

Communication difficulties in adults with Intellectual Disability:

Results from a national cross-sectional study

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ABSTRACT

Background: People with an intellectual disability (ID) are vulnerable to communication impairments, with consequences for employment, education, and social participation.

Aims: To identify the communication skills of a population of adults (40+ years) with ID and explore relationships between individual and environmental factors and communication skills.

Methods and Procedures: Data from a sample of 601 adults with ID was selected from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) addressing communication characteristics, demographics, co-morbidities, challenging behaviours, and social participation. A multiple regression model and a decision-making tree were built to identify factors related to communication abilities.

Outcomes and Results: Overall, 57.9% of participants experienced communication difficulties, with 23.5% reporting severe difficulties. Only 75.1% of participants communicated verbally; more than half found communicating with professionals and non-familiar partners difficult. Level of ID, low social participation, challenging behaviours, and diagnosis of Down syndrome were significantly associated with communication difficulties

Conclusions and Implications: Communication difficulties are prevalent in adults with ID and are influenced by complex factors. Interventions to enhance interaction and quality of life of individuals with ID should consider communication opportunities, needs, and barriers.

What this paper adds?

Although there is a robust literature on the communication profiles of children and youth with intellectual disability (ID), research with adults with ID is relatively sparse. This study, drawn from a large sample ($N=601$) highlights the high prevalence of communication difficulties and the complex inter-relationships between these difficulties and a range of individual and environmental factors. While level of ID, social participation, and residential setting emerged as strongly predictive factors for communication difficulties, the presence of challenging behaviours did not appear as significant as in previous research. Understanding the multi-layered nature of these relationships may help to develop effective interventions to enhance communication interactions and quality of life for individuals with ID.

Highlights

- Over 57% of a population sample of adults with ID reported communication difficulties
- Difficulties were described as severe in almost a quarter of the sample (23.5%)
- Level of ID, residential setting, and social participation were significant factors
- Challenging behaviours, and a diagnosis of Down syndrome were also important risk factors for communication difficulties

Keywords: Intellectual Disability; Communication difficulties; Social Participation; Regression model; Decision-making tree

1 INTRODUCTION

“Communication is both a basic need and a basic right” (Brady, et al., 2016). Communication skills are critical in order to learn, work, form relationships, and participate in social communities (Money, et al., 2016). Communication serves many functions, including the sharing of feelings and ideas, conveying information, the expression of identity, and facilitating social closeness; it exploits multiple modalities including speech, manual sign, gesture, and facial expression; and it engages both linguistic and non-linguistic forms (Beukelman & Mirenda, 2013; IASLT, 2019).

The Communication Bill of Rights asserts that “all people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence” (www.asha.org/njc). Notwithstanding these rights, people with an intellectual disability (ID) are vulnerable to communication impairments (e.g., Belva, Matson, Sipes, & Bamburg, 2012). As many as 45-90% may experience a communication difficulty (Memisevic & Hadzic, 2013), with those with severe ID being most at risk (RCSLT, 2010). The term Intellectual Disability is all-encompassing. Gross estimates of the prevalence of communication difficulties associated with ID can mask the variation in the groups that have been studied (e.g., Belva et al., 2012; Hewitt et al., 2012; Memisevic & Hadzic, 2013) and the aspects of communication explored (e.g., Abbeduto, Brady, & Kover, 2007; Coppens-Hofman, Terband, Snik, & Maassen, 2016).

Individuals with ID may experience difficulties in understanding spoken, signed, or written language and/or in expressively conveying messages (Beukelman & Mirenda, 2013; Marrus & Hall, 2017). They may struggle with the social skills that underpin interactions (e.g., taking turns, staying on topic), and may have poor speech intelligibility and fluency (Coppens-Hofman et al., 2016; Iacono, West, Bloomberg, & Johnson, 2009).

Both individual and environmental factors influence the development and maintenance of communication skills, as illustrated in the biopsychosocial model of the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001). Although each individual's profile of communication skills is unique, certain impairments are associated with particular patterns of difficulties. For instance, people with Down Syndrome typically have poor speech intelligibility, limited grammar complexity, and more difficulties in expressive than receptive language (Martin, Klusek, Estigarribia, & Roberts, 2009). In people with Fragile X Syndrome, receptive and expressive language difficulties usually co-occur with impaired pragmatic skills (Abbeduto et al., 2007; Finestack, Richmond, & Abbeduto, 2009).

Severity of ID is another important impairment factor (Belva et al., 2012; Hewitt et al., 2012). People with severe to profound levels of ID typically function mostly at a pre- or proto-symbolic level (Casella, 2005). They often develop limited speech and language abilities and rely primarily on non-speech modalities, such as facial expressions, movements, body posture or muscle tone (Bellamy, Croot, Bush, Berry, & Smith, 2010; Grove, Bunning, Porter, & Olsson, 1999; Hogg, Reeves, Roberts, & Mudford, 2001; Maes, Lambrechts, Hostyn, & Petry, 2007; Ogletree, Bartholomew, Wagaman, Genz, & Reisinger, 2012). Such communication forms are highly individualized, and generally rely on familiar partners for interpretation (Griffiths & Smith, 2016). The environment, and specifically communication partners within that environment, crucially influence the modes of communication that are recognized, responded to, and interpreted, as well as the perceived success of communicative interactions.

