


Please cite the Published Version

Martin, AM, Andrews, T, Goldbart, J  and Landers, M (2022) Reconciling communication repertoires: navigating interactions involving persons with severe/profound intellectual disability, a classic grounded theory study. *Journal of Intellectual Disability Research*, 66 (4). pp. 332-352. ISSN 0964-2633

DOI: <https://doi.org/10.1111/jir.12921>

Publisher: Wiley

Version: Published Version

Downloaded from: <https://e-space.mmu.ac.uk/629285/>

Usage rights:  [Creative Commons: Attribution-Noncommercial-No Derivative Works 4.0](#)

Additional Information: This is an Open Access article published in *Journal of Intellectual Disability Research*.

Enquiries:

If you have questions about this document, contact openresearch@mmu.ac.uk. Please include the URL of the record in e-space. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from <https://www.mmu.ac.uk/library/using-the-library/policies-and-guidelines>)

Reconciling communication repertoires: navigating interactions involving persons with severe/profound intellectual disability, a classic grounded theory study

A.-M. Martin,¹  T. Andrews,¹ J. Goldbart² & M. Landers¹

¹ School of Nursing and Midwifery, University College Cork, Cork, Ireland

² Department of Psychology, Manchester Metropolitan University, Manchester, UK

Abstract

Background A rights-based agenda, informed by the UNCRPD, that advocates person-centredness, inclusion, empowerment and self-determination is shaping service provision to people with intellectual disability (ID). Listening to their perspectives is fundamental to meeting these goals. However, communication with people with severe/profound ID is challenging and difficult. Therefore, this study aims to generate a theory that explains how people communicate with and understand each other in these interactions.

Methods Classic grounded theory (CGT) methodology was used as it recognises that knowledge can be captured rather than interpreted. According to CGT, capturing rather than interpreting experiences strengthens findings, particularly in relation to participants with severe/profound ID. Concurrent theoretical sampling, data collection and analysis were undertaken. Twenty-two individuals participated in the study: 3 people with severe/profound ID and 19 people with whom they

interact. Data were collected over a 9-month period and involved video recordings, field notes, individual and group interviews. Data were analysed using CGT methods of coding, constant comparison and memoing.

Results The Theory of Reconciling Communication Repertoires was generated. Nurturing a sense of belonging emerged as the main concern and core category that is resolved by reconciling communication repertoires. A communication repertoire refers to the cache of communication skills a person has available to them. To reconcile repertoires is to harmonise or make them compatible with each other in order to communicate. Interactions are navigated through five stages: motivation to interact, connection establishment, reciprocally engaging, navigating understanding and confusion resolution.

Conclusions The Theory of Reconciling Communication Repertoires explains how interactions involving people with severe/profound ID are navigated. While this is a substantive rather than formal theory, it has the potential to inform practice, policy, management, education and research as it outlines how communication with people with severe/profound ID can take place to design, inform and plan person-centred care.

Correspondence: Anne-Marie Martin, School of Nursing and Midwifery, Brookfield Health Sciences Complex, University College Cork, College Road, Cork T12 AK54, Ireland (e-mail: a.martin@ucc.ie).

© 2022 The Authors. Journal of Intellectual Disability Research published by MENCAP and International Association of the Scientific Study of Intellectual and Developmental Disabilities and John Wiley & Sons Ltd.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

Keywords classic grounded theory, communication, intellectual disability, interaction, learning disability

Background

A wealth of research surrounding communication with people with intellectual disability (ID) of varying levels (Brady *et al.* 2016; Lancioni *et al.* 2017; McCausland *et al.* 2017), in varying settings including home, education and healthcare (Ziviani *et al.* 2004; Boardman *et al.* 2014; Wilder *et al.* 2015) and with varying communication partners such as family members, education or health professionals (Lewis *et al.* 2017; O'Toole *et al.* 2018) exists. The challenges and difficulties of these interactions are well recognised and documented (Hughes *et al.* 2011; Johnson *et al.* 2012) particularly in relation to ambiguous and idiosyncratic communication methods. Communication difficulties are common among people with ID (Bonnike *et al.* 2018) but especially so for people with severe/profound ID who have limited ability to use a formal symbolic code and have inconsistent and ambiguous ways of communicating (Grove *et al.* 1999). In their study regarding the identification of pleasure and displeasure by people with profound intellectual and multiple disabilities, Petry and Maes (2006) discuss how level of ID, extent of motor limitations and severity of sensory impairments interfere with cognitive and communicative ability. It is, therefore, challenging to develop high-quality interactions (Neerinx & Maes 2016).

Additionally, there is consensus in the literature that communication partners of individuals with severe/profound ID find interactions challenging. Communicative attempts can be so idiosyncratic (i.e. behaviours and sounds have a meaning that is specific to that person) and subtle that they go unnoticed by communication partners (Porter *et al.* 2001; Wilder & Granlund 2003; Munde & Vlaskamp 2015). Furthermore, a communication signal can hold different meanings across individuals or across different situations for the same person (Hogg *et al.* 2001; Petry & Maes 2006; Munde & Vlaskamp 2015) such as a raised hand can hold a different meaning in school or at a social event. Familiar communication partners often construct meaning through close observation, inference, best guess or examination of

the antecedent and consequential effects of the communication attempt (Olsson 2004; Petry & Maes 2006).

These communication challenges create barriers to fulfilment of the rights of people with severe/profound ID to communicate, express themselves and understand those around them. These negatively impact their rights to inclusion and self-determination and hinder their empowerment. Person-centredness, choice, inclusion, respect and self-determination fundamentally require listening to the person. Furthermore, experiencing high-quality and successful interactions is a determinant of a good quality of life (Petry *et al.* 2007). Research to date adopts quantitative, qualitative and mixed method approaches that often accurately describe the nature or aspects of the interaction. There is, however, a significant lack of theory that explains the interaction.

Therefore, the aim of this study was to generate a theory that explains the methods and processes people use to communicate with and understand each other in interactions involving people with severe/profound ID. To meet this aim, the following objectives were set:

- 1 to identify people's main concern when interacting;
- 2 to discover the reasons for this concern;
- 3 to determine how this concern is addressed; and
- 4 to generate a grounded theory that explains how people with severe/profound ID and their partners communicate with and understand each other.

Design

Classic grounded theory (CGT) guided this study towards meeting its aim. CGT is at the quantitative/qualitative methodological interface (Taylor 2013) or as Glaser and Strauss (1967) assert, it is a general methodology. It aims to generate robust, reasoned theory using a range of quantitative and qualitative principles (Nicholls 2009). It offers a qualitative approach rooted in epistemological objectivity (Annells 1996). Importantly for this study, it is a means of generating theory about the psychosocial processes that present within human interactions (Streubart-Speziale & Carpenter 2011).

Classic grounded theory acknowledges individuality and the influence of different contexts and also recognises and captures patterns and commonalities in participant experiences (Glaser 1978; Foley & Timonen 2015). It is capable of rigorously guiding the study towards meeting its aim and yet is flexible enough to allow for multiple data collection methods that can gather the experiences and perspectives of all participants. Therefore, it enabled inclusion of people with severe/profound ID and significant communication difficulties as participants. Proxy reports raise questions around credibility, trustworthiness (Scott & Haverkamp 2018) and bias. Therefore, it was important to gather participants' experiences in a way that facilitated their means of communicating (i.e. non-verbal, behavioural means). CGT seeks to explain rather than interpret patterns of behaviour people use to address a concern (Vander Linden 2017). This is important to allay concerns regarding misinterpreting the experiences of participants with severe/profound ID in particular.

An important feature of CGT is the simultaneous and iterative process of theoretical sampling, data collection and analysis to enable the researcher to develop concepts and gather further data to elaborate and develop each concept (Elliott & Lazenbatt 2005). According to Glaser and Strauss (1967) and Glaser (1978), theoretical sampling involves concurrently selecting participants, collecting, coding and analysing data and then deciding where to collect data next based on the emerging theory. Importantly, Charmaz and Thornberg (2021) point out that theoretical sampling should not be confused with representative population sampling associated with quantitative research. The goal is theoretical saturation of the emerging concepts, which is reached when more data are gathered but no new properties or characteristics of the emerging concepts are found.

Analysis requires 'fracturing' and coding of the data with constant comparison and questioning of these fragments or behavioural incidents (Glaser 1978, p. 55) in order to move beyond description to the construction of explanatory concepts. Furthermore, ongoing memoing supports the developments of ideas around and relationships between codes and moves the theory from raw data to abstraction.

