the left. Then the transcripts with the axial codes were reread and selectively any data that related to the core variable was identified and added under the umbrella, as for example "confrontation avoidance" based on the codes falling underneath it. This allowed for all relevant data to be linked and re-shaped into the underlying topic (Saldana, 2021).

RESULTS

This chapter captures the results of the conducted field research, consisting of findings from ten held interviews with a length of 55 to 70 minutes each. It consists of overarching themes that emerged during the interpretation process, which are laid out per paragraph below. As described in the data analysis of the method chapter, found themes and their elements that proved relevant to answering the research question were selected, clustered and linked to connecting elements and findings. The themes that emerged from the research data, as well as the clustered elements they consist of, describe: (1) the participants' perception of their social skills, (2) their experiences with integration in society thus far and (3) their found barriers to inclusion. The structure of this three-part division arose from reoccurring emerging elements in the taxonomy (see paragraph I.IV of the analysis plan). The topic list (appendix III) as well as the TalkingMats used, provide material to compare the outcome of the field work to the setup beforehand. In the subsequent chapter, the conclusion, these findings enable the research question to be answered: "What are the experiences of young adults with mild intellectual disability with regards to social inclusion?"

I. PERCEIVED SOCIAL SKILLS

The first theme that emerged from field research consisted of five elements and the selected codes that are clustered under its umbrella. The elements are separated per paragraph.

I.I Humour comprehension

All participants express a general dislike for humour at the expense of others, alongside a lack of understanding when it comes to sarcasm. A few were unfamiliar with the term, but show to have encountered sarcasm when given the definition (definition used from 'Oxford University Press', 2022). All state to find it hard to know when a statement is to be taken seriously or interpreted as a joke. They express experiencing this both with friends and family, as well as strangers. Some have gained insight over time in the mannerisms of close relations as to when they might be joking, whereas other participants appear to never be able to make the distinction. Affective reactions to these types of humour vary from confusion, anger, frustration or sadness to feeling ridiculed or embarrassed.

"Sarcastic people are the worst." (R3)*; "I can never tell when people are serious or being funny."* (R1)

I.II Reading nonverbal cues and insight in motives of others

When it comes to reading nonverbal social cues in contact with neurotypical individuals, there are mixed findings. Some participants struggle with this aspect most of the time, whereas others report to have become conditioned by experiences with certain people in their environment. An example of this is a participant who has become rather wary of trusting new people he meets, as he has grown to attribute certain facial expressions (e.g. smirky smile, frown), body language (e.g. open/closed off stance), and use of voice (e.g. low tone, loud volume) to the person being 'fake' or deceitful, based on past experiences.

"When they show those kinds of signs I just steer clear from them. That's why I don't trust strangers easily, trust needs to be earned." (R3)

Over half of the participants report having trust issues. In all cases when it comes to encountering strangers, some also among their friends and families, but none among acquainted support staff or friends with ID. The participants that struggle with reading nonverbal cues most

of the time, find this element frustrating as they're continuously subjected to a felt need to guard themselves when in social environments. They are aware of the existence of social cues and know others who can read into them, but struggle to pick them up (correctly) themselves. Multiple participants report to appreciate a chaperone of sorts they can trust, to rely on in new social environments.

"... they can come across like 'Ah, hey, da-da-da!', all happy you know, and that's when you get it wrong. It's because you think the body language is quite happy towards you. So you think 'Oh, this is really nice.', whereas actually you're gonna get mucked over. [...] that's why I'm stand-offish to strangers. And my family is really good at body language and talking to people and all this kind of stuff, so they tell me like 'Oh this person is no good and that person is no good'. They're good with people and I'm not." (R2)

About half of the participants also find it hard to comprehend when someone differs significantly from them in views. They assume the other person would want the same as they themselves would want in that situation. They describe multiple occasions where they failed to understand why the other person's behaviour suddenly changed, even though he or she had not expressed any discomfort as to what was going on. An example shows in the following statement:

"The neighbour was outside with his dog and when I said hi, he asked me if I wanted to pet him. He was real nice and I was a bit careful first but then it was all good when he sniffed me. The neighbour chatted to me for a bit and I chatted back, but then when I tried to pet the dog again later, he got all funny and rushed away. I asked if he didn't like that I touched him, but he said it was all good, even though he seemed a bit angry and went back into the house without saying goodbye." (R4)

I.III Emotions and self-regulation

When it comes to coping with negative emotions encountered in social situations, all participants report to have developed some form of constructive coping technique. Most will deviate from conflict situations with strangers, by either walking away, politely expressing their boundaries, communicating their need to go elsewhere or shutting down and ignoring the other person. The majority of participants will self-soothe when in an emotional state after a conflict, with either breathing techniques, listening to music, playing video games, going for a walk or lighting a candle. These participants in question all express having grown in managing their emotions and their responses in a conflict.

"I learned to take a step back" (R10); *"I took an anger management training because I had real anger issues in the past"* (R9); *"I used to stay grumpy a lot longer. Or not know what to do. I can get real emotional sometimes and it's hard to explain then to people. Now I just think I go to my room and lock myself in until I'm calmed down and come out and make up."* (R1)

Most find this somewhat harder to do around family, for a few this also applies to other close relations. On certain accounts some will still struggle with self-regulation in conflict situations. The examples given all encompassed an element of surprise, where they find themselves in an unfamiliar environment and state to feel intimidated. An example is:

"I almost did an accident the other day when someone just budged in front of me at the counter. It gave me a bit of a fright. Like holy hell. I went like 'Excuse me, I was here at this counter first', and they just went and argued. The check out operator told him to move away from me, because I was gonna try hit them. My staff was right behind me and she goes 'No, don't hit them because that will make it complex even more, so…'" (R4)

As to positive emotions, most participants attest to showing highly empathetic behaviour (see statements below), when comfortable with a person. They have a general interest in the wellbeing of others, with both relations and strangers. With the aforementioned guardedness encompassed, most cultivate curiosity about strangers and acquaintances and will have little

shame in asking them questions with genuine interest. People closer to them, they will compliment, try to look after and express gratitude. Most participants claim a high level of genuinity in their desire to accommodate and relate to others.

"I really just like to make people feel welcome. I'll always ask them to make them a hot drink or if they're comfortable. I do checking up on people a lot, like the neighbour kids because I get worried. My friends' kids too or when I'm with elderly people, I'll always go sit with them and ask to make a hot drink." (R5); *"Sometimes it got me in trouble because if people say they need help, I'll always try help. Giving them some money, or once I brought someone back to the house who needed a place to sleep and apparently that was no good."* (R9)

I.IV Assertiveness

This element consists of how the participants perceive their own social skills regarding initiating contact, asking for help, social confidence and group-activity participation. These aspects show a connection with other elements of the overarching theme ('childhood experiences', 'confrontation avoidance' and 'social anxiety & manipulation and assault') from the theme 'Experiences while integrating' (II.) and vary per participant. Most are initially shy when meeting or encountering new people and will wait for the other person or a chaperone to make contact. Two participants prefer to initiate contact themselves in most situations, out of curiosity or to eliminate discomfort. Their social confidence depends on how approachable they perceive the other person(s), which is often judged based on their basal facial expressions and what/who might be their mutual connection. After this stage, the earlier mentioned insight in motives (I.II) and desire to display empathy (I.III) come into play.

As for 'asking for help', there are mixed results that correlate with how guarded, shy or distrusting each participant reports to be. Some struggle or completely refrain from asking for help when possible, others will only feel comfortable doing so with or around staff and few show no struggle to ask for what they want or need. In one case this is because of the conscious attitude the participant takes on around strangers, where he tries not to show any vulnerability and communicates just to get the information or help he needs. Explanations of participants that struggle are: a fear of being judged, rejected or socially excluded. In the past, multiple have been mocked for asking a question or turned away. There is a fear of being considered dumb or 'less than'. At last about half of the participants also find it hard to express what they need at times, especially when emotional.

When it comes to group-activity participation, most experiences regard social gatherings organised by Spectrum Care. Most participants spend the majority of their social participation at the aspiration centres or the staff taking them somewhere. Some are more independent and have a social life outside of these facilities or are somewhat more isolated and don't often join in social environments. These group dynamics mainly consist of other individuals with ID, with limited exposure to non-staff neurotypical members of society. Examples of exceptions are band rehearsals and performances of one participant, work environments or friends- or family gatherings.

I.V Engagement

Regarding the element of engagement, findings relate to the following aspects: the skill level and motivation of active listening, stability and consistency in relations, obtaining and maintaining online relations and the sense of responsibility for others. These too correlate with answers given by participants regarding other elements within the same theme and differ per individual. Some corresponding findings here between participants did arise, as per example the struggle of all participants with active listening for a longer period of time, mostly due to a reported short

attention span or difficulty keeping up with processing information. If another person talks too long about a topic, they state to lack understanding of or lose interest in it. They all report to either try divert the conversation, leave or make up an excuse to discontinue. However, a few participants would want to look up information online or touch on the subject later, may they have an interest.

Most participants share to have stability and consistency in their connections and relationships. In relation to findings in paragraph I.II, they generally take conscious steps towards trusting others, but once trust is gained it often comes with loyalty to the established connection with the other person (staff member, partner, employer or friend). Reasons some give for when they do lose this connection, are distance due to moving, the other person pulling away or when they lose their trust and sense of safety. All participants have a small to moderate social circle, of long-term connections (or lack thereof) and report to hold this dearly. Multiple express an interest in expanding this circle, whereas two participants rather hold their circle small and are content.

About half of the individuals questioned feel a high sense of responsibility towards the wellbeing of others with ID they are familiar with. They all have a social circle that includes others with (more severe levels of) ID, they will protect or stand up for if need be. This same sense of responsibility shows in how serious they take their workload, when employed and comfortable in their position. Even when feeling disrespected, most still try to execute their tasks as well as they can. Three of the participants claim the opposite and say they will only make an effort if there is a noticeable benefit and they enjoy the employment.

II. EXPERIENCES WHILE INTEGRATING

In connection with the perceived social skills of theme one, this second theme 'experiences while integrating' delves further into the lived experiences surrounding those perceptions of the self. It provides new information on how this came to be among the participants and is laid out in paragraphs per element and its selected codes it consists of.

II.I Childhood experiences

A common occurrence among the participants appears to be having been bullied or socially excluded in primary- or high school. All of them share having lived through this, in either one or both phases. For most, this was done either in class, during breaks or physical education by peers, whereas four participants also include being treated unfairly by teachers. Teachers would not possess sufficient constructive strategies to support them, lack compassion or take no notice of them. As for peers, most report offensive comments being made in relation to their ID, being mocked in relation to their appearance or intelligence, being laughed at when making mistakes or when struggling to keep up with the class content. All participants describe some form of prejudice against themselves or their ID specifically.