The co-occurrence of challenging behaviours (an activity limitation within the ICF) may also link to communication skills. The reported prevalence rates of challenging behaviours in adults with ID range between 18.1% - 22.5% (Bowring, Totsika, Hastings, Toogood, & Griffith, 2017; Jones et al., 2008), with a higher incidence in individuals with profound ID

(Bowring et al., 2017; Poppes, van der Putten, & Vlaskamp, 2010). Challenging behaviours often function as a form of communication, when other forms are not available (Mirenda, 1997; Richman, Wacker, & Winborn, 2001; Rojahn, Wilkins, Matson, & Soisjoli, 2010) particularly in people with more severe communication difficulties (Larkin, Jahoda, McMahon, & Pert, 2012). Challenging behaviours may themselves affect the development of communication skills, and the ability to build and maintain social networks (Kevan, 2003).

Finally, the relationship between speech intelligibility, language skills, and functional communication ability is complex. Some individuals with profound speech impairments may benefit from augmentative and alternative communication strategies and successfully navigate many of their communication needs independently. Others with apparently comparable levels of impairment may struggle to assert communicative autonomy. Communication skills develop through interactions within sociocultural contexts. For this reason, environmental factors are critical in their impact on communication, interaction, and on opportunities for and barriers to, participation. Communication environments and social networks are often restricted for people with ID, especially if they live in community and residential care (McCausland, McCallion, Cleary, & McCarron, 2016; McCausland, McCallion, Brennan, & McCarron, 2018). Consequently, they can become socially, societally, and educationally excluded (Chadwick, Buell, & Goldbart, 2019). The impact of social participation and social interactions on communication and quality of life of people with ID is well recognized (Carter & Hughes, 2005; Wormwald, McCallion, & McCarron, 2019). These complex layers of interacting factors reflect the dynamic inter-relationships between levels of the ICF (WHO, 2001) and the inextricable relationship between communication experiences and environmental factors.

Current models of service provision for adults with ID emphasize the importance of social engagement, and participation within local communities (Bigby, Bould, & Beadle-Brown, 2019). In Ireland, services must support individuals to participate in ordinary things in

ordinary places (Health Services Executive, 2012). However, such participation is critically dependent on communication skills. Despite the large body of evidence within the developmental literature, relatively little is documented about the communication abilities of adults with ID (but see e.g., Hewitt et al., 2012; Sutherland et al., 2014). Communication challenges from childhood persist, but additional factors emerge as part of the natural ageing process (Yorkston, Bourgeois, & Baylor, 2010), and/or as a consequence of additional cognitive, (Strydom, Chan, King, Hassiotis, & Livingston, 2013), sensory, and motor changes, and the impact of restricted social networks (e.g., McCausland et al., 2018).

1.1 Research rationale and aims

Poor communication skills and unmet communication needs may have significant consequences for people with ID as they age. Communication deficits affect education and employment opportunities (Bryen, Potts, & Carey, 2007), key avenues of social integration. In addition, communication difficulties may increase vulnerability by limiting opportunities for treatment, social care and health needs advocacy, and reporting of abuse (RCSLT, 2010). Enhancing communication skills is a widely identified intervention priority (Brady et al., 2016; IASLT, 2019; RCSLT, 2010) in order to increase social inclusion and reduce health inequalities for adults with ID. Nonetheless, a high proportion of adults with ID (almost 30% in Sutherland et al., 2014) may have communication needs that remain unmet. The skills of adults differ from those of younger populations, as life experience alone may contribute to behaviors that define communicative profiles, strengths, weakness, and needs (Ogletree et al., 2012). Identifying the factors that increase the risk of communication problems is key in addressing the needs in this population.

This study aimed to identify the communication skills of a population of adults with ID over 40 years old and to explore how these skills related to levels of social participation, cognitive impairment, co-morbidities, place of residence, and the presence of challenging

behaviors. Understanding these complex inter-relationships may inform interventions to promote communicative effectiveness and increase social participation by adults with ID.

2 MATERIAL AND METHODS

2.1 Study design and participants

Data were drawn from Wave 3 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). IDS-TILDA is a national longitudinal study on the ageing profile of adults with ID over 40 years in Ireland. IDS-TILDA commenced in 2009 with a sample of 753 adults randomly selected from the National Intellectual Disability Database (NIDD), to be geographically and demographically representative of the target population (McCarron et al., 2011). Data for Wave 3 were collected on 609 participants between October 2016 and February 2017. This study included 601 adults with ID for whom data on communication difficulties were available.

2.2 Ethical considerations

This study complies with the ethical standards and laws applicable in Ireland. Ethical approval was obtained from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and from the 138 service providers involved.

2.3 Data collection

Details on the data collection process are described elsewhere (McCarron, et al., 2011). In brief, data for Wave 3 were collected using a self-completion pre-interview questionnaire (PIQ) and a face-to-face computer-assisted personal interview (CAPI). The PIQ addressed medical diagnosis, medication usage and healthcare utilization. Wave 3 questionnaires were posted to participants one week prior to interview, to allow time to collect the information, often from existing records. During the face-to-face CAPI, participants were asked about various domains, including demographics, social participation, physical activity, and co-

morbidities. Responses from the PIQ were also confirmed. Participants had the option of responding independently, being supported by a proxy, or relying on a proxy to complete the questions. The proxy had to have known the participant well and for at least 6 months prior to the data collection. All items were designed to be easily understood by people with ID and their proxies (see McCarron, et al., 2011) and validity, ease of administration, and accessibility of the questionnaire items was evaluated as part of the piloting process for the initial protocol. For the purpose of this study, data analyzed comprised: demographics, communication abilities, comorbidities, social participation and challenging behaviours.