The implementation of these strategies will be detailed following an outline of the ethical procedures followed.

Ethics

Ethical approval was granted by University College Cork Social Research Ethics Committee and the Ethics Committees of both research sites. Decision-making was guided by relevant local, national and international policies and codes. All ethical obligations and responsibilities were upheld in this study, but the issue of informed consent to participate required particular consideration and planning.

Consent to participate

The need for informed consent is core to all ethical research studies. It protects participants' autonomy and recognises their right to receive adequate and appropriate information to make an autonomous decision to partake in a study (Halkoaho *et al.* 2016). Historically, people with ID have been considered unable to independently make decisions (Nind 2008). However, the National Disability Authority (NDA 2009) highlights the shift towards supporting them to make decisions under an ethos of dignity, autonomy and equality. It is recognised that there is much tension in the debate surrounding the capacity of people with an ID to give informed consent. Brooks and Davies (2008, p. 130) state that information may need to be absorbed over time with understanding reached by partaking in 'the doing' of the research. Therefore, proxy consent was sought from and provided by parents/siblings of participants with an ID. Proxy consent is not ideal but sometimes may be a necessary compromise (Nind 2008). According to Black *et al.* (2010) and De Vries *et al.* (2013), proxy consent requires assent or at least the absence of dissent from the person proxy consent is provided for. Those providing proxy consent were informed that should the person with ID indicate in any way that they did not wish to participate during a data collection period, data collection would be suspended. If this occurred on three occasions, this would be considered an expression of choosing to withdraw from the study. Exercising a choice to withdraw would supersede the proxy consent provided. During data collection, two participants with ID were intrigued by

and inspected the camcorder. When they saw a video of themselves played back, one smiled and the other clapped. This was considered an indication that they, at least, did not mind being recorded. This is in keeping with the Health Services Executive (HSE) National Consent Policy: Part 3 – Research (2013).

Potential participants without an ID were provided with information regarding the study in a face-to-face meeting and were given an information sheet and consent form with a return stamped addressed envelope. All potential participants took a few days to deliberate, and the majority consented to participate. Those who chose not to participate did so without judgement or consequence.

Participants and recruitment

Theoretical sampling was used to gather communication behaviours/incidents by inviting

individuals who commonly engage in these types of interactions to participate (Creswell 2007). This study required observations of interactions involving individuals with severe/profound ID. Therefore, it was decided to start by recruiting a person with severe/profound ID and their communication partners. Ben (pseudonym), who has a severe ID, was recruited first. Ben's parents, brother and sister-in-law, five support staff and one friend with mild ID in his service-based residence and activity centre/day service participated as his communication partners. Ben was identified in collaboration with a gatekeeper in the first research site. Gaps were identified in the data relating to the influence of severity of ID. Therefore, it was necessary to recruit a person with profound ID. Ben's sister, Rose (pseudonym), has a profound ID and was also included. Some people in Rose's network were also in Ben's. Consequently, inclusion of communication

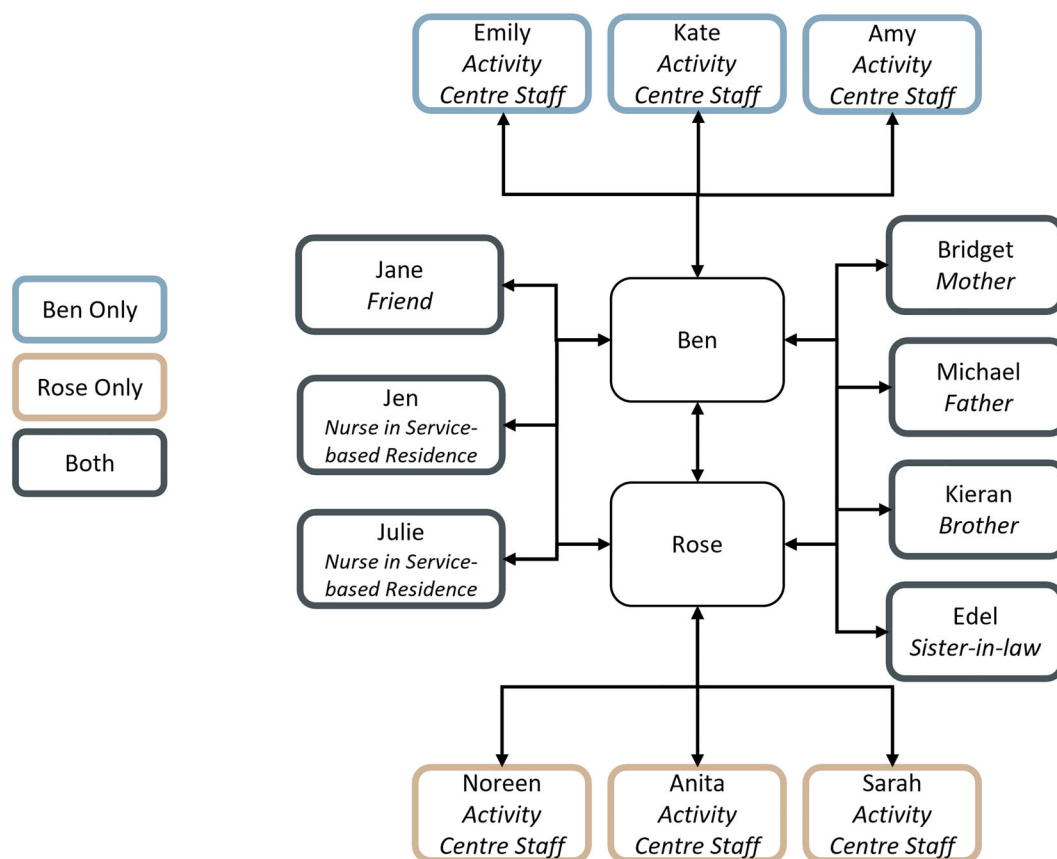


Figure 1. Sociogram for Ben and Rose.

partners from Rose's network expanded the sample by three (Fig. 1).

Including Rose provided opportunity to compare and analyse the influence of severity of ID (while remaining cognisant of interpersonal factors) on interactions. As Ben and Rose had communication partners in common, it was possible to observe and compare communication partners' practices with people of different intellectual ability. Furthermore, it provided opportunity to observe Ben and Rose interacting.

As data collection and analysis progressed, the need to theoretically sample for a participant with a severe/profound ID and physical disability became apparent. Ben and Rose used physical prompts, gestures or could move towards an object when making a request. Many people with severe/profound ID also have physical disabilities and, therefore, it was necessary to analyse interactions in this context. David (pseudonym), who has a profound ID and quadriplegic cerebral palsy, was recruited with the assistance of a gatekeeper in the second research site. Six people from David's network agreed to participate (Fig. 2). As David avails of services from a different provider, there were no participants in common with Ben and Rose's network.

The final sample totalled 22 participants: 3 people with severe/profound ID, Ben, Rose and David, and 19 people with whom they interact. It could be argued that a sample of three people with severe/profound ID

or two parents/family members is insufficient.

However, as per theoretical sampling, participant recruitment was indicated by gaps in the data and continued until saturation was reached. Gaps related to ability/disability in the data were addressed as discussed. However, the influence or nature of relationships did not emerge as a gap in the data. This was surprising but a subsequent review of the literature identified that experiences of communication partners are similar regardless of their relationship to the person with severe/profound ID. Therefore, in considering the sample of this study, it should be recognised that 45 video-recorded interactions were analysed (Table 1). These 45 interactions included 41 dyads plus 4 group (3–5 participants) interactions. The 41 dyads included each participant with ID and an interaction partner (26 pairings) as set out in the sociograms (Figs 1 and 2).