"[...] they sometimes called me dumb or mock me if I didn't know a thing. I got scared easily to get mocked because they would do it when the teacher didn't see or he just would say nothing." (R1); "*Intermediate was the worst for me, I went to a mainstream and the teachers wouldn't care at all about me. Not if I asked for help or stayed quiet, also not if other kids would say gnarly stuff or not let me in. Can really do with a step up there, it's no good for people with ID or anyone really."* (R8)

One participant ended up becoming a bully himself in high school, after putting up a wall and gaining friends that would stick up for him and intimidate others. After feeling vulnerable due to social exclusion, he would imitate similar behaviour towards others as a form of self-protection.

"In college no one came near me, because I hung out with all the older kids. They knew not to mess with me, or I'd just deal with it. I'd tell them pretty straight up what would happen to them if I sent my mates in their direction. Reckon sometimes I was a little too tough on them, got angry quite quick" (R3)

Beside this, six participants explicitly mention some form of social isolation after leaving school due to the loss of their social circle. They struggled keeping in touch with connections due to either an initial lack thereof, not knowing how to stay in touch with peers successfully or the slow decrease in frequency of contact.

As for family dynamics while growing up, there are mixed findings. Eight participants grew up living with at least one parent. The parent(s) either protected and sheltered the individual from extensive exposure to risk, supported the individual fitted to their needs or generally had an adverse impact on their well-being and growth, by a lack of understanding or compassion. The perceived effects of this would vary between becoming upset, traumatised or experiencing feeling 'babied', supported or a sense of belonging. Two participants reported not living with a birth parent but moving homes regularly or residing in foster families. The general attitude towards this is negative, one participant describes it as unstable and felt neglected and unsafe in five out of seven homes.

"When I was very very young, I went to lots and lots of foster families. I'd get abused, get hidings. Then they'd just move me, they didn't care. The only places I missed was the farm I used to live in and [place name], but all the others is really no good. Especially age 12 to 13 to 14, something like that." (R7)

II.II Employment

About half of the participants have previously had some form of employment, which two currently still uphold. Fields of work vary between manual handling, hospitality, the music industry, landscaping and supporting elderly or others with ID. Forms of employment these participants had or have, are either on voluntary basis, under contract by mainstream employers or through an organisation like Spectrum Care. Participants report success stories encompassing positive aspects, experiencing a sense of belonging, as well as an increased sense of fulfilment, autonomy and value.

"It's made me really happy to feel like part of the team and that they liked me doing my job. When it was good it was just, good. All of the day after too I would just be happy." (R4); *"They can't go without me now, it's a big responsibility."* (R2); *"I don't want to leave, but if I want to ever leave I would stay until they find someone new and stay to train them until they're ready."* (R5)

In some of the participants' positive experiences it triggers an added element of boredom, influencing the continuation of employment. An example is one participant who states he had nothing to complain about his job, but because it was the same every day and he found the tasks quite easy, he just decided to stop showing up. Finding a replacement job however, proves to be rather difficult for most. The biggest reason participants give for the lack of success in obtaining a job, is employers not getting back to them after they apply.

The most prominent recurring element in the findings is exploitation. Four of the six participants report having experienced the following, in at least one work environment: a heavy workload, high-stress conditions, physically intense labour, a lack of breaks or working unpaid overtime. The reported experiences overlap in most cases with additional felt harassment or discrimination, thought to be on the grounds of their disability. It manifests among the participants in various forms.

"Sometimes the joking around would go too far, about how I'm too stupid to have intercourse with a woman" (R7); *"I could tell by his expression that if we'd be alone he would do something to me. He was always trying to cause trouble with me, because he knows he can get away with it"* (R9);

II.III Manipulation, assault and social anxiety

Examples of experienced harassment mentioned in the paragraph above, stretches further than the workplace. One participant describes an occasion where she invited someone she had met online over to her family home. He had asked where she lived and seemed nice, but began threatening her upon arrival, escalating into sexual assault. Another participant, who elaborated on the foster families (paragraph I of this chapter), reports having been beaten and abused in multiple homes as a child. The same person has had strangers come into his home and threaten him to assault him on a random night, who followed his flat mate that also had ID back into the house. In total, 24 of similar examples were given. Environments where these took place differ from the aforementioned, to out on the street or in public places, -transport and -facilities. In combination or separate from the assault, most participants also shared experiences of theft. Items stolen vary from phones, money or personal items. Over half of the participants are well aware of how to handle such an occurrence and have learned to get to safety and call the police. Others express to either be too distressed or unsure what to do. All participants actively try to avoid such events, which some report is a part of their social anxiety.

Half the participants reports to be afflicted by social anxiety. An example is the fear of one of the participants to be kidnapped, when approached by a stranger on the street. He states not being able to comprehend where the fear stems from. These five participants prefer the sense of safety, provided by maintaining a small social circle, often mainly consisting of others with ID. They also experience a general fear of strangers and some try to limit their interactions with them, expressing to avoid confrontation where possible.

II.IV Confrontation avoidance

Confrontation avoidance is a factor all participants state to experience in varying degrees. All have a fear of rejection by others, of which they are aware. With most, this began in school environments during either childhood or adolescence, of which some experiences are described earlier in paragraph II.I. Nowadays about half of the participants prefer to stay in their home environment most of the time and have a chaperone with them (friend, family member or support worker) when they do go out. Three others state to be quite independent, but either choose not to mingle too much when out in the community or to be cautious as to who they are in contact with. Multiple add to this they try to adapt as much as possible to their environment, in order to fit in as a precaution or defence. Two participants state to be indifferent and enjoy meeting others, both strangers and acquaintances, experiencing little to no fear most of the time. They do, along with most other participants, express to be cautious with opening up about their disability and try to prevent coming across as vulnerable.

II.V Openness about ID

Continuing on the element above, over half of the participants mention not wanting to be associated with ID or experience a discomfort around how openly they discuss this topic with others. Reasons given are a combination of past experiences, mentioned in the paragraphs above. The intensity of this discomfort depends on the level of acquaintance with the other, the highest being around strangers or acquaintances they fear to be judged by. Six out of the ten participants have an inner circle they are open with when it comes to discussing the effects, needs and struggles related to their ID. It varies whether they would initiate this themselves, or only when the other person does. In most cases their friends and family are somewhat- to well aware of those effects and struggles and adjust to their needs. The other four participants are less open, to completely closed off to their inner circle regarding their ID. This, as either they themselves feel uncomfortable about sharing, (part of) the inner circle doesn't respond to it well

or they find the family dynamics unsuitable to do so. In addition, there is also the element of coping with judgement from others, mainly strangers. Most feel burdened, which refrains them from opening up about this aspect of their lives. For the majority it's easier to hide having ID or deal with the complications either personally or with help of staff, rather than risking a negative outcome by opening up. Three participants state they do not experience any struggle regarding opening up about this topic, as for one it's rather noticeable she differs from neurotypicals and she likes to make people understand. The other takes pride in this side of him and likes to educate others on what ID is and a third feels indifferent about the reactions of others regarding his disability.

III. PERCEIVED BARRIERS TO INCLUSION

This chapter presents the barriers participants come across in their daily lives, trying to navigate inclusion in their communities and society as a whole. The elements are shown per paragraph with the clustered factors they consist of, that came forward during the field research.

III.I Lack of understanding public

Building onwards on the desire of some participants to educate others on what intellectual disability entails, most participants find that there is a general lack of understanding from neurotypical individuals in their environment. They all experience prejudice in various outings from others, often based on basal and limited frames of reference. There is quite a large spectrum of experiences here, where strangers, acquaintances or relatives show a diversity in approaches. Almost all participants share examples where they have been assumed to be too intelligent or incapable to perform a certain task, or that they probably won't have the required knowledge or experience. One participant lays out the pros and cons to this:

"People without experience won't always react well and people who do, tend to put you in a box." (R9)

Others add:

"There's too little knowledge of ID in the mainstream. There's nothing wrong with me, I'm just a slow learner, is all." (R7); *"People don't show interest much. If I'm comfortable I'll talk about it heaps, because then they can ask me questions about me. Or know what to do if they know others with ID who have it more than me. Sometimes I get babied by strangers though, because they don't know"* (R8)

III.II Counterproductive extrinsic motivation (i.e. financial aid, benefits)

As briefly mentioned in paragraph II.II describing their employment experiences, participants raise the necessity of enjoying their job. Due to the additional influencing factor of all participants receiving benefits, they view employment as more of a pass-time than a means to survive.

"It doesn't help that I don't have to. It began to suck so I just stopped going. Got boring." (R10); *"I prefer just taking it easy now, I can see again in a few years. For now I don't have to put up with the stress anymore."* (R7)

Another participant, who is very engaged in his occupation, affirms this with his belief that because they value him at work he feels like it's grown to be a part of him and he has no intention of changing that in the future.

III.III Sense of safety around own people / SC

To get to a point where the participants feel engaged enough to ingrain in a mainstream environment, is reported to be a difficult process by most. Once they're comfortable, it appears to generally be low risk of this changing, but for the majority it's not easy to get there. The negative

experiences and traumas of some mentioned in paragraph II, in combination with the outlined lower level of insights and social skills relating to this, is reported to a desire to stick to their own. One calls it his “safe bubble” (R10). Many mention having tried mainstream schools or employment, but now wish to decompress, stick to their own and join in Spectrum Care’s group-activities that are overall perceived as exciting and little confrontational. Over half of participants state to find some form of safety and support in being around others with similarities to themselves. Multiple find the downside of this to be that it isolates them from mainstream society, but give counter arguments like seeing it as a form of self-protection or their comfort zone.

III.IV Lack of exposure in society

Statements mentioned in the paragraph above, make for too little exposure in society to actually integrate in society, four of the participants conclude. A barrier one of the participants mentions along with this, is the changing of society. She finds it hard to keep up with technology and social media people seem to be into these days and says that over the years, strangers she encounters have become less open to her. Another expresses her opinion on a need for mutual adaptation in order for her to want to get out more:

“It’s easier for me to just steer clear. I can try and try, but if others don’t make an effort or I get funny looks a lot I’d rather just not go into town. I would do it more if I felt like most people were just easier to get along with. People are funny, you never know how they’ll react. Could be different every time, and I just can’t tell most the time” (R2)

The last addition someone had was regarding how unequipped most work environments are for ID. He would like to work at a bar for instance, but states he can’t work a check-out register, nor would he want to.

“If they adapt a place like that just a little bit, I would be very good at the job. Or if I could just only do the other tasks. Now it would be just no good.” (R5)

III.V Organisational level specifically

As for attitude towards Spectrum Care, there is a general consensus of likes and dislikes. Most find the communication from coordinators to be inconsistent and struggle with getting in contact. Multiple states that staff is generally approachable however and almost all have a good relationship with their support worker. However at times it can take a while to get the right matters organised they state. Examples given are when there’s a desire to make a change in housing arrangements or a general enquiry. One participants says:

“They’re so busy. If you’re not high-needs, you’re just put on a back burner. It makes it hard to really make a step forward with making a change, even if you want to.” (R5)

Over-all the participants are content with Spectrum Care’s services. Seven out of ten share examples of their growth on an intra- and interpersonal level, like learning how to manage their emotions and forming a social network with other individuals with ID, since they’ve joined the organisation. Room for improvement is mainly mentioned in the area of structure in their approach.