2.4 Measures

2.4.1 Demographics, comorbidities, and challenging behaviours

Demographic information comprised data on age, gender, level of ID (mild, moderate and severe/profound), aetiology of ID, place of residence, education level, and employment status. Data on comorbidities potentially relevant to communication were also collected. These included: cerebral palsy, dementia, epilepsy, emotional, nervous or psychiatric conditions, and sensory impairments. The latter were determined by the presence of self-reported difficulties with or without the use of glasses or hearing aids. In addition, participants were asked about the presence of challenging behaviours (including self-injury, aggression, and/or stereotyped behaviours).

2.4.2. Communication abilities

Information on participants' communication abilities was drawn from responses to two items in the CAPI, and scores on two subsections of the Test for Severe Impairment (TSI; Albert & Cohen, 1992). The interview questions were: "*Do you have any difficulty speaking or making yourself understood when speaking?*" with answers coded as: No difficulty; Some difficulty; Much difficulty; Cannot do at all; and "*How well are you able to make yourself understood when speaking with members of the family, friends, professionals and service*

provider, and other people?” with answers coded on a similar scale. The Test for Severe Impairment (TSI; Albert & Cohen, 1992) was administered by the interviewer. The Language subsection comprises two subtests: “Comprehension” and “Production”, each encompassing four questions. The Comprehension subtest requires participants to perform a task in response to a verbal command. The language production tasks involve naming items that vary in difficulty (e.g., body parts, common objects). The total score for each section is 4; higher scores indicate better performance. For the purpose of this study, scores were classified as: “weak” (0-2) or “threshold” performance (3-4) for each section. At the end of the interview, the interviewer was asked about the respondent’s communication style (i.e., “verbal”, including speech and/or a manual sign system, or “non-verbal”) and communication modes used during the interview (e.g., words, gestures).

2.4.3 Social participation

Social participation was explored through 4 questions:

- “Do you have friends?” (Yes/Sometimes; No)
- “Do you have a best friend?” (Yes/Sometimes; No)
- “Are you an active member of any organization or society?” (including political party, charitable associations, art, ... Yes; No)
- “Do you take part in social activities with no difficulty?”

Social participation was categorized as “High” for participants who answered positively to 3-4 questions, and “Low” for those with 0-2 positive responses.

2.5 Statistical analysis

Statistical analysis was completed using the Statistical Package for Social Sciences (SPSS) version 24.0 (IBM Corp. 2016). Preliminary analysis involved frequencies and missing values analysis. Only valid percentages are reported. Analyses initially identified associations between communication difficulties and demographics, co-morbidities, challenging

behaviours, and social participation. These relationships were tested for significance using Chi-square tests for independence.

Simple multinomial logistic regression was conducted to determine the predictive value of each variable on participants' communication difficulties. For this purpose, the variables "Some" and "Much difficulty" were considered together. Crude odds ratio and confidence intervals (CI – set at 95%) are reported. A multiple logistic regression model was built to explore the relationship between communication difficulties and ID level, type of residence, sensory impairment, social participation, and challenging behaviours. A second model including the variable "Down Syndrome" was built, given the strong predictive value of this factor on the dependent variable. Purposeful selection of variables for inclusion in the regression model was carried out, based on the literature (Heinze, Wallisch, & Dunkler, 2018). Multicollinearity between independent variables in the multiple regression models was tested by examining the Variance Inflation factor (VIF), with a cut-off value of correlation = 2 (Kutner, Nachtsheim, & Neter, 2004). Variables were entered into the model simultaneously and those cases with at least one missing value were excluded. Adjusted odds ratio and CI (95%) are reported.

A decision-making tree using CHAID (Chi-Squared Automatic Interaction Detection) Growing Method (Milanović & Stamenković, 2016; Song & Lu, 2015) was built to further analyze predictive factors for communication difficulties. This analysis made it possible to maintain the total sample for each node. All variables included in the study were inserted in this model. Significance was set at $\alpha = 0.05$ for all analyses.

3 RESULTS

3.1 Sample description

Table 1 summarises demographic characteristics, co-morbidities, and challenging behaviours of the participant sample. Missing values analysis showed no significant differences

in terms of demographics between the sample included ($n=601$) and the sample originally recruited ($N=609$). Of the participants included, 44% were male. Mean age was 59.21 years ($SD=8.83$; range 48-95 years). The majority of the sample (46.3%) had moderate ID; ID level was not identified for 48 participants.

INSERT TABLE 1 HERE

3.2 Communication abilities

The communication characteristics of participants are outlined in Table 2. Almost half of respondents reported “No communication difficulty” (42.1%); responses for 23.5% of participants indicated that they could not communicate at all, with remaining participants experiencing either “Some” (21.1%) or “Much” (13.3%) difficulty. This information was reported independently by 19% of participants, with the help of a proxy in 33.8% of instances, and 47.3% of the sample relied completely on a proxy. Only 40% of participants who reported no difficulties answered the survey without help (Table 2). Half of the participants reported being completely understood by family and friends (Figure 1). Self- or proxy-reported communication difficulties were significantly correlated to TSI Comprehension ($\chi^2=121,358$, $df=3$, $p<0.0001$) and Production scores ($\chi^2=149,180$ $df=3$, $p<0.0001$) (Table 2). TSI scores were available for 411 participants.