There is much debate regarding the definition and process of reaching saturation. However, O'Reilly and Parker (2012) assert that this debate only exists because the concept has been applied to other methodologies. When considered in the context of its origins, in CGT, there is less debate and confusion. Glaser and Strauss (1967, p. 62) set out the criteria for determining saturation as 'a combination of the empirical limits of the data, the integration and density of the theory and the analyst's theoretical sensitivity'. Therefore, judgement of saturation in this

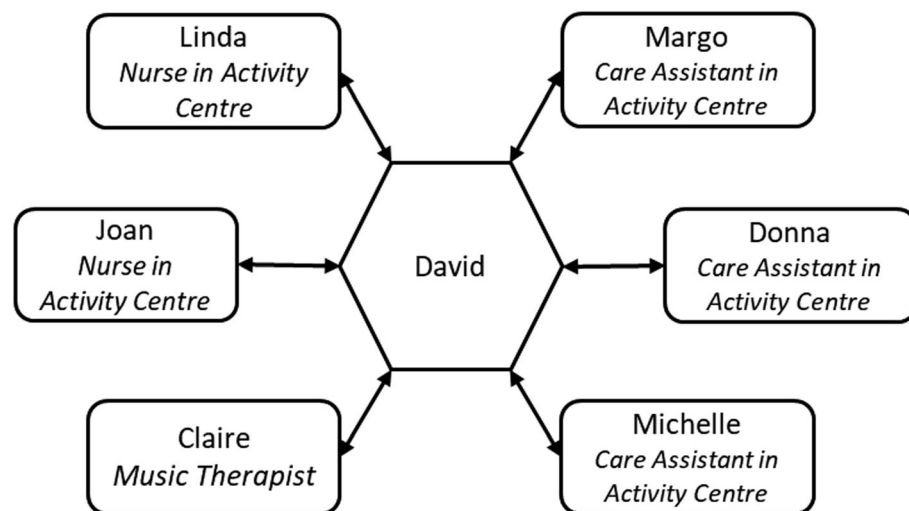


Figure 2. Sociogram for David.

Table 1 Observational data

Total number of recordings	27
Total recorded time	08:42:03
Total interaction time	00:17:11 (3.29%)
Shortest interaction	00:00:03
Longest interaction	00:11:45
Total number of interactions	121
Number of interactions analysed	45 (37%) (as saturation reached)

study was informed by these three criteria. Saturation was reached after analysis of 42 video-recorded interactions and 9 interviews. Three more video-recorded interactions were analysed after this to confirm saturation. As nothing new emerged, saturation was deemed reached.

Data collection

Data were collected using observations, field notes and semi-structured and unstructured interviews across multiple settings including participants' family homes, service-based residences and activity centres/day services. A key determinant of data collection methods was their ability to facilitate insight into the experiences of people who communicate non-verbally. As this group tends to communicate using non-verbal, behavioural means, participant observations were deemed most appropriate. Participant observations capture interactive behaviours that may be momentary or fleeting in real time but can be detected on play back and repeated viewings. Observations were openly recorded using a camcorder and field notes (Table 1).

However, observations are limited to capturing *what* people do (Robson & McCartan 2016). Therefore, interviews were used to capture *why* people act as they do: their motivations and perspectives (Rubin & Rubin 2012). Although participants' emotional experience was suggested in the observations, the interviews uncovered that experience (Pugh 2013). All interaction partners were offered the option of being interviewed. Eleven participated in either semi-structured or unstructured interviews. There were two group interviews with family members and seven individual interviews. Most interviews occurred before or after a recording period. Some were arranged at alternative times

convenient to participants. Participants who chose not to be interviewed did so due to time pressures and without judgement or consequence.

Data processing

Raw data and transcripts were stored, and password protected in accordance with university policy. A document for transcribing the videos was developed that enabled coding of behaviours, moments or incidents (Table 2). Participants' verbal and non-verbal behaviours were transcribed to a relevant column. The code for each behaviour was entered in a 'notes' column to the right of the transcript. Similarly, there was a coding or notes column on the interview transcripts. Field notes were appended to the corresponding transcript.

Data analysis

In keeping with CGT, collection and analysis of the observation, interview and field note data were concurrent. The goal of analysis in CGT is to capture and name patterns of behaviour: generating categories with properties and indicators that explain these behaviours (Glaser 1978). In other words, the unit of analysis in CGT is not people but behaviour. Thus, incidents of specific communication behaviours were sampled. Each individual recorded episode was watched to obtain a macro view of events. It was watched again, and individual interactions were identified and extracted from the recording. These excerpts were analysed in 3- to 5-s intervals with open coding of verbal and non-verbal behaviours of each person in the interaction. Approximately 40 labels or codes were initially generated such as 'choosing opportunities', 'preoccupied', 'mental multi-tasking', 'searching', 'specific effort', 'absence of responses' and 'attentive'. A conscious effort was made to use labels that accurately capture the behaviour/incident rather than using pre-existing concepts from the literature that could potentially misrepresent the identified behaviour. As analysis progressed, these codes were gradually refined and honed into concepts through selective coding, ongoing memoing and constant comparison. Selective coding involved exploring and augmenting the core category to uncover how it organises and integrates the theory (Gibson & Hartman 2014). Constantly comparing, revisiting incidents and memoing assisted in this

Table 2 Video transcript

Recording name: _____ Timing: _____ Clip title: _____										
PwID: _____ Comm. partner: _____										
Verbal content					Non-verbal content					Notes
Comm. part.					Comm. part.					
Time	PwID	Name 1	Name 2	Name 3	PwID	Name 1	Name 2	Name 3		
00:00:03										
00:00:06										
00:00:09										
00:00:12										
00:00:15										
00:00:18										
00:00:21										
00:00:24										
00:00:27										
00:00:30										
00:00:33										
00:00:36										

process. Memos became more focussed and, as discussed above, gaps were identified that informed theoretical sampling.

Emergence of the core category

Initially, 'being connected' appeared to be the core category. However, constant comparison highlighted issues that were incomplete or insufficiently addressed as well as issues around fit. Data collection and analysis was delimited to informing development of the core category and its related concepts. The emergence of acquiescence was a turning point in data analysis. Acquiescence was intriguing because understanding was not reached, and misunderstanding was not addressed yet interactions continued. Incidents were compared to explore why understanding did not matter. An initial code of 'being with' explained this behavioural pattern. This later became *nurturing a sense of belonging*. This was participants' main concern that is resolved by reconciling communication repertoires, essentially, the core category of the theory. This was identified as the core category as it explains variability in

behavioural patterns and connects all other categories and their properties. It integrates the theory.

Over time, analysis progressed to theoretical coding where the theoretical framework (or what CGT refers to as the theoretical code) emerged. Strategising emerged as the theoretical code for this CGT as participants actively and consciously choose and adjust their communication methods throughout the process to meet their interaction goal. This method enabled careful development of a detailed theory grounded in the data.

Results

The core category of this theory is 'nurturing a sense of belonging'. This is participant's motivation to interact. In CGT terms, this is the core concern of the participants that they are trying to resolve. The core strategy used to resolve this concern is to 'reconcile communication repertoires'. To reconcile repertoires is to harmonise or make them compatible with each other in order to communicate and interact. This concern and strategy are evident at each stage of the theory and thus augment their status as core to the theory. Cognisant of this, an overview of the emergent

theory, Theory of Reconciling Communication Repertoires (TRCR), follows.

Overview of the Theory of Reconciling Communication Repertoires

The TRCR (Fig. 3) is a substantive theory that sets out the strategies people use to communicate in interactions involving people with severe/profound ID. While this theory presents a micro-level analysis, two overarching findings should be noted.

Firstly, the TRCR highlights that understanding is not always the interaction goal. Often it is about nurturing a sense of belonging.

Secondly, while recognising the diversity of communication repertoires, the theory notes all individuals, people with severe/profound ID and their partners, use the same strategies to navigate interactions. The range of the persons' repertoire influences the extent to which they can reconcile. A wider repertoire indicates greater availability of communication skills to draw from. Therefore, this TRCR sets out the strategies, both people with severe/profound ID and their partners use to interact.

The TRCR comprises a core category of *reconciling communication repertoires* with five distinct stages or sub-core categories: *motivation to interact*, *connection establishment*, *reciprocally engaging*, *navigating understanding* and *confusion resolution*. While presented linearly, it is clear this is an evolving process of strategic navigation shaped by the outcomes of each stage.

Reconciling communication repertoires

Reconciling communication repertoires is the core strategy used to nurture a sense of belonging (the core category, see stage 1: motivation to interact) and resolve difficulties encountered throughout the interaction. A communication repertoire is a cache of communication skills and aptitudes the person can draw on when interacting. This is how and why this theory highlights abilities rather than disabilities.

Successful interactions require individuals to reconcile their communication repertoires by adopting strategies that complement their communication partner's repertoire. This is difficult, but usually informed by experiential knowledge gained through previous interactions. Greater reconciliation responsibility tends to be placed on individuals with a wider repertoire, due to greater availability of skills/strategies to draw from. This is not to suggest individuals with a narrower repertoire are unable to reconcile. Rather, the extent of individuals' repertoire influences the extent to which they can reconcile.

The extent of the communication repertoire fluctuates as the interaction progresses and roles evolve. Different skills and strategies are required at different stages. For example, a wider repertoire of expressive strategies enables greater scope to reconcile with a partner's receptive repertoire and vice versa.