“It’s all very cruisy. Which is usually nice, I feel at home. But just sometimes I feel like it’s hard to get anywhere and I get impatient. (R3)

DISCUSSION

I. CONCLUSION

In this chapter the meaning of the results are interpreted and linked to the research question. It provides an answer to: *what new findings are made as to lived experiences of young adults with mild intellectual disability, regarding social inclusion.* The minority group's (1) experiences, (2) social skills and (3) barriers form the three main themes. They're each intertwined, and are laid out here as a coherent framework of their journey thus far to answer the research question.

Experiences of individuals with ID interacting with the able majority, indicate an overarching belief among them that a place in society for individuals with ID is 'granted', mainly driven by sympathy or charity. The stories of participants explain the overall attitude from the public towards them still being rather incomprehensive and excluding, with exceptions of cases where compassion and (to its extreme infantilising tendencies) are encountered. Exclusion here appears to lead to both insufficient support for the individuals with ID to flourish, as well as an adverse effect of crippling wariness and caution portrayed by the minority group. Thus far, the general lack of adequate comprehension of ID from the able society, has appeared to have led to narrowing down their opportunity to become autonomous. By the continuation of discrimination and harassment, the individuals with ID struggle to take their place in society. Where literature states the element of 'independence' is necessary for this integration process (Burchardt, Le Grand & Piachaud, 2002; Morin et al., 2019), participants share not to be fuelled enough by their own cultivated engagement to reach that point thus far.

Not just the current exposure on a societal level has an effect, also their upbringing and other experiences in childhood appear to play a role. Parents were in most cases rather protective and sheltering in their approach according to the participants, and provided little stimulation to gain their position in society or become experienced in practising autonomy. In some cases parents showed the opposite behaviour, with an experienced lack of compassion towards their disability. This too, provided no support to gain a position in society or practise autonomy, with the addition of fuelling a felt lack of self-worth.

As to school environments, all individuals experienced forms of unregulated bullying and social exclusion from a young age. This included perpetrators that held an exemplary role. Most individuals describe an unstable to traumatising childhood. In that stage of life they report frequently being put down, put in a box (prejudice), and experiencing a general lack of understanding of their disability, by their surroundings. Most lost touch with people in these surroundings after school, as there was little opportunity or external stimulation to stay connected. It was potentially in this period, where most developed what they describe as an 'avoidance of confrontation'. It proves to influence their level of assertiveness according to the participants, which varies between them. Their assertiveness currently is said to be shaped by a combination of the experienced hardships of being an outsider, as well as being underdeveloped in this competency due to their disability. The individuals describe themselves and others with ID as generally either shy, curious yet naive, or guarding towards others.

There is a higher risk of manipulation, assault and social anxiety, combined with the actuality of traumatising experiences and the apparent higher prevalence of social anxiety. This is claimed to have led to avoidant behaviour, hindering the individuals' path to inclusion. Most individuals show to be closed off about their intellectual disability, as they experience little safety or space by their environments to share. There is an evident lack of exposure, awareness, room, and understanding

among the able majority. Few view this aspect rather as a challenge, and are motivated to educate others on ID.

A combination of the factors mentioned above, appear to have led to little intrinsic motivation of most individuals with ID to engage in employment. In addition, there exists little extrinsic motivation to work, due to financial benefits they receive. Combined, it makes for a hinder in attaining a job. As to keeping a job when they are employed, the individuals often struggle when they don't feel like what they do matters. This, as the majority experience the adjoined difficulty of getting bored fast. There are success stories of employment however, in varying roles. These appear to have a great impact on their progress towards social inclusion, which corresponds with literary findings about the significance of employment for societal participation (Altermark, 2016).

The unsuccessful stories around employment reveal to have become barriers to social inclusion however, with severe effects on the well-being of the individuals and their desire to be included. In response to this, they express a need for more support, as well as a structure of implementation of this support. This applies to their general lack of exposure in society, not just employment. Their aforementioned fear forms a barrier here too, enhanced by the bridge between use of technology, social media and other fast-paced changes that have developed within society.

This concludes for the experiences of the intellectually disabled minority regarding social inclusion, showing it to be a long-term and complex process. All of the mentioned (1) experiences, (2) dissimilitude in social skill-levels and (3) perceived barriers have an amplifying effect on each other. Currently it decreases the ability for this group to add to their community and to start on the upward cycle of gaining a sense of accomplishment and belonging. There is potential and varying forms of desire to be more included, but negative experiences have created fear and resistance. The outside world lacks in fuelling their motivation to engage in society more and appears not to be ready, or equipped enough to fully receive them constructively. The intellectually disabled group longs for a change, mutual understanding and willingness for adaptation from both parties within their communities.

II. DISCUSSION

This chapter provides an evaluation of the research and elaborates on what answers are still missing. As literature stated, social inclusion for the minority group with an intellectual disability accompanies a critical need for adjustment and a constructive method for gradual exposure from both parties. Both this need, and the predicted undermining of the hardships that come with integration (Altermark, 2016), prove to be an actuality here in New Zealand.

II.I Findings per theme

a. The participants' perception of their social skills

As for the first overarching theme, a number of elements relevant to social inclusion emerged on a personal level, corresponding with predicted elements in the topic list. During the fieldwork, insights were gained in (1) the comprehension of humour, (2) ability to read nonverbal cues, (3) insight in the motives of others, (4) emotions and self-regulation, and (5) assertiveness. In addition, the field research revealed another element on a personal level to play a role. This is (6) engagement, experienced in various ways by the participants.

The following findings that emerged, correspond with the diagnostic characteristics of ID (American Psychiatric Association, 2013). All participants struggle understanding when a statement is to be taken seriously or *interpreted as a joke*. This too goes for *reading nonverbal cues* and the general lesser *apprehension of deceit* that characterises their disability (American

Psychiatric Association, 2013). In congruence with findings in the theoretical framework, most participants claim a high level of *genuinity* in their desire *to accommodate* and *relate to others* (Abbott & Mcconkey, 2006; PsychBite, 2022). This feeds into the *heightened risk* of being *manipulated* and *abused*, proves from the second theme describing their experiences with integrating. It shows a need for guidance in this field in the process of social inclusion and is an argument for the recommendation in paragraph II.II.

A finding deviating from literature regarding ID characteristics, is how surprisingly good the minority group is at *self-regulation* of emotions. Nothing was found about the predicted potential lack of behavioural regulation skills, that could potentially form a barrier. This was to be as, in overall mainstream environments there exists a risk of others misinterpreting such behaviour as hostile or uncivilised (Aro et al., 2012). However, findings show that the individuals seem to have under guidance developed a level of *emotion regulation* and a certain extent of *introspection*, which is an argument of the potential this group holds as to successful integration.

b. The participants' experiences with integration in society thus far

As for the second overarching theme, a number of elements relevant to social inclusion appeared to correspond with predicted elements in the topic list here too. Surrounding this theme, insights were gained in (1) Employment and (2) Manipulation. New elements that surfaced, which were later combined with the element of manipulation, were 'assault' and 'social anxiety'. This, as both showed to be reoccurring, linked elements in the expression of experiences of the participants. They were clustered as the elements intertwined in their stories. Other new elements that surfaced were (3) Confrontation avoidance and (4) Openness about ID. The fifth element 'childhood experiences' was clustered separately, as a fair amount of experiences that participants shared, showed reoccuring similarities between them. This too connected with literary findings in the theoretical framework regarding aspects of in- and exclusion of people with ID in the phase of childhood.

The following findings accord with predicted experiences in the theoretical framework, that were found in literature: *shorter attention span*, *impulsivity* and *lack of insight* with regards to *long term goals* (American Psychiatric Association, 2013). The most prominent recurring element in the findings was *exploitation* of people with ID (Morin et al., 2019). The reported experiences overlap in most cases with additional felt *harassment* or *discrimination*, believed to be on the grounds of their disability. This is a known actuality (Burchardt et al., 2002; Jones et al., 2012), which manifests among the participants in various forms, showing to be a serious factor to include in the development of an intervention. Beside this, the widely described *assault* of people with ID as a reoccurring phenomenon, is now, here too proven to be an actuality. The higher prevalence of *social anxiety* among people with ID (Einfeld et al., 2011), does as well prove to be reflected in the target audience and the final element of their experience that correlated with wider findings was their tendency to *avoid confrontation* (Morin et al., 2019). This proves their experiences to be part of a wider, structural hindrance of individuals with ID to integrate in society, highlighting its need for more attention.

c. The participants' found barriers to inclusion

As for the third overarching theme, elements that emerged in correspondence with predicted elements from the theoretical framework were (1) lack of exposure in society and (2) lack of understanding of the public. In this theme the majority of elements clustered through selective coding were new, as this theme had a very open, explorative nature (found barriers to inclusion) in order to prevent bias or directing the interview in a restrictive manner. This allowed participants to share their own views on perceived barriers and showed findings in the elements of (3) counterproductive extrinsic motivation regarding employment, (4) the sense of safety in

the Spectrum Care bubble and (5) information that surfaced on the organisational level. Anticipated elements from the topic list that proved either less relevant or did not come to show for this theme, were 'desire to be included in social groups' and 'money as incentive to participation'.

The finding of a *general lack of understanding* from neurotypical individuals in their environment, experiencing *prejudice* in various outings from others, appears to correlate with literature, however on a *more frequent scale* than averagely reported in other countries (Tøssebro et al., 2012; Houtenville & Boege, 2019). This could be a point of concern, which would require more research to draw a concise conclusion regarding, but surely makes it a large factor to take into consideration in the forming of an adequate intervention.

Besides this, the additional influencing factor of all participants *receiving benefits*, resulting in their *attitude shift* towards employment (not a necessity to survive), correlates too with predictions from the theoretical framework (Altermark, 2016). Individuals with ID stating they stopped showing up at their workplace, contradicts the finding in literature of the trait of *consistency* and *stability* individuals with ID tend to find in environments they get used to (American Psychiatric Association, 2013). Two participants commented on this by saying that is due to a lack of feeling like what they do *matters*. This feeds into the belief regarding the barrier of there being *too little exposure* in society to actually integrate in society. As the factors influence and increase each other, they appear to be conditions for a potential solution to be successful. An essential last factor to be taken into account with this, is the *inconsistent communication* from the organisation's end, that leads to the belief that they are put on a 'back-burner' if their needs aren't pressing enough. The long time it takes the individuals to initiate change, could if unresolved potentially turn Spectrum Care's support towards inclusion in certain cases into obstruction instead.