According to interviewer reports, 354 participants (74.8%) communicated verbally; within this group, 233 (66.2%) reported no communication difficulty (Table 2). For the remaining 119 participants, communication was mostly non-verbal; four participants within this group were reported to have no communication difficulty. Figure 2 summarizes the communication modes used by participants, according to interviewer reports.

INSERT TABLE 2 HERE

INSERT FIGURE 1 HERE

INSERT FIGURE 2 HERE

3.3 Social participation characteristics

Characteristics of individuals' social participation are presented in Table 3. The majority of the sample (55%) showed low levels of social participation. More than half (52.3%) had a best friend, which in most cases (63.7%) was a person with ID. Others included a staff member (15.8%), a family member (8.6%), or other (6.8%). Although 55% of participants reported difficulties in participating in social activities, communication or language problems were cited as key factors in only 27% of these cases.

INSERT TABLE 3 HERE

3.4 Associations with communication difficulty

Among participants' demographics, co-morbidities, challenging behaviours, and social participation variables, communication difficulty was most significantly associated (i.e., $p < 0.001$) with level of ID, type of residence, sensory impairment, epilepsy, challenging behaviours, and social participation (Table 4).

INSERT TABLE 4 HERE

3.5 Multinomial and multiple logistic regression

Simple multinomial logistic regression analyses were performed to determine the predictive value of individual variables on having moderate ("Some/Much") and severe ("Cannot do at all") communication difficulties (Table 5). The most significant predictor for communication difficulty was level of ID: those with severe/profound ID were 12 times more likely to have moderate (OR=12.62; CI:5.92-26.88) and 220 times more likely to report severe communication difficulties (OR=220.93; CI:68.97-707.66), than those with mild ID. People living in a residential care were 3 times and 12 times more likely to experience moderate and severe communication difficulties respectively, compared to those living independently. People with Down syndrome were 2.6 times more likely to have moderate communication difficulties (OR=2.69; CI:1.63-4.45), and 1.9 times more likely to report severe communication

difficulties (OR=1.9; CI:1.07-3.38) than those with ID not associated with this syndrome. The presence of challenging behaviours was a predictive factor for moderate (OR=2.53; CI:1.64-3.88) and severe communication impairments (OR=4.45; CI:2.61-7.56). Finally, people with low social participation were twice as likely to have moderate communication difficulties (OR=1.76; CI:1.21-2.57) and seven times more likely to report severe communication difficulties (OR=7.3; CI:4.41-12.18). Other factors are outlined in Table 5.

INSERT TABLE 5 HERE

Tables 6 and 7 show the results for the multiple logistic regression employed to investigate the relationship between communication difficulties and the selected predictors (level of ID, type of residence, sensory impairment, challenging behaviours, social participation), with and without DS, respectively. The reference category was “No communication difficulty”; 428 participants were included in both analyses (71.2% of original sample). No variables were excluded for reasons of multicollinearity (no VIF > 2).

When the variable Down syndrome was not included, the model was statistically significant ($\chi^2=237.362$, $df=14$, $p<0.0001$), (i.e., able to predict the dependent variable better than the null model). Specifically, it predicted participants’ communication abilities in 59.8% of cases. The strongest predictors for “Moderate communication difficulty” were having moderate ID, severe/profound ID and having challenging behaviours, while severe ID level and low social participation were predictive for “Severe communication difficulty” (Table 6).

The model including the variable “Down Syndrome” was statistically significant ($\chi^2=247.031$, $df=16$, $p<0.0001$) predicting participants’ communication ability in 61.7% of instances. In this model, the presence of Down syndrome increased the odds of moderate and severe communication difficulty by 2.72 (CI=1.39-5.33) and 2.96 (CI=1.17-7.48), respectively (Table 7).

INSERT TABLE 6 HERE

INSERT TABLE 7 HERE

3.5 Decision-making tree

A decision-making tree using the CHAID Growing Method was built to identify the most significant predictive variables for communication ability. For this purpose, participants were divided in two groups: “No communication difficulties” and “Communication difficulties” (including “Moderate” and “Severe” impairments; Figure 3). The first variable predicting those with and without communication difficulties was ID level ($p<0.0001$). The group “Severe/Profound ID” did not split again, as it presented high risk of communication difficulty (92.6%) compared to other groups. Within those with moderate ID, having challenging behaviours was a further risk factor ($p<0.0001$); for those who did not report challenging behaviours, having Down syndrome was a predictive factor ($p=0.001$). For participants with moderate ID, communication difficulties were more likely to occur within those with Down syndrome (44.4%) than those with ID associated with other aetiologies (22.2%) ($p=0.043$). For the latter group, having an emotional, nervous or psychiatric condition was a risk factor for having communication difficulties ($p=0.018$). This model could correctly classify participants in 74.4% of cases.

INSERT FIGURE 3 HERE

4 DISCUSSION

This study found a high prevalence of self- or proxy-reported severe communication difficulties among adults with ID (23.5%). To our knowledge, this is the first population-based study exploring communication difficulties in adults with ID. In line with previous studies with children, level of ID was the strongest predictor of communication difficulties in our sample. However, it is unlikely that this effect reflects a linear relationship between level of impairment and functional capacity. People with severe ID present complex disabilities (Maes et al., 2007), with comorbidities (e.g., sensory impairments, challenging behaviours) that themselves impact

on communication, as seen in our data. In addition, they often have fewer opportunities to live in a typical community environment, have less variety in their daily activities, and fewer opportunities for social participation (McCausland, et al., 2018), illustrating the interconnectedness of the levels of the ICF (WHO, 2001). While level of ID may be useful in predicting the presence of a communication difficulty, it does not predict the nature of that difficulty, or the impact on any specific individual. Nonetheless, findings reported here confirm the concerns identified in studies of children with ID: Compromised social participation continues in adulthood.