The rotation of roles between sender and receiver and corresponding shift between repertoires adds to

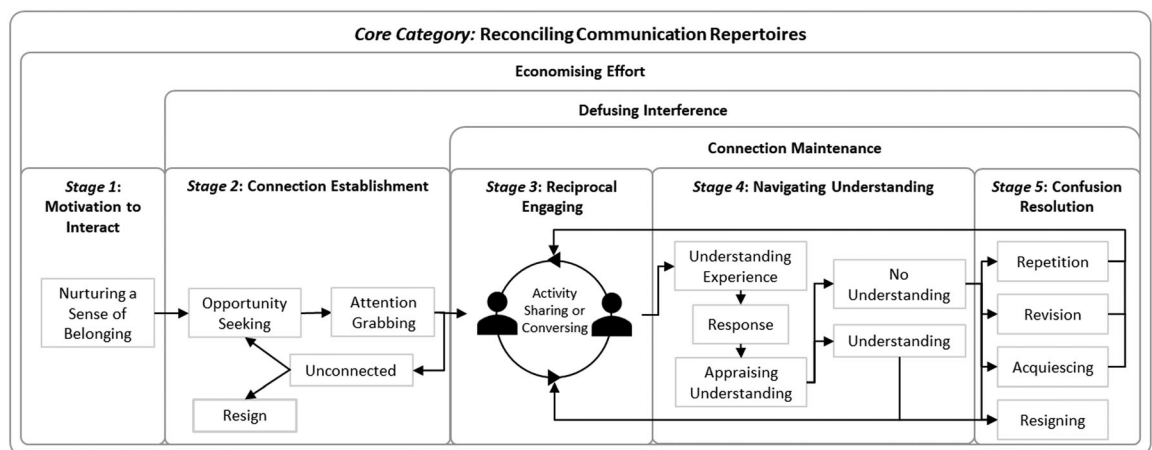


Figure 3. Theory of Reconciling Communication Repertoires.

the effort demand of these interactions. Individuals manage this by economising effort. As illustrated in Fig. 3, effort is a condition influencing each stage of the interaction.

Economising effort

Economising effort is a condition that influences a person's actions. The effort demanded to interact successfully is a consideration for both people with severe/profound ID and their partner. Effort demand increases in parallel to a widening disparity between communication repertoires. A narrower communication repertoire is aligned with experiencing shorter and/or less frequent interactions. Effort demand is considered alongside motivation strength and most probable outcome. The appeal of potential/actual interferences, interaction complexity and presence of demands external to the interaction are considered. An interference is any factor that disturbs the interaction such as environmental, personal and/or interaction-related factors. Interaction complexity refers to the extent of reconciliation required to successfully navigate the interaction. Demands are those factors that are competing for priority against the motivation to interact such as time constraints or workload/tasks. Effort demand increases with the presence of each of these factors.

People will walk away from them too because they ... are not getting through to them ... they feel that they are not going to understand anyway so why bother. (Bridget, Ben and Rose's mother)

Furthermore, the effort demand can countereffect the duration and/or frequency of interactions. High effort interactions tend to be shorter as resignation is more likely. However, stronger motivation and/or probability of success aligns with higher likelihood of expending effort.

Stage 1: motivation to interact

Concerns regarding isolation and loneliness due to short, infrequent interactions stir a desire to interact. This emerged as the main concern resolved by reconciling communication repertoires. Interaction partners do not know if the person with ID feels isolated/lonely. However, they conclude that short,

infrequent interactions coupled with a narrow communication repertoire increase susceptibility to isolation and loneliness.

... that's all anybody wants in life is to be accepted and be included Every one of us needs that ... that's a very normal thing to want ... to be accepted and to be included It's part of humanity really (Bridget, Ben and Rose's mother)

To alleviate these concerns, a conscious effort is made to interact. In this study, attempts by both individuals with ID and their partners to interact tended to follow an extended period without interaction, suggesting a motivation to nurture a sense of belonging. The hope, for interaction partners, is that feelings of isolation will be alleviated for the duration of the interaction as a minimum.

... it's about here and now and being. Being with somebody. It's not all about tomorrow (Claire, David's music therapist)

Stage 2: connection establishment

Stage 2 of TRCR comprises two subcategories of connection establishment and its subsequent maintenance. Establishing a connection is critical. Without it, there is no interaction, and a sense of belonging cannot be nurtured. Connection establishment comprises two distinct strategic actions: opportunity seeking and attention grabbing.

Opportunity seeking. Opportunity seeking involves waiting and monitoring for a favourable moment to attention grab. In doing so, the person is economising effort (Fig. 4). The length of time spent opportunity seeking is varied by the presence of interferences. Low interference appeal lessens the time as it is effort efficient to act. The more appealing the interference, the more time spent opportunity seeking.

Interfering variables are considered against the likelihood of successfully attention grabbing. If interference appeal is too strong, one of three strategies will be adopted. The person may resign and not establish a connection. Alternatively, they may opportunity seek until the interference passes. Thirdly, they might interrupt the interference by using a more appealing attention grab.

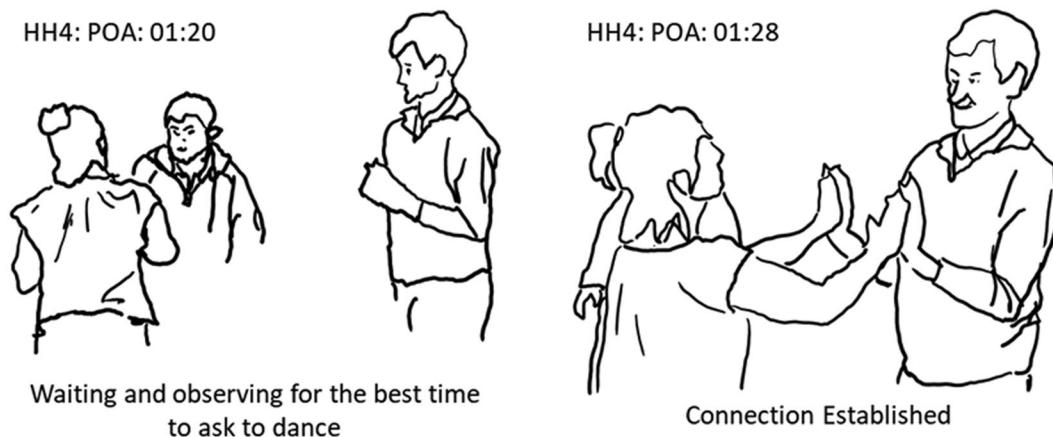


Figure 4. Opportunity seeking.

Attention grabbing. An effective attention-grabbing action draws the partner's attention and establishes the connection such as speaking/vocalising, touch. The attention grab may not relate to the interaction motivation. Its only purpose is to establish a connection.

It must, however, appeal to the partner and/or hold greater appeal than any interference. This is key to successfully establishing a connection. Overt methods have inherently high attention-grabbing appeal. As attention-grabbing methods become more subtle, their appeal factor reduces accordingly. Hence, a repertoire of low appeal methods raises the challenge of attention grabbing. However, a wider repertoire does not imply less difficulty. If the partner's receptive repertoire is narrower, the challenge of reconciling is raised.

If the attention grab fails to establish a connection, the person may opportunity seek again, repeat the attention grab or try an alternative method. Trying again indicates the motivation strength. The person may resign if the interference is deemed too powerful or the repertoire disparity too wide to reconcile. Essentially, the effort demand is too high. If alternative attention-grabbing methods are available, resigning may indicate low motivational strength.

Establishing a connection is a critical juncture as an interaction cannot occur in its absence. Therefore, progressing to stage 3, reciprocal engagement, requires successful establishment and maintenance of the connection.

Connection maintenance

Maintaining the connection is prioritised through the remainder of the interaction. The connection brings about the sense of belonging and provides the platform for reciprocal engagement. The difficulty of maintaining it is amplified by its delicacy and fragility. Disconnection can occur at any point, including as soon as it is established. Connection strength fluctuates throughout the interaction along a continuum (Fig. 5) ranging from 'connected' through 'connection jeopardising' to 'disconnected'.

A strong connection exists when both people are concurrently attending to each other or a common interest and reciprocally engaging. It is sustained while the engagement activity is appealing and effort efficient. The presence of interference, a rise in effort demand or waning motivation jeopardises the connection. Interference is caused by environmental, personal and/or interaction-related factors. Environmental factors include distractions external to the interaction that interrupt or interfere with its progression such as one person being called, a sudden sound or the presence of someone/something of interest. Personal factors are individual characteristics that jeopardise the connection such as breadth of communication repertoire, transient factors such as attention and enduring factors such as cognitive and/or physical variables.