II.II Remarks

There appear to be three factors with a potential to have influenced the results of this research. The first one being, it consists of the findings out of ten semi-structured interviews. That is but a relatively small selection of its target group, not to be seen as an accurate reflection of reality. In addition, this study is based on the experiences, needs and obstacles of individuals Spectrum Care supports, and can therefore not be generalised for every care institution that assists people with ID and their integration process in society. Potentially these participants, albeit being diverse in demographics, could have specific views in common based on their specific experiences with Spectrum Care, as per example the information they provided regarding a desire for more structure and clear communication. This could have coloured their narrative regarding communication with the able society in general, resulting in altering the research results towards this narrative.

Secondly, the answers of the participants rely on their lived experience and cannot be verified. They may include socially desirable answers, or be coloured by their then-current frame of mind, which could have influenced the results and thus the conclusion of this study. An example of this is the description of some participants' own self-regulation in social interactions as constructive and rather positive, but in that same description downplaying their own initiated violent behaviour as 'doing an accident'. The by their disability characterised underdeveloped insight in one's own behaviour (American Psychiatry Association, 2013), could result in distorted views of the overall picture of the situation.

At last, the empirical findings confirmed, added to and nuanced a vast amount of existing literature. This adds new value to the knowledge base of the disability field. However, the narrative of the experiences from participants has a rather negative connotation. In the

conducted interviews, there could have been more of a focus on the potential and unique abilities of the target group, in order to provide a more complete answer to the practical- and research question.

II.III Recommendations for future research

Current legal regulations and administrative solutions alone, prove not to be sufficient to instigate social inclusion for the population with ID. What shows to be necessary, is the emphasis on making a mutually shared understanding a reality. The majority of society has little knowledge and experience with the disabled minority. The minority group also shares examples of their side of alarming occurrences, as discussed in subparagraph 'II.I a'. Yet, little is still known on the present-day attitude of society's end towards ID, even though this appears to be a factor of great influence in the process of social inclusion, but hasn't actively been targeted. What is their perspective on this process? An accompanying recommendation is specifically more research into lived experiences of current/former employers to transcend one-sided insight. What are their considerations, found struggles and pros and cons?

Beside this, the childhoods of all participants appear to contain traumatising elements, potentially due to the factor of the little exposure to ID the able majority has had. If society is little exposed, how does it play out when a person with this lack of experience has a child with ID, in a community with the aforementioned prejudice? Many people with disabilities are not well prepared to start working, not solely concerning qualifications. Qualities like positive self-assessment, high motivation to work and realistic evaluation of one's potential also play a role (Ager et al., 2001; Altermark, 2016). What part do parents play in stimulating the development of these qualities? Considering the hindering experiences participants have shared, is there a potential parents limit the child's chances of independence in their adult life? What role does the attitude of family play in effectively preventing an intellectually disabled person from achieving independence, and thus employment? Do parents help their disabled children in all tasks and what does that mean?

III.I Practical recommendations

As to the practice question of what Spectrum Care can do to support people with a mild intellectual disability better in order for them to experience social inclusion, the following can be said. In terms of knowledge and insights for Spectrum Care, the research has yielded that individuals they support show progress in built up social- and emotional skills, through their facilitation. Most also contest to benefitting from good relationships with support workers, and gratefulness for the inclusion in the Spectrum Care community. However, there is claimed to be little structure in the communication and organisation, as they appear to be overworked and under-staffed. Participants report to get put on a back-burner if they are not high needs, which makes progress slow, or even stagnates when their intrinsic motivation and external stimulation is low. The people Spectrum Care support believe better structure or protocol could help towards the goal of social inclusion.

III.II Intervention potential

As a first impetus to the development of an intervention to enhance social inclusion for individuals with ID, a number of skills appear to be important to enabling them in overcoming limitations in this process. In addition, it could contribute to lowering resistance of the enabled majority of society, by taking a step towards integration. Each skill stated, encompasses the substantiation of its relevance, based on the findings from this research. See paragraph I.IV of the first appendix to see what elements are represented in which intervention skill.

There are multiple forms that an intervention implementing and addressing these skills could have. A recommendation would be to develop a training of multiple sessions with one for each individual skill, where participants join weekly to learn about, and practise the below portrayed skills — under guidance of a professional. It would consist of an introduction per theme, an open discussion in group form, room to practise and reflect individually, and in teams. Afterwards there could be a group reflection with assignments to practise at home within their own frame of reference. Recommended would be to use a structure throughout the training, to ensure enabling to obtain each skill methodologically. During the training several dimensions of learning would be recommended to work through, these are the five dimensions of Marzano (1992):

- fuelling motivation to learn the skill;
- acquiring and integrating new knowledge and skills;
- broadening and deepening knowledge and skills;
- applying knowledge and skills in meaningful situations;
- the reflection.

This is chosen so the participants will learn to understand, process and apply the new information within their frame of reference. In its most ideal form, the training will be able to teach a skill to ten to twenty participants at a time.

a. Gaining understanding of their individual, unique potential

The discussion stated too little focus on the potential of the minority, opposed to their perceived barriers and 'shortcomings'. The results displayed a felt desire for being occupied with something that mattered, making a difference. This, as well as a desire for engagement in their activities and surroundings. With the current occurrence of counterproductive extrinsic motivation, the groups' form of expression through employment is rather demotivated. This shows potential in growth of the individuals, which can be stimulated by building onwards on these desires. This will also improve the element of their found discomfort regarding being open about ID, once they learn to understand the benefits to being open about the potential they hold. At last, literary findings state a need for this skill, in order to establish social inclusion (Ager et al., 2001; Altermark, 2016). In the training, this skill can be worked through in layers as discussed above, fuelling the motivation and creating a felt need for establishing this first step by openly discussing the benefits of focusing on each individual's potential.

b. Forming and establishing goals that enhance engagement

This links the in results newly found element, based on a desire to meet new people and their felt responsibility towards others, to a solution for the safe 'SC bubble' they are currently stuck in and would be a first autonomous step towards overcoming their social anxiety and balancing out the negative experiences thus far with more positive ones. Will strengthen a long term connection as to social inclusion. It will also cover the second dimension of Marzano (1992), by acquiring and integrating new knowledge and skills regarding their own potential.

c. Autonomously making choices that shape their future

This will tackle a fair few elements found in the field research. It approaches the complaints of participants regarding having to await SC staff to make a change for them, it will fuel their engagement, as well as approach the lack of exposure and help balance out the counterproductive external motivation with a then enlarged intrinsic motivation. Plus, literature states (Aro et al., 2012), autonomous decision making with regards to one's own future is an important pillar for the path towards social inclusion.

d. Growth of connections by initiating actions towards others in their community

This skill, in the fourth phase of the intervention, will make use of the method of Marzano's dimensions (1992), explained below. It would apply the knowledge and skills that were learned in earlier phases (heading a, b & c) in meaningful situations. It will deepen resilience and engagement, strengthen the sense of autonomy and their overall social skills due to exposure, as well as a reduction in social anxiety (Myers et al., 1998; Aro et al., 2012). This, with the connotation of appropriate guidance, to prevent their attempts to open up from backfiring and having the opposite effect, once more.

e. Independently protecting and expressing their own interests

This last skill will allow space for the individuals to reflect on their progress thus far, linking in with the last dimension of Marzano (1992) of reflection. Once they are able to understand their own interest and desire (goals, steps, plan) with regards to social inclusion, they can use the practised autonomy- and social skills to communicate this to others and sustain it as an ongoing progress. It'll include touching on the elements of emotions and self regulation, handling non-verbal cues and in particular approach the openness about ID, confrontation avoidance and 'safety bubble'.

These skills can be trained with regards to any context, whether it'd be the social setting of employment or obtaining a social network. This would align with the initial areas of focus to improve in, as per the practice question of Spectrum Care.

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APPENDICES

The appendices include all materials used in the study, such as the topic list, instructions, recruitment documents, analysis plans (taxonomy and code tree) used in the study and an ethical justification.

I. ANALYSIS PLAN

This paragraph provides insight into how the data, based on the chosen methods described in paragraph five of the 'Method' chapter, was analysed accordingly. As it entails qualitative data, examples of the following executed steps are shown: a transcript, open coding, axial coding, selective coding and the taxonomy. Below shows an example of a transcript with its open coding.

I.I Transcripts

Interviewer 2:02
Interesting. Hey, and now this one's the opposite. This is "knowing when people are being serious" . Would you say you're 'Good at that' or 'Okay', or maybe 'A bit tricky'? 1

Interviewer 2:14
There's no right or wrong. Just go with whatever you think.

Participant 1 2:27
Hmm, I don't know. A bit hard maybe. Especially with friends and family. 1 2

Interviewer 2:31
Oh yeah. Do you have like an example of when you find that a little hard maybe?

Participant 1 2:36
Well, I don't know if that's an example 3 but like, when my dad says that he's gonna say that he will wear shorts. And put a tissue up his nose when he walks me down the aisle, I don't know if that is serious.

Interviewer 3:17
Fair enough. So that's like one of those examples where it might be a joke maybe?

Participant 1 3:22
I don't know if he's serious or.. 3

Interviewer 3:26
Yeah. So what do you do then when he says that? How do you react to that?

Participant 1 3:33
I am thinking 4 I get upset or angry and think "don't be stupid, dad!"

Interviewer 3:41
Ah, so it confuses you a little bit then 4 and then you don't like that?

Participant 1 3:45
Yeah.

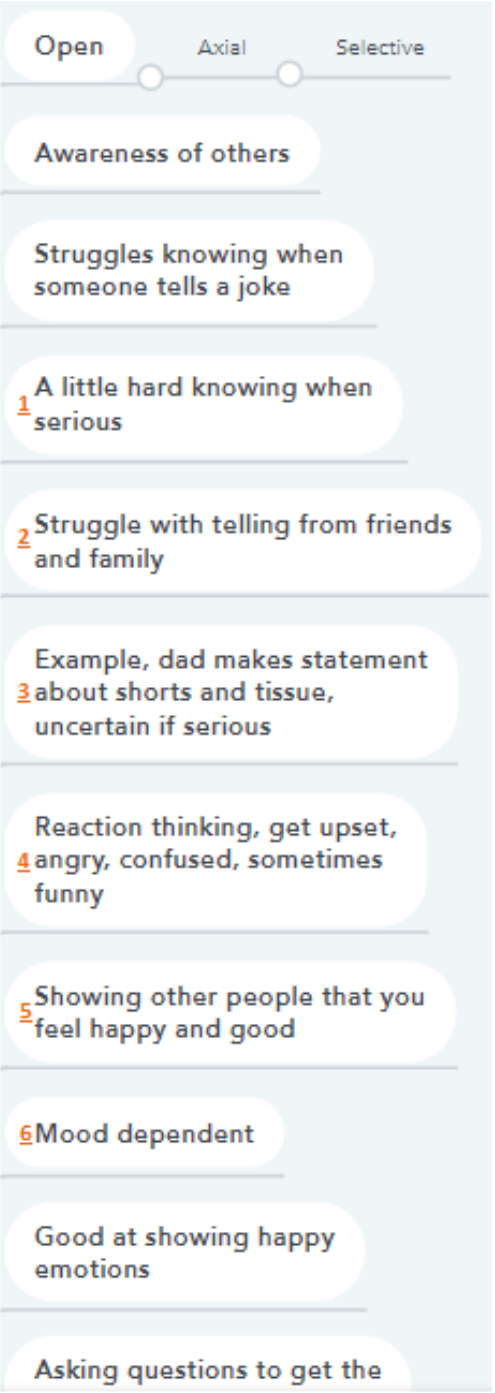
Interviewer 3:45
What did you say to your dad in that particular situation?