4.1 Estimating communication abilities

Valid, reliable, and meaningful assessment of communication abilities of adults with ID is challenging. Skills are context-sensitive and inextricably linked to the abilities of communication partners, particularly with more severe levels of ID (Griffiths & Smith, 2016). The data reported here come from self- or proxy-report and performance on subtests of the TSI (Albert & Cohen, 1992). Some participants with severe communication difficulties did not rely on proxy for report; others with no communication difficulties relied on proxies. This finding may have different explanations. Self-reporting on communication abilities requires meta-skills in order to evaluate current skills relative to desired skill status. Participants may have perceived few difficulties in interacting with others but still have been unable to reflect on how easily they achieved their communication goals. Furthermore, individuals with ID may have responded positively (i.e., reported no difficulties) in order to ‘please’ an interviewer. Alternatively, proxies who reported “no difficulties” might have underestimated the communication difficulties experienced by participants. The tendency of family and staff to underestimate communication difficulties, (especially receptive skills), is well-recognized (Kevan, 2003).

In general, results from the objective assessment (TSI) were strongly associated with the self-report, suggesting both measures captured the same kind of information. However, there were also anomalies. Five participants who scored at “Threshold” on the TSI Comprehension tasks, and a further three who achieved these levels on the Production tasks were categorized as “unable to communicate”. This finding highlights the challenge of using static standardized assessments to measure communication in a group where demonstration of competence is closely linked to skills of the communication partner (Griffiths & Smith, 2016).

Only 4 participants who did not use verbal communication were reported to have either “no” or “some” communication difficulties, suggesting that participants who relied on non-speech communication were more likely to be categorized as having severe communication impairments. Non-speech communication is often difficult to interpret and may be highly idiosyncratic. Identifying the abilities of individuals who rely on these modes is challenging and may lead to an underestimation of communication potential (Beukelman & Mirenda, 2013).

4.2 Impact of communication impairment: Complex inter-relationships

Social participation is fundamental for communicative interactions, and communication skills are the glue that enables successful interactions. Up to 64% of the sample reported that their communication was only partially understood by staff. This is particularly important given the social interaction that this population has with professionals, especially within residential care. Overall, as a group they were most likely to be able to communicate with family and friends and least likely to be successful with others.

While over 92% had friends, only 52% had a best friend; even fewer were active members of an external society or organization, with over 55% reporting difficulty in taking part in social activities. These data highlight the risk of social isolation experienced by adults with ID who have communication difficulties. Communication skills evolve in contexts where

communication is expected and is supported (Beukelman & Mirenda, 2013). People living in residential facilities and who have more severe ID are vulnerable to social exclusion just by virtue of their residence (McCausland, et al., 2018). In an investigation of leisure activities offered to adults with ID in a residential facility, Zijlstra and Vlaskamp (2015) found that older clients (> 38 years) were offered fewer interactions and less variety and choice of opportunities, when compared to younger people. In addition, people with lower adaptive and communicative skills and lower activity levels may receive less positive staff contact may be offered less stimulating activities, and experience more custodial care (Maes, et al., 2007).

In this study, we found that participants with low levels of social participation were also those with more severe communication difficulties. Hence, we can hypothesize that people with more severe levels of ID who live in residential care and who present with more severe communication difficulties are at increased risk of fewer opportunities for social interactions and thereby fewer opportunities to develop effective communication skills. These inter-relationships are complex and multi-layered; the profoundly interconnected nature of all components of the ICF (WHO, 2001) illustrates the need for multidimensional approaches to supporting the needs of individuals with ID.

The importance of communication partners and the impact of their interaction skills on both the frequency and complexity of the communication of people with severe-profound disabilities is well documented (Bloomberg, West, & Iacono, 2003; Granlund & Olsson, 1993). Training staff to support people with ID who have no access to verbal communication can be effective in increasing frequency and quality of interactions and, consequently, increasing the individual's social inclusion and quality of life (e.g., Maes, et al., 2007; Scheps & Reid, 1995). Increasing opportunities for successful communication is a more realistic goal than aiming to change the communication resources of an individual with severe ID; emphasizing participation as the target outcome is key to delivering effective interventions.

4.3 Additional contributing factors

Although challenging behaviours were reported in over 60% of participants the impact of this factor seemed relatively weak, compared to other studies. The relationship between communication difficulties and challenging behaviours reflects correlation and not causation (Kevan, 2003): challenging behaviours may function as communicative if no other acceptable form of expression is available to the individual (e.g., Ali, Blickwedel, & Hassiotis, 2014).

When inserted in the regression model, the variable Down Syndrome was significantly predictive of moderate and severe communication difficulties. Children with Down Syndrome show a consistent profile of relative strengths in receptive rather than expressive language, and stronger vocabulary than syntax (Martin et al., 2009). Previous studies of adults with ID concluded that these patterns may remain stable from late adolescence through at least 50 years (Rondal & Comblain, 2002), although pragmatic skills may decline with the progression of dementia (Nelson, Orme, Osann, & Lott, 2001). Our study was not able to identify a correlation between communication difficulties and dementia probably due to small sample size. However, we acknowledge the possibility that the high prevalence of this condition at an early age in people with Down Syndrome may be important in interpreting the prevalence of communication difficulties in this population.