It happens an awful lot where you want, you want to say something to Rose or Ben and they are ...



Figure 5. Connection continuum.

you look at them and you say Oh look she's there looking for her belts. There's no point saying anything to her now. (Michael, Ben and Rose's father)

Interaction-related factors relate to the interaction itself. These include uncomfortable pacing or unappealing reciprocal engagement activity. Although the connection is maintained, these interferences must be defused by raising the appeal of the engagement activity or removing the interference.

Disconnection, either purposeful or non-purposeful, occurs when the individuals are not attending to each other. A purposeful disconnection or resignation occurs when the person is in control of the disconnection. S/he decides to resign from the interaction because the motivation is fulfilled, and/or the interaction reaches its natural end. It may be that one person does not want to interact and so disconnects. Alternatively, the effort demand to continue may be too high. A non-purposeful disconnection is not controlled by the person. The motivation to interact is unmet but an unmanaged interference caused the disconnection. Strategically, the person may opportunity seek again or resign if re-establishing the connection is effort inefficient.

If the person selects to continue the interaction, defusing interference is just one strategy to maintain a connection. Reciprocal engagement (stage 3) also supports connection maintenance.

Stage 3: reciprocally engaging

Reciprocally engaging is a dual-purpose strategy that maintains the connection and nurtures a sense of belonging. Connection maintenance and reciprocal engagement are symbiotic and intrinsically linked. If the reciprocal activity has insufficient appeal, the connection is jeopardised. If there is no connection, reciprocal engagement cannot occur. Therefore, it is advantageous to adopt an appealing, effort efficient reciprocal engagement method.

Activity sharing. Activity sharing is particularly effective in nurturing a sense of belonging and achieving understanding. The need for spoken language is reduced, thus reducing the effort demand and the repertoire disparity. Being present together and/or co-operatively contributing to the activity nurtures a sense of belonging. Participation can occur on a parallel or collaborative basis. Parallel participating is indicated by engaging in the same activity but independently of each other. Collaborative participating involves engaging in an activity that requires co-operation and/or turn-taking.

Routine/patterned activities increase probability of understanding, thus strengthening the connection and lowering the effort demand. Understanding is supported through predictability of and familiarity with routines. This method does require a repertoire for retention and recall.

Predictability is enhanced by high pattern consistency or the extent to which a routine's procedure is the same from one occasion to the next, thus increasing the chances of understanding. Inconsistency causes confusion.

Familiarity is supported by high experiential frequency, thus supporting understanding. Experiential frequency relates to how often the person is involved in the routine.

Ben does an awful lot of observation ... I think an awful lot of times when he understands you it's based on what he is observing rather than what he is hearing. (Michael, Ben and Rose's father)

Conversing. A second commonly used engagement strategy, conversing, is more challenging and complex. Reconciling repertoires is difficult and evidenced by infrequent understanding achievement (Fig. 6). Rotation of roles between sender and receiver adds to the effort demand. Repertoire disparities can relate to expression, attention, reception, interpretation, imagination, understanding and connection maintenance. Therefore, conversing strategies must be prudently and carefully selected to



Figure 6. Misunderstanding in conversation type of interaction.

maintain the connection and manage the effort required.

Individuals use different strategies to converse. Conversing strategies must be prudently and carefully selected to maintain the connection. Three conversing strategies, subtle hinting, multi-messaging and routine conversing, are now presented. Subtle hinting and multi-messaging tend to be problematic strategies. Routine conversing can be more successful to nurture a sense of belonging and achieve understanding.

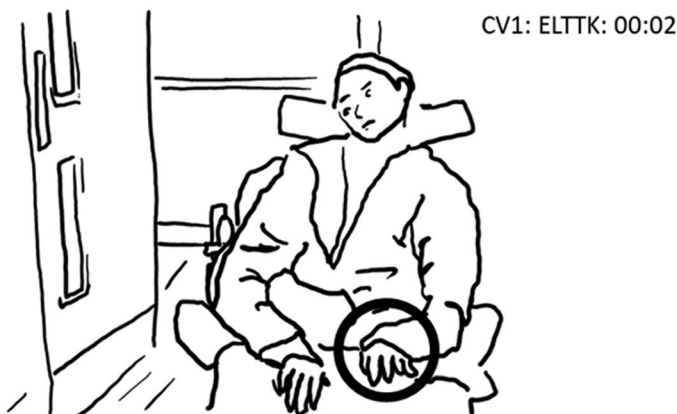
Subtle hinting. Individuals with a narrower expressive repertoire tend to use unconventional and/or subtle expressive methods. Subtle hinting (Fig. 7) is particularly problematic. A subtle hint has two main properties. Firstly, it is not a close representation of the intended message. Secondly, it is easily missed or unrecognised. This directly impacts one's chance of being understood due to increased scope for misinterpretation and/or reduced probability of recognition. However, subtle hinting can work when the partner is familiar with and sensitive to their meaning. In other words, if this sensitivity is in the partner's receptive repertoire, a mutual communication space can be found.

Multi-messaging. Difficulties not only relate to narrow repertoires. A broader expressive repertoire brings about its own challenges. This is because the availability of multiple expressive methods can result in the use of multiple expressive methods.

Multi-messaging (Fig. 8) occurs when two or more messages are inadvertently conveyed: one intentionally (e.g. verbally) and the remainder unintentionally (e.g. a hand gesture). People with a wider communication repertoire tend to multi-message more frequently because they have more skills available. The partner receives, interprets and responds to the expressive method that is closer to the mutual communication space and their receptive repertoire. If this is the unintended message, confusion ensues.

Subtle hinting and multi-messaging are not conducive to connection maintenance, achieving understanding or nurturing a sense of belonging. They both usually imply the conversation is occurring on the peripheries of or outside the mutual communication space. This jeopardises the connection, causes confusion and is effort inefficient. While these strategies demand much effort, one conversing strategy, routine conversing, is particularly successful at nurturing a sense of belonging.

Routine conversing. As with routine activities, the predictability and familiarity of routine conversing support understanding and connection maintenance. It involves following a similar or possibly identical dialogue several times a day or a week. The topic is usually subjectively appealing and had a positive outcome previously. The content is irrelevant but powerful for reciprocal engagement, connection maintenance and nurturing a sense of belonging. As it



David looked towards staff in the kitchen, stretching his fingers on his left hand and raising it slightly. He tried a second time but still did not attention grab. He revised his method by adding a low, short vocalisation. The staff member responded. David's initial method of grabbing attention was too subtle to be recognised by his interaction partner.

Figure 7. Subtle hinting.



Rose turns away when Jen puts out her hand. Although Jen is asking Rose to slow down, her body language and gestures could indicate she is about to take the glass from Rose.

Julie: You ok? Are you watching the telly?
 Rose: [Doesn't move or reposition but holds eye contact with her; no change in facial expression; looks Julie up and down; breaks eye contact]
 Julie: Are you? Were you at home with Daddy?
 Rose: [Looks to the TV and around the room]
 Julie: Go out with the cows?
 Rose: [Looks around the room and quickly makes eye contact with Julie when she mentions cows]
 Julie: Were you?
 Rose: [Holds eye contact with Julie]
 Julie: Well? Were you milking cows?
 Rose: [Looks to Julie and holds eye contact]
 Julie: Were you having a good time?
 Rose: [Looks down to the belts and then back up to Julie, small smile]
 Julie: Oh the smile ... were you having a good time? You were, weren't you?
 Rose: [Looks at Julie and continues to smile]

Figure 8. Multi-messaging.

is rehearsed and proven, and the mutual communication space is already established, it is effort efficient.

(Routine conversation between Julie and Rose that was repeated on three separate video-recorded occasions over 1 week)

In short, conversing is a more challenging method of reciprocally engaging than sharing activities.

However, if the repertoires are reconciled to a mutual communication space, a sense of belonging and connectedness can be achieved. Although understanding may not occur to the same extent while conversing rather than sharing activities, its achievement strengthens the connection and sense of belonging further.

Stage 4: navigating understanding

Navigating understanding is the fourth stage of this theory. Two distinct understanding viewpoints are recognised: firstly, understanding as experienced and, secondly, understanding as appraised.

Experiencing understanding. Understanding a person's expressive behaviours involves two stages: message recognition and jigsawing clues. This distinction is important as a message must be recognised before it can be interpreted. Difficulty with either or both skills result in non-achievement of understanding.