Participant 1 3:47
That sometimes I laugh when I think it's funny but he can't just be like this all the time. 4

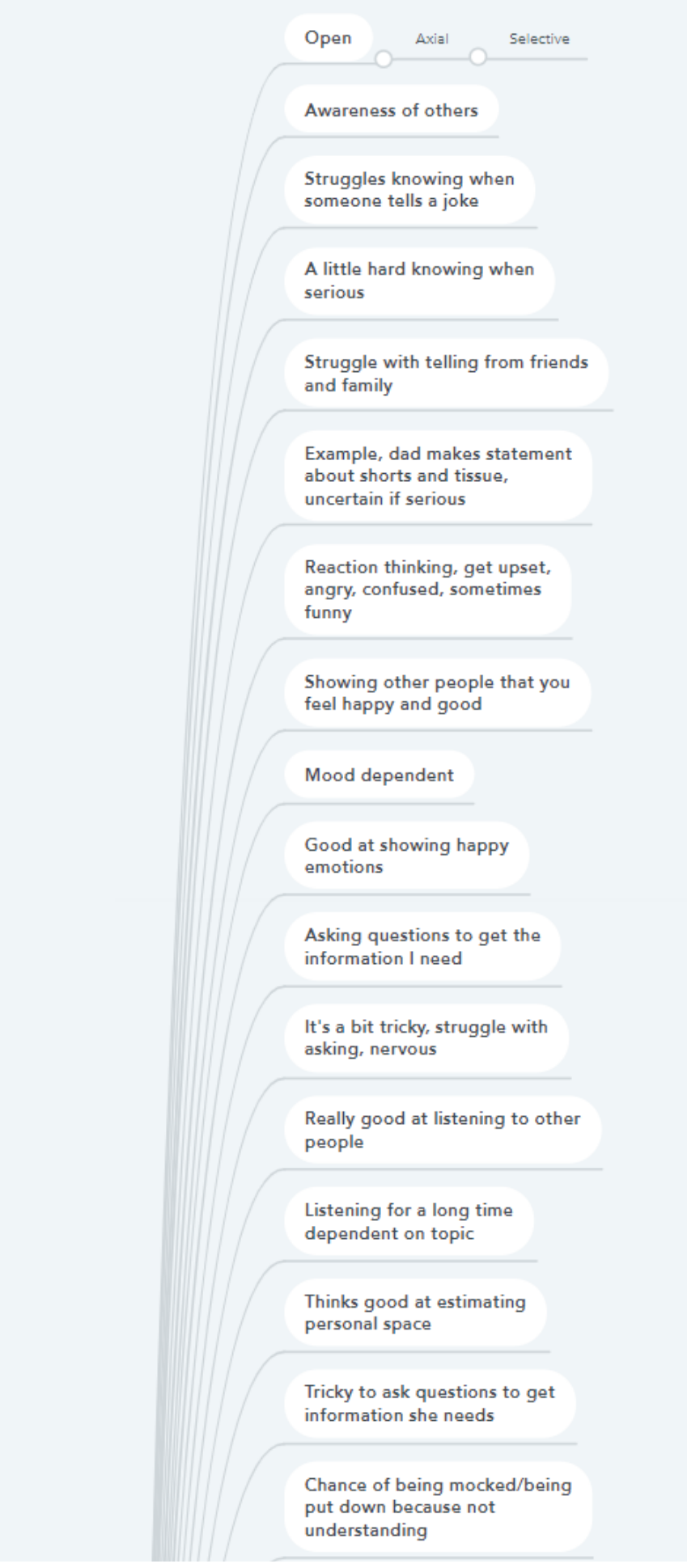
Interviewer 3:50
So sometimes it's funny, but sometimes not? [participant nods] No, fair. 4

Interviewer 3:58
Hey and, yeah how good would you say, or how do you find it to be "showing other people that you feel happy and good"? 5 Would you say you're 'Pretty good' at showing other people? Or do you think you're 'Okay', or is it ' bit tricky?

Participant 1 4:15
Depends on my mood. 6



I.II Open codes

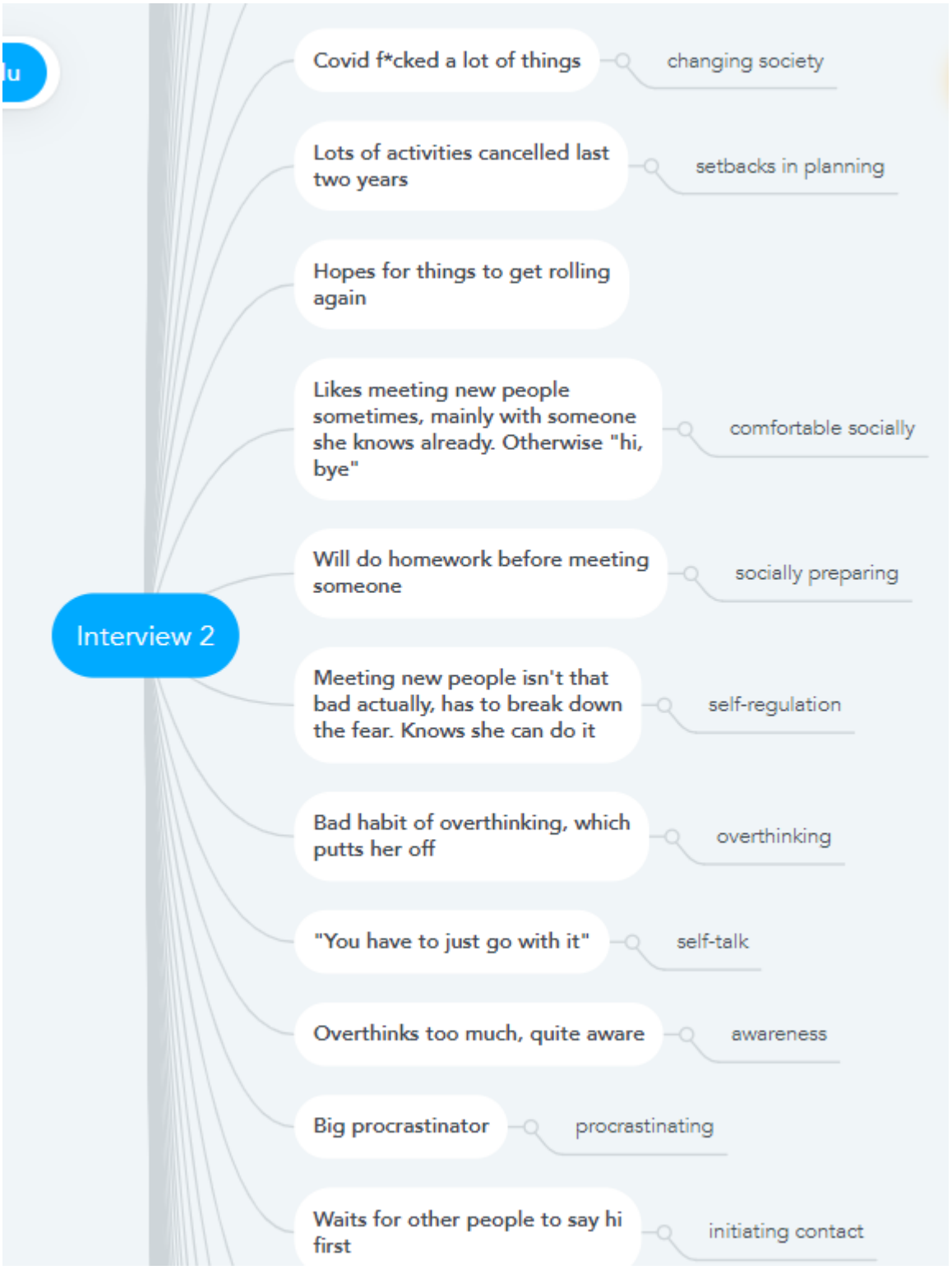


Interview 1
Not knowing answer herself
Brave to share
Cares about others' feelings when they seem happy
Both with strangers and familiar people
Cares about other' feelings when they seem upset
Argues with fiancé sometimes
Results in not talking to him
Or kissing and making up
Used to stay grumpy after arguments a lot
A lot less now. Growth
Different with family, stays grumpy longer
Sometimes feels (not) okay if someone thinks differently
Does accept when others are different from oneself
Likes difference in people
Likes showing interest in others
Feels shy when meeting new people
Tries to talk if not too shy
Asks them questions
Likes meeting new people
Likes giving others compliments
For instance about how they look
Will sometimes encourage others