This study found weak to moderate correlations with emotional, nervous or psychiatric conditions. Previous research has suggested a correlation between mental health disorders and social and adaptive skills deficits or excesses (Matson, Terlonge, Gonzalez, & Rivet, 2006; Rojahn et al., 2010). In this study mental health diagnoses were partially predictive of communication difficulties in those groups with relatively higher levels of cognitive ability. Evidence of mental health difficulties may be sought primarily in changes in interaction behaviours and in verbal expression, making it much more difficult to infer the mental health state of individuals with severe-profound communication difficulties.

4.4 Strengths and limitations

A strength of this study is the size and representativeness of the sample, which, to the authors' knowledge exceeds existing studies on communication difficulties in adults with ID. Another important factor contributing to its uniqueness is the number of variables collected, allowing a broad investigation of the participants' profile relative to communication abilities.

However, as with any phenomenon as complex as communication, capturing valid and reliable information is challenging. Much of the data reported here was based on self- or proxy-report, introducing a risk of misattribution bias. The potential limitations of the measurement tools (e.g., the TSI) must also be considered. Finally, the retrospective nature of the study further limits the implications that can be drawn.

4.5 Implications and conclusions

Despite the above limitations, our findings illustrate the complex factors contributing to communication deficits in adults with ID and the range of domains to consider in managing communication needs in this group. Our study found that more than half the participants had difficulties communicating with professionals and non-familiar communicative partners. This highlights the need to support all stakeholders in order to enhance communication across contexts and communication partners, and to evaluate the impact of such interventions in increasing social participation.

Communication difficulties were mainly predicted by greater levels of ID, lower levels of social participation and challenging behaviours, all of which interact to contribute to poor social integration. A potentially fruitful line of future research would be the extent to which these patterns are consistent across sub-groups within the data (e.g., those with physical disabilities; those described as non-verbal). Given the importance of communication contexts and partners, careful consideration of communication opportunities, needs, and barriers

(Beukelman & Mirenda, 2013) may support family, caregivers, and support staff to enhance interactions and ultimately the quality of life of individuals with ID.

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TABLES AND FIGURES

Table 1. Sample demographics, comorbidities and challenging behaviours.

Variable		f	%
Gender (n=601)	Male	265	44.1%
	Female	336	55.9%
Age (n=601)	<50	71	11.8%
	50-64	374	62.2%
	65+	156	26.0%
Level of ID (n=553)	Mild	135	24.4%
	Moderate	256	46.3%
	Severe/Profound	162	29.3%
Type of residence (n=601)	Independent/ Family	94	15.6%
	Community group home	241	40.1%
	Residential Care	266	44.3%
Education (n=518)	Primary	287	55.4%
	Post-primary	8	1.5%
	Other	61	11.8%
	None	162	31.3%
Occupation (n=594)	Retired	146	24.6%
	Employed/ Self-employed	177	29.8%
	Unemployed	234	39.4%
	Other	37	6.2%
Down Syndrome (n=601)		107	17.8%
Cerebral Palsy (n=600)		45	7.5%
Dementia (n=600)		51	8.5%
Sensory impairment (n=591)		174	29.4%
Epilepsy (n=600)		213	35.5%
Emotional, nervous, psychiatric condition (n=601)		313	52.1%
Challenging behaviours (n=475)		285	60.0%

Table 2. Communication characteristics of the sample

	Total		No difficulty		Some difficulty		Much difficulty		Cannot do at all	
Communication difficulties	601	100.0%	253	42.1%	127	21.1%	80	13.3%	141	23.5%
Report (n=601)										
Self-report only	114	19.0%	101	89%	10	9%	2	2%	1	1%
Self-report and proxy	203	33.8%	110	54%	62	31%	23	11%	8	4%
Proxy only	284	47.3%	42	15%	55	19%	55	19%	132	46%
TSI Language Comprehension (n=411)										
Weak	95	23.1%	24	10.4%	18	18.2%	20	45.5%	33	86.8%
Threshold	316	76.9%	206	89.6%	81	81.2%	24	54.5%	5	13.2%
TSI Language Production (n=411)										
Weak production	103	25.1%	19	8.3%	24	24.2%	25	56.8%	35	92.1%
Threshold	308	74.9%	211	91.7%	75	75.8%	19	43.2%	3	7.9%
Communication style (n=473)										
Verbal	352	75.1%	233	98.3%	97	88.2%	22	36.7%	0	0%
Non-verbal mostly	117	24.9%	4	1.7%	13	11.8%	38	63.3%	62	100%

Table 3. Social participation characteristics of the sample

Variable		f	%
Do you have friends? (n=599)	Yes	554	92.5%
	No	45	7.5%
Do you have a best friend? (n=554)	Yes	313	52.3%
	No	286	47.7%
Are you an active member of any organisation or society? (n=600)	Yes	261	43.5%
	No	339	56.5%
Do you take part in social activities with no difficulty? (n=590)	Yes	264	44.7%
	No	326	55.3%
Social participation (n=589)	Low	324	55.0%
	High	265	45.0%