Message recognition happens concurrently with message expression. It involves attending to expressive behaviours and recognising that these hold meaning. There are three potential outcomes of message recognition: the intended message is recognised and received; an unintended message is recognised and received; or no message is recognised, hence none received. Jigsawing clues can only take place if a message is recognised.

Jigsawing involves piecing these clues together creating a picture from which meaning is drawn. Once meaning is drawn, it is reviewed for probability of accuracy. A strong correlation between the interpretation and the environment strengthens the assumption of correct understanding.

This theory delineates five ways understanding can be experienced (Table 3): correct understanding, oblivious understanding, cognisant confusion, oblivious misunderstanding or no understanding.

Correct understanding occurs when the message is interpreted as intended. The probability of accurate interpretation is high. Oblivious understanding is indicated when the correct meaning is drawn but there are concerns regarding interpretation accuracy. The message may be expressed out of context causing doubt such as asking persons if they would like something to eat while in a music room. Cognisant confusion arises when the meaning drawn is not as intended but the misunderstanding is recognised. Oblivious misunderstanding occurs when the meaning drawn is not as intended but this is not recognised. The interpretation is thought to be accurate. No understanding is indicated when no meaning is drawn.

The type of understanding experienced is unknown to the sender until a response is provided. This response is used to appraise understanding. Although several types of understanding are experienced, understanding is appraised as achieved or not.

Appraising understanding. Understanding is appraised by attending to the response and based on two criteria: response fit and response delay (Table 4).

Response fit refers to the extent to which the response relates to the intended message. If the response fits, understanding is assumed. If the response is deemed non-fitting, no understanding is assumed. Seeking clarification or expressing confusion is considered a fitting response. In other words, if understanding is not achieved, it is fitting to express this.

Response delay refers to the length of time between message expression and receiving a response. A faster response is aligned with an increased likelihood of understanding. This appraisal method is less accurate as a fast response can occur with oblivious misunderstanding. A delayed response signposts difficulty. It suggests a requirement for more time to understand. An extended delay indicates a non-

Table 3 Typology of understanding

	Aware	Unaware
Correct meaning drawn	Understanding	Oblivious understanding
Incorrect meaning drawn	Cognisant confusion	Oblivious misinterpretation
No meaning drawn	No understanding	

response. A disconnection may have occurred. Alternatively, if the connection is maintained, no understanding is assumed except for one situation. When a choice is offered, a non-response may be interpreted as contentment with the status quo; understanding is assumed. The 'non-response' fits with the intended message; choosing to remain as is.

If understanding is appraised, reciprocal engagement will continue, or the interaction will end through resignation. In circumstances of misunderstanding, confusion resolution may be necessary.

Stage 5: confusion resolution

Confusion resolution is only required in contexts of misunderstanding or no understanding. Effort efficiency and motivation strength determine if it will be attempted. Repertoire reconciliation skills are tested in this scenario.

If the communication repertoire allows, the communication method might be revised or modified. Revising requires awareness of the problem causing confusion so it can be amended. However, a fundamental problem is that the original method is usually selected because it is deemed most suitable. Therefore, when this is unsuccessful, the second-choice method may be less suitable. Furthermore, changing methods necessitates the availability of an alternative. This can significantly hamper individuals with a narrow repertoire.

If an alternative method is unavailable, the person may choose to repeat the original method perhaps with greater intensity to magnify the message (Fig. 9). This highlights the significance of having a narrower repertoire. Strategic options to resolve confusion may be limited.

Sometimes, confusion resolution is not attempted as the person may decide to acquiesce to the

Table 4 Matrix of appraising understanding

		Response fit	
		Fitting response	Non-fitting response
Response delay	Fast/prompt response	Understanding	No understanding
	Delayed response	Understanding	No understanding
	Non-response	Understanding	No understanding/disconnect

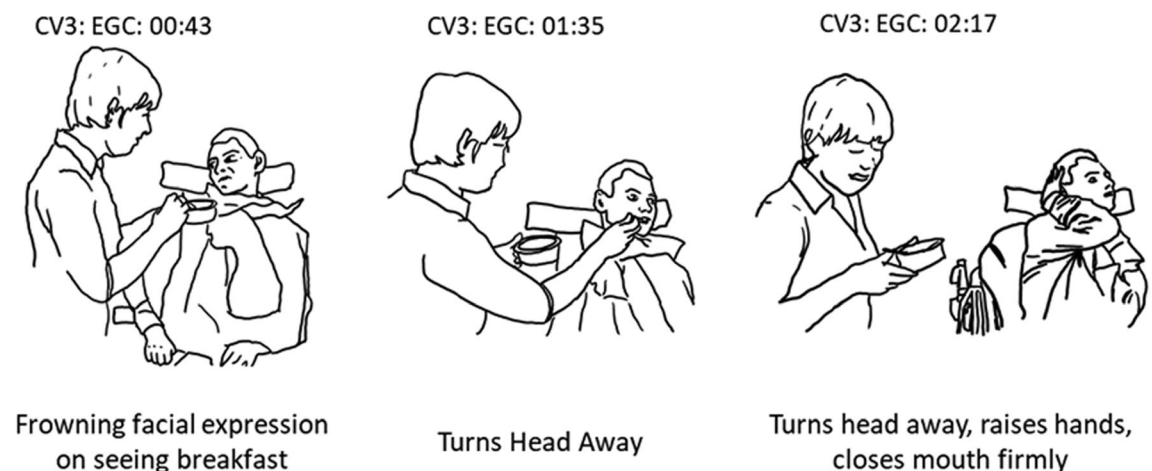


Figure 9. Revising/modifying by increasing intensity.

misunderstanding or resign from the interaction. Acquiescing (Fig. 10) demonstrates that resolving confusion is not necessarily about achieving understanding. It is used when understanding is unnecessary and the motivation to nurture a sense of belonging is high. A choice is made to avoid jeopardising the connection by attempting to resolve confusion. Instead, the misunderstanding is acquiesced to as the reciprocal engagement is maintaining the connection. Attempting to achieve understanding is deemed too risky. Acquiescing is a successful way of managing confusion, maintaining a connection and nurturing a sense of belonging because the process is more important than understanding.

Resigning is another strategy adopted in the absence of understanding. Resignation may occur because the motivation is fulfilled, or the interaction reaches its natural end. Alternatively, to economise effort, the person may choose to resign because the effort demand is too high.

You want to say something to Rose or Ben ... you look at them and you say There's no point saying anything to her now. You do not bother. (Michael, Ben and Rose's father)

Regardless of the reason for choosing this strategy, resigning will end the interaction.

Discussion

This CGT study examined interactions involving people with severe/profound ID. The emergent

TRCR explains how people navigate these interactions. It presents a five-stage process moving from motivation to interact to establishing a connection, reciprocally engaging, navigating understanding and confusion resolution. Successful interactions rely on effectively reconciling communication repertoires and maintaining the connection on which the interaction occurs.

Key to successfully reconciling repertoires is recognition of ability rather than disability. This is in keeping with Griffiths and Smith (2017) who asserted that one of the most important ideas to emerge from their study is that people with severe/profound ID can and do communicate and their communication is comprehensible and interpretable. Bunning *et al.* (2013) also found that, despite their severely limited communication repertoire, students with profound intellectual and multiple disabilities were able to contribute to the interactions. However, a repertoire disparity was recognised, and it was noted that staff dominated interactions.

This TRCR also supports Griffiths and Smith's (2016, 2017) finding that the difference in breadth of communication repertoires is the single factor that distinguishes this type of interaction from others and has most influence on navigating the interaction. Griffiths and Smith (2016, p. 124) describe the difference as a 'communication gulf' highlighting the resultant high frequency of misunderstanding, concurring with the present study. Neerincx and Maes (2016, p. 574) discuss 'harmonization among behaviours' in relation to the two-way process of finding joint attention. Griffiths



Figure 10. Acquiescing.

and Smith (2016) and Neerinckx and Maes (2016) agree that the extent to which this calibration, attuning or harmonisation is achieved determines the quality and success of the interaction.

The TRCR refers to the process as *reconciling* to reflect the continuous fluctuations in and need for responsivity to unpredictable variables (e.g. attention, interference and expressive/receptive abilities) throughout the interaction. This study found that a single adjustment is insufficient to lay a foundation for successful interaction. Rather, it is a continuous and dynamic navigation through multiple variables during the entire interaction. Therefore, the TRCR extends these findings by recognising the unstable and shifting nature of attunement and harmonisation. Furthermore, it illustrates that even if reconciliation is unsuccessful, the interaction can continue through acquiescence. This is important because it demonstrates that interactions can occur in the absence of attunement or harmonisation and in the presence of a strong motivation.