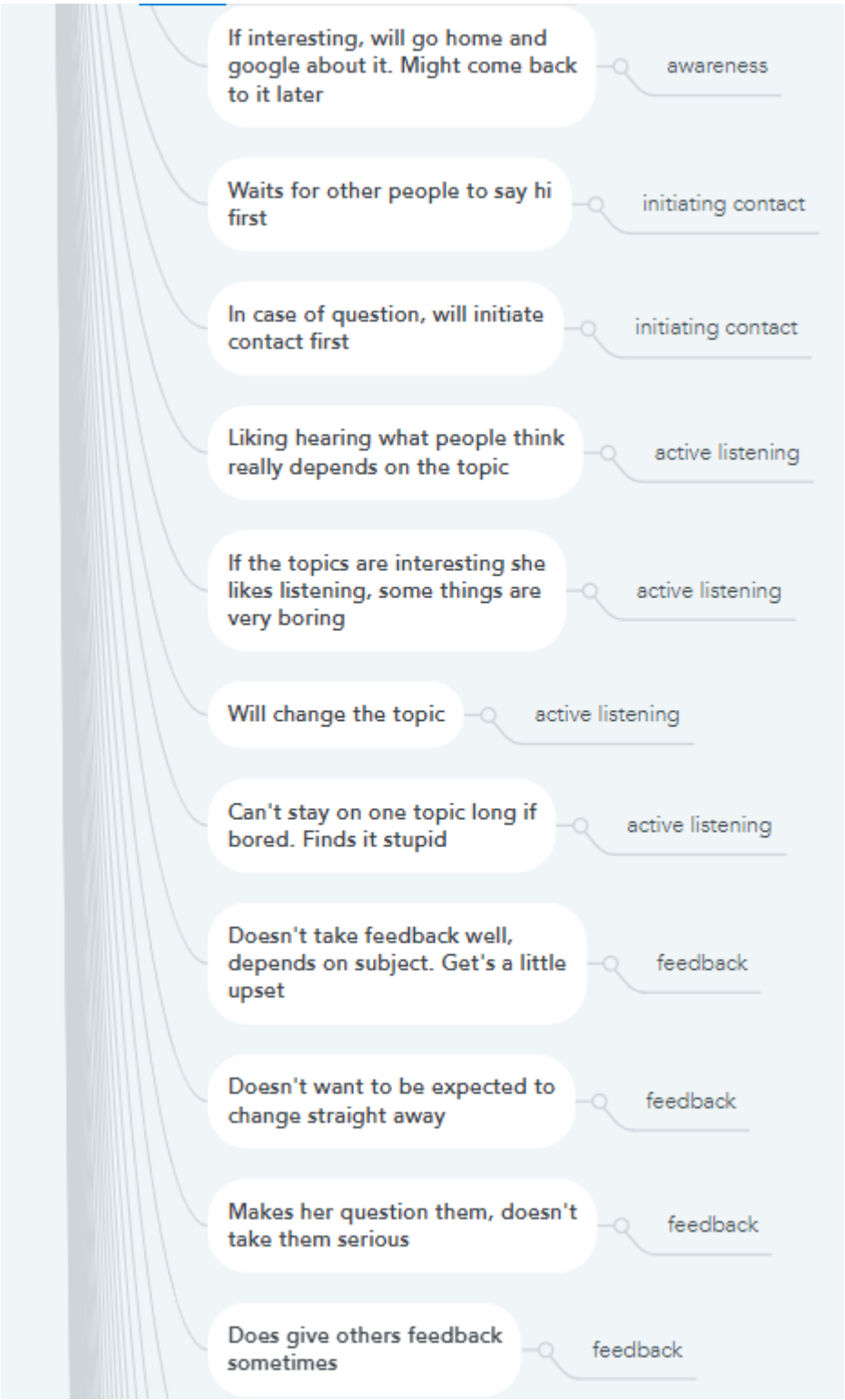
Sometimes that's a bit tricky as unsure what to say
Will sometimes feel confident around new people, is sometimes shy
Helps if there's someone she knows around
Will sometimes ask for help when needed, but often not. Finds it really hard
Scared to ask for help, afraid to be turned away, afraid of them judging when they don't know her
Has been ignored a few times, potentially as others didn't understand how to help
Has had times where they did help
Does often join in activities/groups she takes interest in. Not hard
Regarding help, is hard because she gets quite emotional and finds it hard expressing feelings and what she needs help with
Some people around her understand
Never avoids groups/activities even if she wants to go
Not shy to join things. Strength
Will sometimes speak up and tell people what she thinks, sometimes too nervous to say something
Takes her a while to say something
Hard to say what she thinks around family
Around fiance and people she's only known for about a few months it's easier

The figure above shows the entirety of open codes from the first half of interview one, in chronological order. All code overviews are split into a ‘part 1’ and ‘part 2’ to hold alongside each other. The benefit of the program MindMeister (2023) is the possibility to start off in chronological order, but shift the codes later on to regroup them in the next phase. Also it allows the option to link more codes to the initial open code, which can be shifted as well. How the codes were formed is explained in paragraph ‘V.II’ of the data analysis chapter of the method. The methods of Saldana (2021) were used in executing all steps of the coding process.

I.III Axial codes in code tree



As mentioned in the paragraph above, the program allows for axial codes to be added to the open codes, as can be seen above. The next step taken was reordering the codes and clustering them, which can be seen in an example below.



Both these examples were from the first half of the second interview. After this process, clusters of axial codes from both halves of the interview were combined together, to form complete clusters per interview. The third step was to start selecting codes that were deemed relevant to the research. The next paragraph shows an overview of the selected codes in a code tree, providing the structure of which the results chapter was based. Which considerations were held into account when clustering and selecting the codes, can be found in paragraph 'V.II' of the data analysis chapter of the method.

I.IV Selective codes in code tree

II. MATERIALS

This chapter entails what materials were used, such as interview protocol and shared documents. This clarifies how the operationalization has been thought through.

II.I Interview protocol

The level of difficulty is adjusted to fit the target group, in line with the practical manual for research with people with ID (Landelijk KennisNetwerk Gehandicaptenzorg, 2004) and reviewed by Spectrum Care's team of Speech-and-Language Therapists.

Following aspects were taken into account:

- The necessary level of 'concrete' opposed to 'abstract' thinking, although different participants will be at different levels.
- The tool for the interviews, the Talking Mats, needs to be specific, with pictures.
- The target group tends to be people pleasing, which needs to be taken into account. They might wonder what the *desirable answer* is that the researcher is after, and provide the most *socially fitting* answer.
- With egocentrism being one of the characteristics of the disorder however, others might do the exact opposite and focus a lot on *their own perspective* and *go off topic*. This is another reason Talking Mats are a justified method, as they will assist with keeping on track during the interview (Murphy & Cameron, 2008).
- Permission is asked for any step taken before, during and after the interview as described in the consent easy read (II.II b.) and ethical accountability (II.III)
- Explicit checking if the participant is comfortable with a question, comfortable answering and in the right state of mind to continue. This includes offering breaks or allowing silences.

All steps and methods applied to the process of the interviews have been based on the following resources:

- *Gedragscode praktijkgericht onderzoek voor het hbo* (Andriessen et al., 2010)
- *Basisboek kwalitatief onderzoek: Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek* (Baarda et al., 2021)
- *Systematic methodological review: developing a framework for a qualitative semi-structured interview guide* (Kallio et al., 2016)
- *Onderzoek met mensen met een verstandelijke beperking: Handreikingen voor de praktijk.* (Landelijk KennisNetwerk Gehandicaptenzorg, 2004)
- *The effectiveness of Talking Mats® with people with intellectual disability* (Murphy & Cameron, 2008)
- *Methodieken en technieken van onderzoek* (Saunders, Lewis & Thornhill, 2016)

II.II Shared documents

This paragraph includes texts offered to the participants: the instructions and recruitment. Debriefing was done verbally and none of the participants required external participation of consent.

a. Recruitment email

Good day,

My name is Ires and I am a student, working on a project within Spectrum Care to improve the lives of people with an intellectual disability. I have been working on a new research study and would appreciate your help.

Our goal of this new study is to see what the struggles are of getting and staying connected to other people, so we can come up with something to help make this easier. It could be struggles when going into new places and meeting new people, or struggles with making new friends and keeping up with those friendships. Anything you might find hard (or easy) in being connected to other people.

If we are able to understand what the biggest struggles are, we can come up with a solution what will help both you and the other people you're trying to connect with. This will help many people with intellectual disabilities! It would help us very much to actually talk to you about what this is like for you, instead of only hearing stories from other people.

Would you like to help? To see what we're asking, please read the description below.

- You will be having a chat with me, Ires, for 30 minutes about what it's like for you to be social
- It will just be you and me and we'll have our own room, so you can speak freely
- I will not share any of the information with other people, including your family or support workers/coordinators
- I'll be showing you some pictures of topics and you could tell me what they are like for you
- It would take place at [...] on Thursday 17th of November / Friday 18th of November, time [...]
- The meeting is only one time, and will get [don't know if you usually use an incentive? Get them a coffee/snack/voucher/etc?]

If you are interested in helping, reply to this email or let your support worker know.

Please let me know if you have any questions we could answer. Thank you for helping to improve the lives of people with intellectual disabilities!

Kind regards,

Ires Romijn

Trainer & Coach | Applied Psychology

phone 022 090 8964

email ires@psychologieinhetonderwijs.nl

b. Consent form - easy read

All participants signed a complete physical copy of the form shown below, before the start of participation. These are kept securely for anonymity purposes and therefore there are no copies made, nor added to this document. If necessary, anonymous copies will be provided upon request.

Consent Form – sharing Talking Mats

Talking Mats are a tool to help you communicate. It helps you tell people what you think.

Taking photos and videos of Talking Mats helps us:

- remember what you've said
- show other people what you've said

Sharing stories can help give other people ideas about what they can do.

Sharing stories can help train more staff to use Talking Mats to help people communicate. We will not use *your name* or let anyone know it was *you* who said things.

We will only share things about you if you have given **consent**.

Consent means you:

- know what will be shared
- know who it will be shared with
- agree it is ok to share.

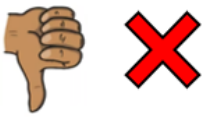
Consent Form

Date: _____
My name: _____
(We will not tell anyone your name or show it anywhere)

This form is about sharing my:

- ☐ Video
- ☐ Story

(We will not share anything of you personally, or *about* you anywhere. Things you share we'll write by **'person X'**.)



Choose what you agree to:

- ☐ No – you cannot share my story or photo.

Yes:

- ☐ You can share my story
- ☐ You can share my video

(If you ever change your mind, you can still say no and we will delete the things you have said)

You can share my story/video:

- ☐ Staff at Spectrum

- ☐ Teachers at the school in the Netherlands (Fontys)

II.III Ethical accountability

'During the execution of this research, the code of conduct for applied research for higher professional education (Andriessen et al., 2010) has adhered, as well as the rules and regulations of Spectrum Care, the client.

a. Objectivity of information

What steps have been taken to objectively seek information?

The development of expertise has been part of this research. For example, asking for continuous feedback so that the strengths and weaknesses of the researcher became known. When necessary, expert advice has been seeked and applied to obtain a quality to the expected standard. The researcher reflected weekly on their own actions. There was a weekly intervision group with fellow students and an expert supervisor, as well as weekly appointments with the supervisor from Spectrum Care. If alarming situations were to be discussed, the signalling function of the investigating psychologist would be called on and i If necessary, a referral would be made. This as, ensuring the ethical aspects of research is part of the researcher's expertise.

b. Informing of participants and consulting of impact research

How was ensured that participants were well informed and participated voluntarily? Which committees were consulted about the impact of the research and the intervention?

As the target group consists of people with a higher level of vulnerability, characterised with a lesser intellectual understanding of situations, it was highly necessary for the wellbeing of the individual, as well as the validity and effectiveness of the research, that all precautions were taken to ensure this process was handled and guided accordingly. Therefore all forms of field research were done in agreement, with consent and open communication with the research coordinator Piri Rutherford, with the support worker in question of the individual in question, with their family and/or primary caregiver and the individual him- or herself. This was based on the methods from the practical guidelines for research with people with ID, from the Dutch national knowledge network for disability care (Landelijk KennisNetwerk Gehandicaptenzorg, 2004). The moral implications that come with the suggested research outset were reviewed through this method. This happened during the preparation of the research, the gathering of information, the processing of it and the planning and logistics of it. An example of one of the moral implications is the sense of autonomy and the right to choose to participate or not, without any consequences for the individual, being an important factor with this target group. This has explicitly been pointed out by and to all parties involved. Another example that is linked to this process is the ability of empowerment to communicate thoughts and feelings on the matter, that is with this particular target group stimulated by repeatedly initiating communication. It was not only a learning curve for the student researcher, but also for the participants. A third example that links with this is the right level and method of communication, that was once again in agreement with all parties. 'Easy reads' were used, created by the researcher in cooperation with Spectrum Care's Speech and Language Therapist, who is specialised in effectively communicating with the target group. After each form of contact or interview, the results were reviewed and analysed together with the research supervisor and if in any doubt, the Speech and Language Therapist was consulted. This too applied to the impact of the research and potential intervention. If a particular aspect of the current approach seemed ineffective, the approach would be altered. What is also important is that not too much is asked for from the individuals and that there is a support base from them for the cause (i.e. they understand the need and feel the desire to contribute to the research). Transparency was key here too (P. Rutherford, personal communication, October 5, 2022; Landelijk KennisNetwerk Gehandicaptenzorg, 2004).

c. Guaranteeing anonymity and respect

How was the anonymity of the participants guaranteed? How can others see the researcher was respectful with the various stakeholders (e.g. client, participants, training)?