Table 4. Associations between communication difficulty and risks factors

	Total		No difficulty		Some difficulty		Much difficulty		Cannot do at all		P-value
Age (n=601)											0.249
<50	71	11.8%	23	9.1%	14	11.0%	17	21.3%	17	12.1%	
50-64	374	62.2%	165	65.2%	77	60.6%	41	51.3%	91	64.5%	
65+	156	26.0%	65	25.7%	36	28.3%	22	27.5%	33	23.4%	
Gender (n=601)											0.458
Male	265	44.1%	104	41.1%	60	47.2%	40	50.0%	61	43.3%	
Female	336	55.9%	149	58.9%	67	52.8%	40	50.0%	80	56.7%	
Level of ID (n=553)											<0.0001
Mild	135	24.4%	101	44.3%	25	21.6%	5	7.0%	4	2.9%	
Moderate	256	46.3%	115	50.4%	75	64.7%	37	52.1%	29	21.0%	
Severe\Profound	162	29.3%	12	5.3%	16	13.8%	29	40.8%	105	76.1%	
Type of residence (n=601)											<0.0001
Independent	94	15.6%	65	25.7%	18	14.2%	4	5.0%	7	5.0%	
Community	241	40.1%	110	43.5%	62	48.8%	35	43.8%	34	24.1%	
Residential Care	266	44.3%	78	30.8%	47	37.0%	41	51.3%	100	70.9%	
Down Syndrome (n=601)											0.001
Yes	107	17.8%	28	11.1%	28	22.0%	24	30.0%	27	19.1%	
No	494	82.2%	225	88.9%	99	78.0%	56	70.0%	114	80.9%	
Cerebral Palsy (n=600)											0.522
Yes	45	7.5%	18	7.1%	13	10.3%	4	5.0%	10	7.1%	
No	555	92.5%	235	92.9%	113	89.7%	76	95.0%	131	92.9%	
Dementia (n=600)											0.017
Yes	51	8.5%	13	5.1%	11	8.7%	13	16.3%	14	9.9%	
No	549	91.5%	240	94.9%	115	91.3%	67	83.8%	127	90.1%	
Sensory impairment (n=591)											<0.0001
Yes	174	29.4%	53	20.9%	37	29.1%	34	42.5%	50	38.2%	
No	417	70.6%	200	79.1%	90	70.9%	46	57.5%	81	61.8%	
Epilepsy (n=600)											<0.0001
Yes	213	35.5%	78	30.8%	31	24.6%	36	45.0%	68	48.2%	
No	387	64.5%	175	69.2%	95	75.4%	44	55.0%	73	51.8%	
Emotional, nervous, psychiatric conditions (n=601)											0.244
Yes	313	52.1%	120	47.4%	71	55.9%	42	52.5%	80	56.7%	
No	288	47.9%	133	52.6%	56	44.1%	38	47.5%	61	43.3%	
Challenging behaviours (n=470)											<0.0001
Yes	285	60.0%	91	44.6%	66	66.0%	42	68.9%	86	78.2%	
No	190	40.0%	113	55.4%	34	34.0%	19	31.1%	24	21.8%	
Social participation (n=589)											<0.0001
Low	324	55.0%	99	39.9%	58	47.9%	50	63.3%	117	83.0%	
High	265	45.0%	149	60.1%	63	52.1%	29	36.7%	24	17.0%	

Table 5. Multinomial logistic regressions for communication difficulty

		p-value	Crude OR	CI (±)	p-value	Crude OR	CI (±)
		SOME/MUCH DIFFICULTY			CANNOT DO AT ALL		
Age	<50	0.278	-	-	0.345	-	-
	50-64	0.035	0.531	(0.294; 0.956)	0.397	0.746	(0.379; 1.469)
	65+	0.210	0.662	(0.347; 1.262)	0.329	0.687	(0.323; 1.460)
Gender	Male	0.122	1.339	(0.925; 1.939)	0.678	1.092	(0.720; 1.657)
Level of ID	Mild	<0.0001	-	-	<0.0001	-	-
	Moderate	<0.0001	3.279	(2.022; 5.318)	0.001	6.367	(2.164; 18.731)
	Severe/ Profound	<0.0001	12.625	(5.928;26.889)	<0.0001	220.938	(68.978;707.664)*
Type of residence	Independent	<0.0001	-	-	<0.0001	-	-
	Community	0.001	2.605	(1.495; 4.539)	0.017	2.870	(1.203; 6.846)
	Residential Care	<0.0001	3.333	(1.882; 5.903)	<0.0001	11.905	(5.170; 27.411)
Down Syndrome		<0.0001	2.696	(1.630; 4.458)	0.028	1.903	(1.071; 3.381)
Cerebral Palsy		0.648	1.174	(0.589; 2.341)	0.993	0.997	(0.447; 2.222)
Dementia		0.013	2.434	(1.207; 4.912)	0.076	2.035	(0.928; 4.462)
Sensory impairment		0.001	1.970	(1.298; 2.990)	<0.0001	2.329	(1.464; 3.707)
Epilepsy		0.698	1.081	(0.728; 1.606)	0.001	2.090	(1.367; 3.196)
Emotional, nervous, psychiatric conditions		0.127	1.332	(0.922; 1.926)	0.077	1.454	(0.960; 2.200)
Challenging behaviours		<0.0001	2.530	(1.647; 3.887)	<0.0001	4.450	(2.619; 7.560)
Social participation	Low	0.003	1.767	(1.212; 2.575)	<0.0001	7.337	(4.417; 12.187)

* This finding is justified by the fact that almost all people with severe/profound ID (92.6%) reported either a moderate or severe communication difficulties.