The main motivation identified in this study was nurturing a sense of belonging. Having a sense of belonging is recognised as a basic human need (Maslow 1943). Its importance is recognised repeatedly in the literature including as a core dimension of quality of life (Petry *et al.* 2005; Hostyn *et al.* 2011) and foundational in supportive, social relationships (Beauchamp & Anderson 2010). Individuals with narrower communication repertoires experience greater difficulty establishing and maintaining interactions, causing considerable concern for those in their network. This concern has been echoed in the literature for decades (Krauss & Erickson 1988; Kennedy *et al.* 1990; Krauss *et al.* 1992; Robertson *et al.* 2001). Research identifies that people with severe/profound ID have few social relationships and these are mostly with family members and paid workers (Kamstra *et al.* 2015). McLean *et al.* (1996) identify the characteristic communication difficulties as contributing to this situation.

Strengths and limitations

The outcome of this study is a theory based on conceptualisation. While this is an advantage in some regards, others have highlighted that conceptual theories do not capture individual experiences or

perspectives (Richards & Farrokhnia 2016). There is no claim of offering individual perspectives, rather an explanation of their interactive behaviours is provided.

Further, this is not a formal theory but a theory relating to one substantive area developed using CGT methodology. Similarly, we recognise that only three people with severe/profound ID were included. Application to other contexts, situations or groups requires further research. Work continues on developing this theory with a view to theoretically sampling for more diversity of participants and dyads including range of abilities, relationship type and environments. Although the literature reviewed for this study indicates this may not make a considerable difference, it is important this work continues to be developed. This is in keeping with the CGT methodology quality criterion of modifiability.

Additionally, as the TRCR is a CGT, we do not claim generalisability to communication for all people with severe/profound ID. Instead, we hope that the theory holds relevance to individuals and their partners. By relevance, we mean as it is put forward by Glaser and Strauss (1967) as one of four measures to assess the quality of a CGT. Glaser and Strauss (1967, p. 239) contend that a 'grounded substantive theory ... will make sense and be understandable to the people working in the substantive area'. This understanding sensitises individuals to the problems they face and offers an opportunity to understand how they, potentially, can make their situation better. This was the fundamental reason for undertaking this study. People involved in interactions of this nature are challenged daily to connect with each other. It is hoped this theory will offer insights to how their experiences can be improved.

The study is further strengthened by the meaningful inclusion of people with severe/profound ID as participants. The methodology was selected due to its ability to guide the study towards meeting its aim, which included gaining insight into the experiences of people with a severe/profound ID. Including this group as participants in research has been noted as difficult. Coons and Watson (2013) discuss the ethical and practical implications of including participants with ID in qualitative research. However, despite these challenges, it is particularly important that this group is included in research that explores their experiences and efforts are taken to

avoid proxy reporting. Lloyd *et al.* (2006) assert the value of gaining experiences and perspectives from an individual directly. This study is an example of how people with severe/profound ID can participate in research and the value of their contribution to research and knowledge. Their inclusion in this study strengthens the findings as issues related to proxy reporting do not apply.

In line with this, one of the strengths of this study lies in the rigorous adherence to CGT methods. The theory generated captures and explains what happens in these interactions. It is a parsimonious integration of rich and dense concepts that have the potential to inform practice, policy, research and education.

Implications

In a landscape where person-centredness, quality of life, choice, self-determination and rights are emphasised and advocated across policy, practice, education and research, measures must be taken to ensure they are realised in individuals' lives. The TRCR identifies that this population has abilities that are unrecognised and/or underestimated. Some authors argued that inappropriate responses are exacerbating existing disabilities (Grove *et al.* 1999; Halle *et al.* 2004; Bunning *et al.* 2013). Therefore, one of the key recommendations emerging from this study is that policies shaping supports provided to individuals with severe/profound ID are developed through a lens that recognises ability and seeks to maximise not only potential but maximise ability. The findings of this study can inform practice by supporting understanding and awareness of the nature of interactions, the facilitators and barriers to successful interactions and understanding attainment. It also offers insights to the experiences of persons with severe/profound ID. Similarly, education and training of communication partners has the potential to support their personal development, including confidence, during interactions; develop and maintain skills; and, consequently, improve the quality of life of people with ID (Healy & Noonan Walsh 2007). A training programme developed in collaboration between third-level educational institutes, service providers and advocacy groups that increases staff awareness of their non-verbal communication methods and

sensitivity to subtle communication methods is recommended.

Work on developing this theory continues with a view to theoretically sampling for more diverse abilities, disabilities, relationship types and environments. Further, the TRCR explains the strategies people use to navigate interactions involving people with severe/profound ID. In so doing, it has highlighted areas that warrant further exploration and research. People with severe/profound ID experiencing short and infrequent interactions are a particular concern. Further study is warranted to identify and create opportunities to increase the frequency of interactions. This study identified some barriers and facilitators during interactions. However, research that specifically focuses on the barriers and facilitators to the frequency of interactions, strategies to break those barriers and to augment and strengthen those facilitators is required. In this study, for example, the competing variables of effort and time demands were found to influence the frequency of interactions. This is in keeping with Felce *et al.* (1991) and Felce and Perry's (1995) findings from almost 30 years ago where higher staff : individual ratios did not impact on frequency of interactions due to the intensity of support needs. Similarly, participants in Forster and Iacono's (2008) study, over 10 years ago, reported that organisational policy and practices were a barrier to their preferred methods of interacting. Research is required that will provide guidance to policy developers and organisations on removing systemic barriers to interpersonal interactions.

Conclusion

This study explains how people communicate with and understand each other in interactions involving people with severe/profound ID. It was undertaken to increase knowledge and understanding of these interactions against a backdrop of a rights agenda and policies and strategies aiming to improve individuals' quality of life. Principles of person-centredness, inclusion, empowerment and self-determination underpin these agendas. The TRCR generated adds to existing knowledge and evidence supporting these endeavours.

Acknowledgement

Open access funding provided by IReL.

Source of Funding

No external funding was received for the research reported in the paper.

Conflict of Interest

No conflicts of interest have been declared.

Data Availability Statement

Data are not shared.

Ethical Approval Statement

Ethical approval was granted by the University Social Research Ethics Committee and the Ethics Committees of both research sites.

References

- Annells M. (1996) Grounded theory method: philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research* **6**, 705–13.
- Beauchamp M. H. & Anderson V. (2010) SOCIAL: an integrative framework for the development of social skills. *Psychological Bulletin* **136**, 39–64.
- Black B. S., Rabins P. V., Sugaraman J. & Karlawish J. H. (2010) Seeking assent and respecting dissent in dementia research. *The American Journal of Geriatric Psychiatry* **18**, 77–85.
- Boardman L., Bernal J. & Hollins S. (2014) Communicating with people with intellectual disabilities: a guide for general psychiatrists. *Advances in Psychiatric Treatment* **20**, 27–36.
- Bonnike D. R., Douglas K. H. & Stoner J. B. (2018) Social positioning: increasing the nonsymbolic and symbolic communication of students with complex communication needs. *International Journal of Special Education* **33**, 152–70.
- Brady N. C., Bruce S., Goldman A., Erickson K., Mineo B., Ogletree B. T. *et al.* (2016) Communication services and supports for individuals with severe disabilities: guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities* **121**, 121–38.
- Brooks M. & Davies S. (2008) Pathways to participatory research in developing a tool to measure feelings. *British Journal of Learning Disabilities* **36**, 128–33.
- Bunning K., Smith C., Kennedy P. & Greenham C. (2013) Examination of the communication interface between students with severe to profound and multiple intellectual disability and educational staff during structured teaching sessions. *Journal of Intellectual Disability Research* **57**, 39–52.
- Charmaz K. & Thornberg R. (2021) The pursuit of quality in grounded theory. *Qualitative Research in Psychology* **18**, 305–27.
- Coons K. D. & Watson S. L. (2013) Conducting research with individuals who have intellectual disabilities: ethical and practical implications for qualitative research. *Journal on Developmental Disabilities* **19**, 14–24.
- Creswell J. W. (2007) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, 2nd edn. Sage, Thousand Oaks.
- De Vries R., Ryan K. A., Stanczyk A., Applebaum P. S., Damschroder L., Knopman D. S. *et al.* (2013) Public's approach to surrogate consent for dementia research: cautious pragmatism. *The American Journal of Geriatric Psychiatry* **21**, 364–72.
- Elliott N. & Lazenbatt A. (2005) How to recognise a 'quality' grounded theory research study. *Australian Journal of Advanced Nursing* **22**, 48–52.
- Felce D. & Perry J. (1995) The extent of support for ordinary living in staffed housing: the relationship between staffing levels, resident characteristics, staff : resident interactions and resident activity patterns. *Social Science and Medicine* **40**, 799–810.
- Felce D., Repp A., Thomas M., Ager A. & Blunden R. (1991) The relationship of staff: client ratios, interactions and residential placement. *Research in Developmental Disabilities* **12**, 315–31.
- Foley G. & Timonen V. (2015) Using grounded theory method to capture and analyze health care experiences. *Health Services Research* **50**, 1195–210.
- Forster S. & Iacono T. (2008) Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual and Developmental Disability* **33**, 137–47.
- Gibson B. & Hartman J. (2014) *Rediscovering Grounded Theory*. Sage, London.
- Glaser B. (1978) *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Sociology Press, California.
- Glaser B. G. & Strauss A. L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Sociology Press, California.
- Griffiths C. & Smith M. (2016) Attuning: a communication process between people with severe & profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities* **29**, 124–38.
- Griffiths C. & Smith M. (2017) You and me: the structural basis for the interaction of people with severe and profound intellectual disability and others. *Journal of Intellectual Disabilities* **21**, 103–17.