The researcher acted with respect towards the participants and other stakeholders. Any characteristic or personal information is anonymised. It is important that neither Spectrum Care, nor the families of participants know which supported person with ID gave which answers, so that Spectrum Care cannot address or confront the participants. For this reason, typical information is omitted. In conversations with Spectrum Care, reference is made to 'a participant' instead of '[name]'. This is also taken into account in writing. For example participant 'R1', instead of characteristic information. Since there is a small population for the sample that is enlisted in Spectrum Care's services, this is especially important. When research data was shared with the client, it was sent encrypted via Spectrum Care's intranet. In this way data leaks were prevented. This also prevented the information from reaching third parties.

The topics that were discussed can be sensitive to the people Spectrum Care supports, as well as their families or support workers. It's about what social skills they / their family member / their client possessed and what they 'lack'. It is possible that participants experienced a threshold to be honest about this. For this reason, it was clearly communicated prior to the participation of the interview that the research results were to be anonymized. This was discussed again at the start of the interview. Participants were also informed of the retention period of the research data via informed consent. Participants were made fully aware of the motivations and methods of the survey. The researcher also checked afterwards how the participant experienced the interview, with a focus on the cases that a participant is one of the supported people with ID. When necessary, the researcher gave the participant the opportunity to talk about this. If the researcher were to be concerned about the participant's wellbeing or comfort, he or she would be advised to discuss this. No distinction was made between the participants on the basis of ethnicity, age, religion, et cetera. The researcher adopted a non-judgmental, professional attitude. Furthermore, the research was of a voluntary nature and participants could stop participating at any time. This was communicated through informed consent.

d. Accounting for setup of research

How and where was the design of the research accounted for?

This was guaranteed by delivering high-quality research. Scientific literature and professional literature are used in the theoretical framework, conducting interviews and will as well be during the development of the intervention. The researcher acted in a well-founded manner and reports are complete. The researcher made choices in what was necessary and what contributed to the research objective, especially regarding this target group, requiring extra care and responsibility. In addition, the researcher took responsibility for protecting the results to ensure that the results are not misused insofar as this can be influenced. For example, the researcher made clear agreements with Spectrum Care about the retention period and the conditions of use of the research report. The researcher handled the collection and presentation of the data with integrity. In order to guarantee honest dealings with the data subjects, no characteristic personal data was shared. In addition, no further questions were asked about themes that fall outside the research objectives. The APA style was used in every form of presentation of the research results. This contributes to a reliable and fair presentation of the research. The references to the sources used ensure transparency in the origin of information. In this way it is made clear which findings are not part of our own research and which are. Given the timeframe of the investigation, a clear, defined aspect of the problem was explored. The researcher was honest about this with Spectrum Care. In order to create realistic expectations, the researcher ensured a thorough delineation of the request for advice.

e. Ethical and professional codes

With which ethical and professional codes were abided by and what does this mean for the research?

As readily described above, the code of conduct for practice-oriented research for higher professional education (Andriessen et al., 2010) was complied with. This too applied to the earlier explained handbook for practice regarding research with people with an intellectual disability (Dutch National Knowledge Network Disability Care, 2004). And the readily laid out code of conduct for the TalkingMat method (Murphy, J. & Cameron, 2008), along with its consequences for the research.

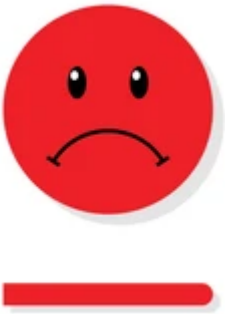
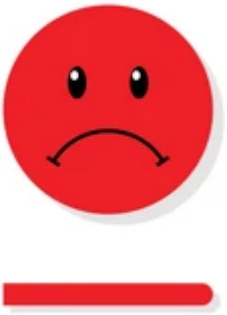
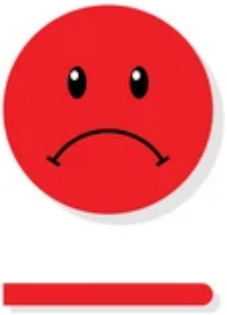
Another base of the methods regarding this research, was the code of ethics from the Netherlands Institute of Psychologists (2015). Within this code, there are four important pillars in the field of ethics that every psychologist must adhere to: responsibility, integrity, respect and expertise. What these four pillars meant for the research are too laid out in the paragraphs above.

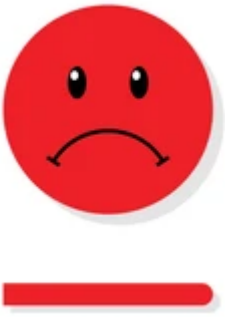
II.IV Consent form digital knowledge base

HBO knowledge bank form. The program places (a selection of) theses with a mark of 7 or higher in the HBO knowledge bank. Currently, first the client will determine whether the research report may be made public in this way, which will be reported back to the institute as soon as they review the final product.

II.V Talking Mats

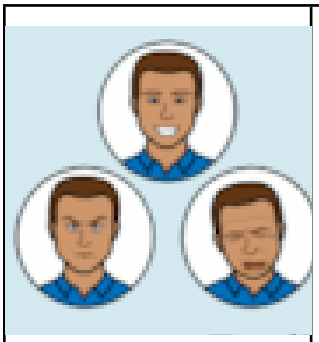
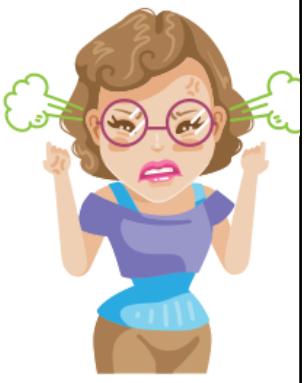
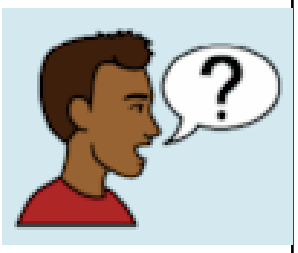
SCALES

		
I'm good at this	I'm okay	It's a bit tricky
		
Most of the time	Sometimes	Hardly ever
		
I want to do this more	Keep doing the same	I want to do this less

		
Really important	**A bit important**	**Not so important**

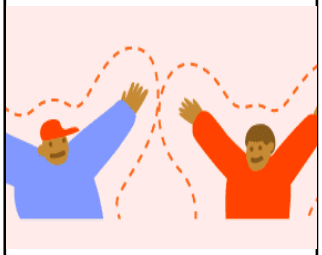
I. FEELINGS

I'm good at this — I'm ok — it's a bit tricky

				
Staying in control when I feel angry	Keeping my cool when I feel angry	Using strategies to help me be calm	Knowing when I am feeling annoyed or angry	Knowing when I feel happy and good
				
Knowing when I feel sad	Figuring out why I feel a certain way	Telling people what I think	Making decisions for myself	

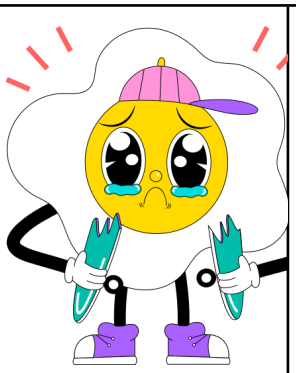
2. AWARENESS OF OTHERS

I'm good at this — I'm ok — it's a bit tricky

Knowing when someone tells a joke	Knowing when people are being serious	Showing other people I feel happy and good	Asking questions to get the information I need	Listening to other people
				
Listening to other people for a long time	Giving people enough personal space			

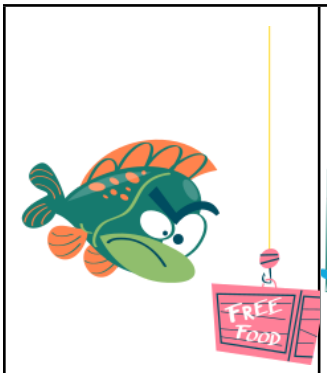
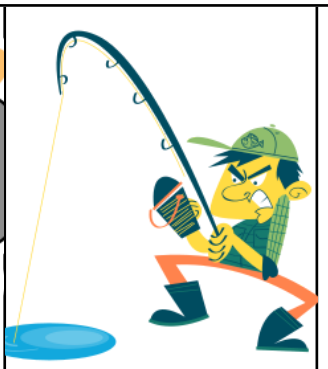
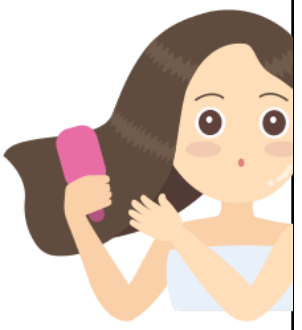
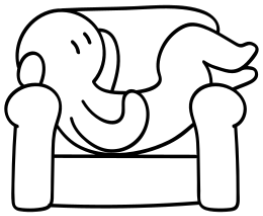
3. EMPATHY

Most of the time — sometimes — hardly ever

				
I care about the other person's feelings, when they seem happy	I care about the other person's feelings, when they seem upset	If I have an argument, it ends with both of us feeling ok and happy	Ending an argument but staying grumpy at each other	I feel ok if the other person thinks something different from me
I accept it when the other person is different to me	Showing interest in the other person	Telling other people nice things/compliments	Encouraging other people	

4. RISK AND JUDGEMENT

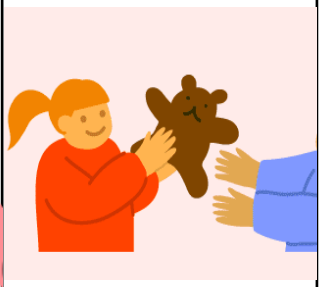
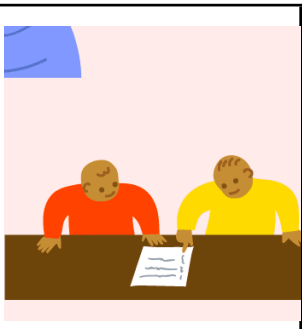
Most of the time — sometimes — hardly ever