Table 6. Multiple logistic regression model (no Down Syndrome)

		p-value	Adjusted OR	CI (±)	p-value	Adjusted OR	CI (±)
		SOME/MUCH DIFFICULTY			CANNOT DO AT ALL		
Level of ID	Mild	-	-	-	-	-	-

	Moderate	0.002	2.549	(1.421; 4.569)	0.033	5.195	(1.144; 23.586)
	Severe/ Profound	<0.0001	12.255	(4.814; 31.196)	<0.0001	193.161	(38.180; 977.248)*
Type of residence	Independent	-	-	-	-	-	-
	Community	0.756	1.125	(0.535; 2.366)	0.554	0.655	(0.161; 2.661)
	Residential Care	0.519	1.291	(0.595; 2.803)	0.355	1.885	(0.492; 7.216)
Sensory impairment	No	-	-	-	-	-	-
	Yes	0.087	1.617	(0.933; 2.805)	0.143	1.729	(0.832; 3.597)
Challenging behaviours	No	-	-	-	-	-	-
	Yes	0.029	1.764	(1.059; 2.939)	0.195	1.644	(0.776; 3.484)
Social participation	High	-	-	-	-	-	-
	Low	0.525	0.849	(0.513; 1.406)	0.009	2.741	(1.291; 5.818)

Table 7. Multiple logistic regression model (including Down Syndrome)

		p-value	Adjusted OR	CI (±)	p-value	Adjusted OR	CI (±)
		SOME/MUCH DIFFICULTY			CANNOT DO AT ALL		
Level of ID	Mild	-	-	-	-	-	-
	Moderate	0.004	2.393	(1.326; 4.319)	0.042	4.827	(1.062; 21.946)
	Severe/ Profound	<0.0001	12.003	(4.692; 30.709)	<0.0001	188.809	(37.360; 954.206)*
Type of residence	Independent	-	-	-	-	-	-
	Community	0.535	1.274	(0.592; 2.741)	0.634	0.711	(0.175; 2.896)
	Residential Care	0.276	1.564	(0.699; 3.497)	0.255	2.187	(0.568; 8.418)
Sensory impairment	No	-	-	-	-	-	-
	Yes	0.107	1.588	(0.906; 2.784)	0.166	1.689	(0.805; 3.546)
Challenging behaviours	No	-	-	-	-	-	-
	Yes	0.024	1.821	(1.084; 3.060)	0.159	1.724	(0.808; 3.681)
Social participation	High	-	-	-	-	-	-
	Low	0.570	0.862	(0.517; 1.438)	0.008	2.813	(1.315; 6.020)
Down Syndrome	No	-	-	-	-	-	-
	Yes	0.004	2.720	(1.387; 5.332)	0.022	2.961	(1.172; 7.481)

Figure 1. How well are you able to make yourself understood when speaking with...?

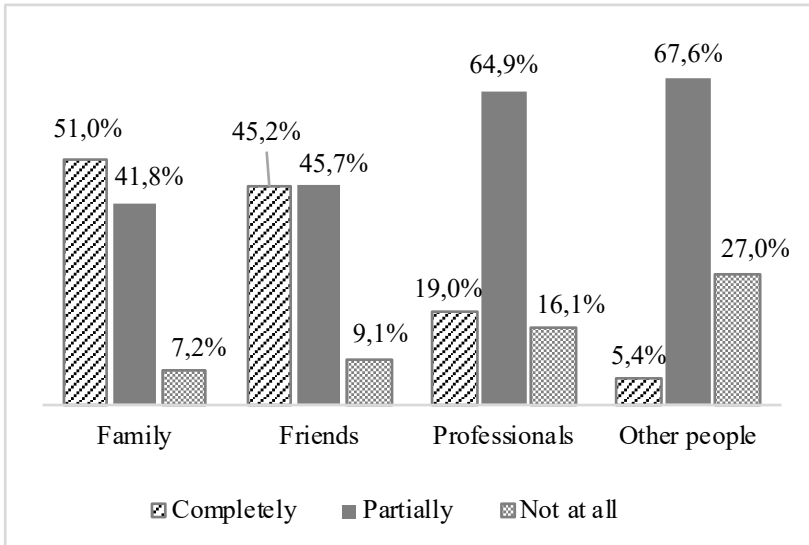


Figure 2. Communication channels used by participants (n=477)

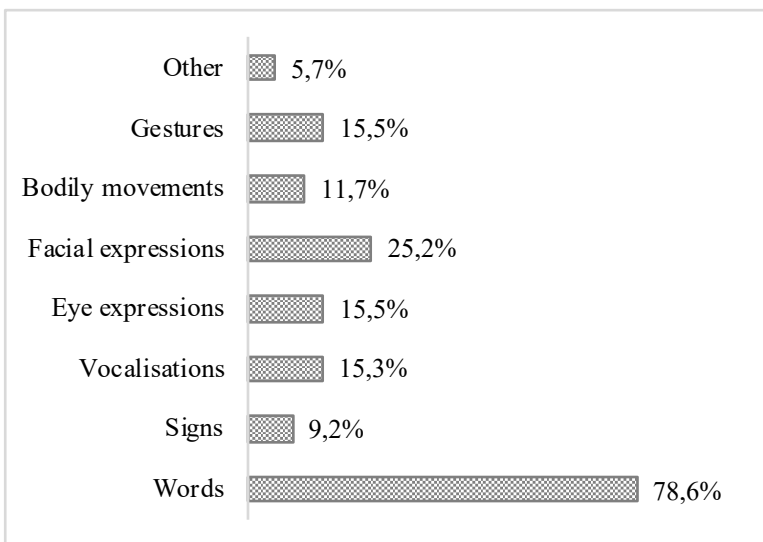


Figure 3. Decision-making tree