- Grove N., Bunning K., Porter J. & Olsson C. (1999) See what I mean: interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **12**, 190–203.
- Halkoaho A., Pietilä A.-M., Ebbesen M., Karki S. & Kangasniemi M. (2016) Cultural aspects related to informed consent in health research: a systematic review. *Nursing Ethics* **23**, 698–712.
- Halle J., Brady N. C. & Drasgow E. (2004) Enhancing socially adaptive communicative repairs of beginning communicators with disabilities. *American Journal of Speech-Language Pathology* **13**, 43–54.
- Health Services Executive. (2013) National Consent Policy. Available at: <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy.html>
- Healy D. & Noonan Walsh P. (2007) Communication among nurses and adults with severe and profound intellectual disabilities. *Journal of Intellectual Disabilities* **11**, 127–41.
- Hogg J., Reeves D., Roberts J. & Mudford O. C. (2001) Consistency, context and confidence in judgements of affective communication in adults with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research* **45**, 18–29.
- Hostyn I., Petry K., Lambrechts G. & Maes B. (2011) Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and direct support staff: a preliminary application of three observation scales from parent-infant research. *Journal of Applied Research in Intellectual Disabilities* **24**, 407–20.
- Hughes R. P., Redley M. & Ring H. (2011) Friendship and adults with profound intellectual and multiple disabilities and English disability policy. *Journal of Policy and Practice in Intellectual Disabilities* **8**, 197–206.
- Johnson H., Douglas J., Bigby C. & Iacono T. (2012) Social interaction with adults with severe intellectual disability: having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities* **25**, 329–41.
- Kamstra A., van der Putten A. A. J. & Vlaskamp C. (2015) The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities* **28**, 249–56.
- Kennedy C. H., Horner R. H. & Newton S. (1990) The social networks and activity patterns of adults with severe disabilities: a correlational analysis. *The Journal of the Association for Persons With Severe Handicaps* **15**, 86–90.
- Krauss M. W. & Erickson M. (1988) Informal support networks among ageing persons with mental retardation: a pilot study. *Mental Retardation* **26**, 197–201.
- Krauss M. W., Seltzer M. M. & Goodman S. J. (1992) Social support networks of adults with mental retardation who live at home. *American Journal on Mental Retardation* **96**, 432–41.
- Lancioni G. E., Singh N. N., O'Reilly M. F., Sigafoos J., Alberti G., Perilli V. *et al.* (2017) Supporting leisure and communication in people with visual and intellectual disabilities via a smartphone-based program. *British Journal of Visual Impairment* **35**, 257–63.
- Lewis P., Gaffney R. J. & Wilson N. J. (2017) A narrative review of acute care nurses' experiences nursing patients with intellectual disability: underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing* **26**, 1473–84.
- Lloyd V., Gatherer A. & Kalsy S. (2006) Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research* **16**, 1386–404.
- Maslow A. H. (1943) A theory of human motivation. *Psychological Review* **50**, 370–96.
- McCausland D., Carroll R., McCallion P. & McCarron M. (2017) Social participation. In: *Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland. Evidence from the First Ten Years of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)* (eds M. McCarron, M. Haigh & P. McCallion), pp. 23–56. Trinity College Dublin, Dublin.
- McLean L. K., Brady N. C. & McClean J. E. (1996) Reported communication abilities of individuals with severe mental retardation. *American Journal on Mental Retardation* **100**, 580–91.
- Munde V. & Vlaskamp C. (2015) Initiation of activities and alertness in individuals with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research* **59**, 284–92.
- National Disability Authority (2009) Ethical Guidance for Research with People with Disabilities. NDA, Dublin.
- Neerinx H. & Maes B. (2016) Joint attention behaviours in people with profound intellectual and multiple disabilities: the influence of the context. *Journal of Applied Research in Intellectual Disabilities* **29**, 574–84.
- Nicholls D. (2009) Qualitative research: part two – methodologies. *International Journal of Therapy and Rehabilitation* **16**, 586–92.
- Nind M. (2008) *Conducting Qualitative Research with People with Learning, Communication and Other Disabilities: Methodological Challenges*. National Centre for Research Methods, Southampton.
- Olsson C. (2004) Dyadic Interaction with a Child with Multiple Disabilities: A System Theory Perspective on Communication. *Augmentative and Alternative Communication* **20**, 228–42.
- O'Reilly M. & Parker N. (2012) 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research* **13**, 190–7.
- O'Toole L., Nelson S., O'Connor M. & Carey E. (2018) Interprofessional working between intellectual disability nurses and speech and language therapists. *Learning Disability Practice* **21**, 27–31.

- Petry K. & Maes B. (2006) Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual and Developmental Disability* **31**, 28–38.
- Petry K., Maes B. & Vlaskamp C. (2005) Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities* **18**, 35–46.
- Petry K., Maes B. & Vlaskamp C. (2007) Operationalizing quality of life for people with profound multiple disabilities: a Delphi study. *Journal of Intellectual Disability Research* **51**, 334–49.
- Porter J., Ouvre C., Morgan M. & Downs C. (2001) Interpreting the communication of people with profound and multiple learning difficulties: interpreting communication. *British Journal of Learning Disabilities* **29**, 12–6.
- Pugh A. J. (2013) What good are interviews for thinking about culture? Demystifying interpretive analysis. *American Journal of Cultural Sociology* **1**, 42–68.
- Richards C. & Farrokhnia F. (2016) Optimizing grounded theory for policy research: a knowledge-building approach to analyzing WTO e-commerce policies. *International Journal of Qualitative Methods* **15**, 1–14.
- Robertson J., Emerson E., Gregory N., Hatton C., Kessissoglou S. & Hallam A. (2001) Social networks of people with mental retardation in residential settings. *Mental Retardation* **39**, 201–14.
- Robson C. & McCartan K. (2016) *Real World Research*, 4th edn. John Wiley & Sons, UK.
- Rubin H. J. & Rubin I. S. (2012) *Qualitative Interviewing: The Art of Hearing Data*, 3rd edn. Sage, Thousand Oaks.
- Scott H. M. & Haverkamp S. M. (2018) Comparisons of self and proxy report on health-related factors in people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **31**, 927–36.
- Streubart-Speziale H. & Carpenter R. (2011) *Qualitative Research in Nursing: Advancing the Humanistic Imperative*, 5th edn. Lippincott Williams and Wilkins, Philadelphia.
- Taylor B. (2013) Grounded theory. In: *Qualitative Research in the Health Sciences: Methodologies, Methods and Processes* (eds B. Taylor & K. Francis), pp. 30–55. Routledge, New York.
- Vander Linden K. L. (2017) Patterns of theoretical similarity. *Grounded Theory Review: An International Journal* **16**, 71–4.
- Wilder J. & Granlund M. (2003) Behaviour style and interaction between seven children with multiple disabilities and their caregivers. *Child: Care, Health and Development*, **29**, 559–67.
- Wilder J., Magnusson L. & Hanson E. (2015) Professionals' and parents' shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities. *European Journal of Special Needs Education* **30**, 367–83.
- Ziviani J., Lennox N., Allison H., Lyons M. & Del Mar C. (2004) Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual and Developmental Disability* **29**, 211–25.

Accepted 31 January 2022