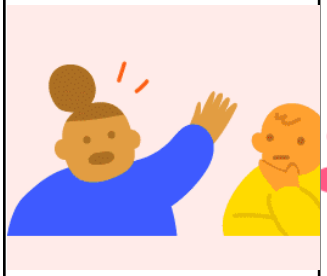
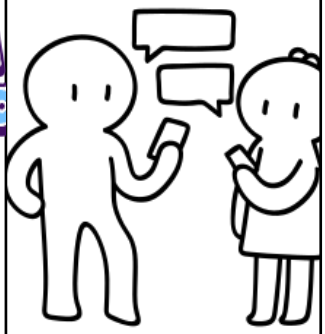
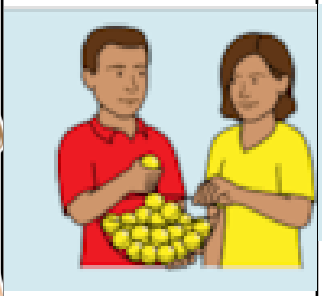
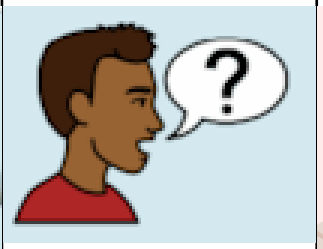
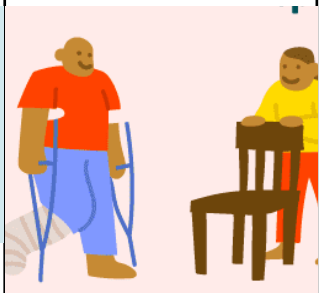
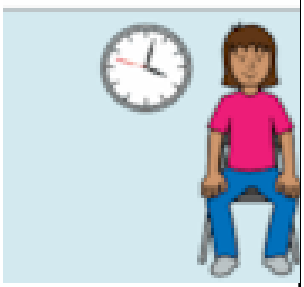
				
I know when people are telling the truth	I know who to trust	I trust everyone I meet	I know when people are tricking me / pretending	I know when people are lying to me
				
When I make decisions, I think about what will happen in the future	I mostly make decisions based on what I want to do now	People get to know me	People get to know me before they decide what to think of me	People decide what they think of me before they get to know me

People assume they know what I will be like because of my disability	I get treated differently to everyone else	I get treated the same as everyone else

5. COMMUNICATION

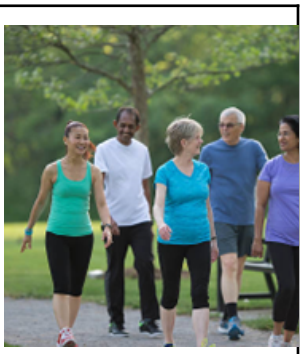
Most of the time — sometimes — hardly ever

I feel confident with people I know	I feel confident with new people	I can ask for help when I need it	I join in activities/groups I'm interested in	I avoid new activities/groups even if it's something I want to do
				
I speak up and tell people what I think	I tell people what I want	I like meeting new people		
				

I wait for other people to start talking before I do	I have questions for people when I see them	I say hello to people	I like hearing what other people think	I like learning from other people
				
I would follow instructions from people	I can talk about 1 thing for a long time – if it's something I don't like talking about	I can talk about 1 thing for a long time – even if I don't know much	I change topics when I get bored	I change the topic when I get confused
				
I feel sad when someone tells me something I can do better	I feel good when someone tells me something I can do better	I tell other people what I think about them	I'm polite to other people	I wait and am patient

6. MOTIVATION

I want to do this more — keep doing the same — do less
&
Really important — a bit important — not so important

				
Fitting in with other people	**Feeling like I belong in the group that I'm in**	**Being part of a team at work**	**Being with my friends**	**Having enough friends**
Being part of a sport club	**Being part of a social club (e.g. youth group, church)**	**How much money I get paid in a job**	**Having fun at my job**	**Having friends at my job**

III. TOPIC LIST

This topic list is based on social skills relevant to finding, obtaining and maintaining a job, friendly or romantic relationships, a social network and participating in other forms of mainstream environments. As mentioned in the method, the content is based on literature from the theoretical framework. The themes and dimensions are converted in questions formatted to multiple individual sections of the TalkingMat tool, as to be found in II.V Talking Mats. As described in the method, each topic will be delved into further by asking open questions to elaborate on the topic, with lived examples of experiences. This might lead to more in-depth information and other themes/elements regarding relevant experiences, which are not prematurely included in the topic list.

Theme	**Dimension**	**Talking Mat question**	**Top scale** **'I'm good at this - I'm ok - it's a bit tricky'**
1. Feelings	Anger (self control)	*When you feel angry, can you control that feeling in the moment?*	Staying in control when I feel angry Keeping my cool when I feel angry
	Regulating behaviour (cognitive flexibility)	*When you feel upset, can you help yourself become more calm?*	Staying calm when I am upset Using strategies to help me be calm
	Expressing feelings (letting people know when you feel good, when you're feeling bad, when hurt, when angry)	*Do you know what to do in an emotional stage? → you're feeling hurt/happy/angry/sad*	Knowing how I feel Knowing when I am feeling annoyed or angry Knowing when I feel happy and good Knowing when I feel sad or sick
	Understanding feelings (knowing what initiates certain emotions)	*In that moment, do you know why you feel those emotions?*	Figuring out why I feel a certain way Knowing what makes me have my feelings
	Assertiveness (decision making)	*Can you speak your mind if you want to make a decision?*	Telling people what I think Making decisions for myself Telling other people what I have decided
2. Awareness of others' thoughts and experiences (e.g. egocentrism)	Humour	*Do you understand when someone makes a joke and when they are serious?*	Knowing when someone tells a joke Knowing when people are being serious Knowing why other people are laughing Making other people laugh

	Positive attitude	*Do you show your happiness around other people?*	Showing other people I feel happy and good
	Understanding how oneself is perceived	*When you ask people questions, do you often get the answer you want?*	Asking clear questions Asking questions to get the information I need
	Active listening	*Do you listen when someone wants to share their story with you?*	Listening to other people Listening to other people for a long time
	Personal space	*Do you know with what space the other person feels comfortable?*	Giving people enough personal space
			Top scale **'Most of the time - sometimes - hardly ever'**
3. Empathy	Interest in other people's feelings when happy / upset	*Do you care about the other person's feelings, when they seem upset?* *Do you care about the other person's feelings, when they seem happy?*	I care about when the other person is happy I care about when the other person is upset
	Conflict resolution	*Do you find it important to solve an argument?*	If I have an argument, it ends with both of us feeling ok and happy Ending an argument but staying grumpy at each other
	Accepting others (differences)	*Do you accept the other person, even when they are different from you?*	I feel ok if the other person thinks something different from me I accept it when the other person is different to me
	Showing interest	*Do you often show interest in the other person?*	Showing interest in the other person
	Complimenting others	*Do you give the other person compliments?*	Telling other people nice things/compliments Encouraging other people

4. Risk awareness and social judgement	Gullible	*Do you believe the other person straight away on their word?*	I know when people are telling the truth I know who to trust I trust everyone I meet
	Susceptible to manipulation (exploitation by others and possible victimization, false confessions, and risk for physical and sexual abuse)	*Can you tell when someone's not telling you the truth?*	I know when people are tricking me / pretending I know when people are lying to me
	Impulsivity	*Do you think about an action before you act it out?*	When I make decisions, I think about what will happen in the future I mostly make decisions based on what I want to do now
	Stigma and prejudice	*Do you feel like someone has a different opinion of you than you really are?*	People get to know me People get to know me before they decide what to think of me People decide what they think of me before they get to know me People assume they know what I will be like because of my disability
	Discrimination	*Do you feel like they treat you differently than others?*	I get treated the same as everyone else I get treated differently to everyone else
5. Interpersonal communication skills	Verbal communication (expressing desire, tone and volume of voice)	*Do you feel like you use your voice well when talking to this person?*	My voice tells people how I feel (e.g. I get loud when I'm really excited, gets slow when I'm tired)
	Eye contact	*Do you make eye contact with the other person easily?*	I find it easy to make eye contact I feel uncomfy when I look directly at people
	Social confidence (daring to participate, asking for help/assistance)	*Do you let the other person know when you want help?* *Do you let the other person know when you want to join in?*	I feel confident with people I know I feel confident with new people I can ask for help when I need it I join in activities/groups I'm interested in

			I avoid new activities/groups even if it's something I want to do I speak up and tell people what I think I tell people what I want
	Initiating contact (initiating conversations with peers)	*Do you start talking to a person when you want to chat with them?*	I like meeting new people I wait for other people to start talking before I do I have questions for people when I see them I say hello to people
	Cooperating (attending to instructions, accepting other people's ideas)	*Do you feel like you accept ideas from the other person?* *Do you follow instructions from the other person?*	I like hearing what other people think I like learning from other people I would follow instructions from people (maybe break this down – from staff, from work, from flatmates, from parents)
	staying on the same topic	*Do you stay on the same topic in a conversation?*	I can talk about 1 thing for a long time – if it's something I don't like talking about I can talk about 1 thing for a long time – even if I don't know much I change topics when I get bored I change the topic when I get confused
	Giving and receiving feedback	*When someone gives you a tip about yourself, do you know how to respond?* *When you're giving the other person a tip about themselves, do you feel like you can do this well?*	I feel sad when someone tells me something I can do better I feel good when someone tells me something I can do better I tell other people what I think about them
	Manners (asking nicely, wait for turn, greet others)	*Can you wait for your turn?*	I'm polite to other people I wait and am patient

		Do you greet the other person when you see them? *Do you ask politely when you want something?*	
	! [Define terms 'inclusion' and 'belonging' towards interviewee before starting this mat – e.g. *feeling like people want you there, you want to be there. You know each other well and care about each other.*]		**Top scale:** **'I want to do this more - keep doing the same - do less'**
6. Motivation	Sense of belonging (to group in question)	*Do you feel like you fit in with this person?* *When you are in a group with them, do you feel like you belong there?*	Fitting in with other people Feeling like I belong in the group that I'm in
	Desire to inclusion employment	*Would you like to be part of a work team?*	Being part of a team at work
	Desire to inclusion friendships	*Would you like to be a part of a friendship(s)?*	Being with my friends Having enough friends
	Desire to inclusion social groups (sports/clubs)	*Would you like to be a part of a social / sport club?*	Being part of a sport club Being part of a social club (e.g. youth group, church)
			Top scale: **'really important - a bit important - not so important'**
	Money as incentive to participation (employment)	*If you were to have a job, do you find it important how much you get paid?*	How much money I get paid in a job Having fun at my job Having friends at my job

IV. STATEMENT OF AUTHENTICITY

I hereby declare firmly

1. that I wrote this research report myself, without the help of third parties;

2. that I have indicated and mentioned in my report all direct, verbatim quotations from the literature and all indirect quotations and ideas from other authors.

I am fully aware that violation of this statement may have negative consequences for me (such as taking credits).

In case fraud can be proven, I am liable for the costs of the investigation.

Place, date	Auckland, New Zealand	November 29th, 2023
Name	Ires Romijn	
Student number	3718336	
Signature		