

**A diagnostic tool for the identification of noise in
Augmentative and Alternative Communication: A case study
about adults with Complex Communication Needs.**

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Abstract

Approximately 1.5% of individuals in western countries have Complex Communication Needs (CCN), meaning that they lack the spoken word skills needed for their daily communication. Therapeutic methods, called Augmentative and Alternative Communication (AAC), are available to help these people to communicate, but the use of such techniques and devices is typically complex and challenging. The identification of where communication breakdowns occur is one of the major challenges within the unique environment of those with CCN. Having a tool that allows users to identify this interference or, noise, could provide a means to address this issue.

This thesis describes two studies, and the design of a physical artefact. The first study is archival research I conducted in a disability day centre that caters for adults with CCN. This showed that AAC aids were stored at the centre, but seemed to have little use there. This led to a second study that investigated communication challenges in the centre given that lack of use. In that second study, I used focus groups to gather information from staff about challenges to their daily routine, specifically in their communication with clients. This was followed by observations of those communication interactions. Results showed that very few AAC aids and techniques were used, and provided some explanation for why this was the case. I concluded the second study by conducted interviews with two mothers of CCN participants, and with a group of centre staff members. The mothers spoke about the benefits of AAC, and staff members agreed that there was a lack of AAC use in the centre, giving some reasons for that.

A designed artefact is presented. This is a physical, diagnostic tool embodying and extending both the literature reviewed, and the research data analysed in this thesis. This tool is intended to be used to identify noise in communication among adults with CCN.

The research in this thesis is analysed in the context of current understandings of CCN, the implications of this impairment on the individual and society, and the nature of disability as distinct from impairment. Disability studies and communication theories are drawn on to discuss challenges that are faced by adults in the AAC process. In the examination of a CCN environment, the research identifies communication challenges among people with impairments, identifies the types of noise that can affect their message exchange, and the effect of shared experiences among impaired and other communication partners.

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Thanks go to my family and friends, for their care, understanding, and patience throughout this process.

Student Declaration

This thesis:

- Contains no material that has been accepted for the award to the candidate of any other degree or diploma, except where due reference is made in the text of the thesis.
- To the best of the candidate's knowledge contains no material previously published or written by another person except where due reference is made in the text of the thesis.
- Where the work is based on joint research or publications, discloses the relative contributions of the respective workers or authors.

A handwritten signature in black ink, consisting of a stylized, cursive 'S' followed by a horizontal line.

Table of Contents

Abstract	ii
Acknowledgments	iii
Student Declaration	iv
Table of Contents	v
List of Figures	x
List of Tables	xii
List of Abbreviations	xiii
Chapter 1: Introduction	1
1.1 CCN and AAC	1
1.2 Impairment and Disability	2
1.3 Thesis structure	2
1.4 Use of design in this thesis	5
1.5 Organisation, location, and participants	6
1.6 The disability day care centre	7
1.6.1 The centre	7
1.6.2 The staff	8
1.6.3 The clients	9
Chapter 2: CCN and AAC	11
2.1 Complex Communication Needs (CCN)	11
2.1.1 Developmental impairments	13
<i>Intellectual Disability</i>	<i>13</i>
<i>Autism Spectrum Disorder</i>	<i>13</i>
2.1.2 Developmental and acquired impairments	15
<i>Cerebral Palsy</i>	<i>15</i>
2.1.3 Acquired impairments	15
<i>Acquired Brain Injury</i>	<i>15</i>
<i>Aphasia and Brain-Stem Impairment</i>	<i>16</i>
<i>Dementia</i>	<i>16</i>
2.1.4 Summary of impairments causing CCN	16
2.1.5 Implications of CCN	17

2.2 Augmentative & Alternative Communication (AAC)	19
2.2.1 Description of AAC	19
2.2.2 AAC assessment, selection and training	24
<i>Assessment of abilities</i>	25
<i>Assessment of functioning with AAC</i>	25
<i>AAC Selection</i>	26
<i>AAC training</i>	26
2.2.3 Barriers to and supports for effective AAC	28
<i>Gaps in current research</i>	28
<i>Design</i>	29
<i>Use of AAC</i>	30
<i>Barriers and support</i>	31
2.3 Summary of chapter 2	34
 Chapter 3: Impairment and disability	 35
3.1 Disability: philosophy and history	35
3.1.1 Marx	36
3.1.2 Discussion: Marx and CCN	37
3.1.3 Foucault	38
3.1.4 Discussion: Foucault and CCN	40
3.2 Culture and disability	42
3.2.1 Cultures	42
3.2.2 Disability culture	43
3.2.3 Discussion: culture	45
3.3 Disability rights, models, and barriers	46
3.3.1 The Disability Rights Movement	46
3.3.2 Models of Disability	49
<i>The Medical Model</i>	49
<i>The Charity Model</i>	50
<i>The Economic Model</i>	50
3.3.3 Discussion of the DRM, and resistance to models	51
3.3.4 Social Models of disablement	53
<i>Normalization</i>	53
<i>Social Role Valorization (SRV)</i>	54
<i>Social model of disability</i>	55
3.3.5 Social Barriers: Disability	58
<i>Attitudinal barriers</i>	58
<i>Environmental barriers</i>	58
<i>Institutional barriers</i>	59
3.3.6 Discussion of the DRM, and adoption of social models	60

3.4 Summary of chapter 3	65
Chapter 4: Communication.....	66
4.1 Processes of communication.....	66
4.2 Models of Communication.....	67
4.2.1 General communication models	67
<i>Linear Model</i>	67
<i>Interactional model</i>	68
<i>Transactional model</i>	70
4.2.2 Discussion of general communication models for AAC users	71
4.2.3 Encoding Decoding Model: power relations	72
4.2.4 Discussion of the Encoding Decoding model	73
4.2.5 AAC and related models.....	74
<i>Closed Cycle Control System for Speech</i>	75
<i>Components of Communication</i>	76
<i>Communication Cycle Model</i>	77
<i>AAC Communication Model</i>	79
4.2.6 Discussion of AAC and related models	81
4.2.7 Summary of Communication models.....	82
4.3 Types of Communication.....	83
4.3.1 Interpersonal communication	84
4.3.2 Mediated communication.....	85
4.3.3 Intercultural communication.....	86
4.3.4 Summary of communication types for AAC users	86
4.4 Communication Theory.....	87
4.4.1 Two overviews of communication theory.....	87
4.4.2 Mediated-communication theories.....	89
<i>Media Ecology</i>	90
<i>Differences between communication forms</i>	91
<i>Successful communication despite limitations</i>	91
<i>Similarities of communication forms</i>	92
4.4.3 Discussion of mediated-communication theories	93
4.4.4 Power-related communication theories	94
<i>Standpoint theory</i>	94
<i>Muted Group theory</i>	94
<i>Co-cultural theory</i>	95
4.4.5 Discussion of power-related communication theories	98
4.4.6 Summary of communication theory	98
4.5 Summary of chapter 4	99

Chapter 5: The Integrity of Message Model	101
5.1 The IMM design process	102
5.1.1 The brief	103
5.1.2 Design development.....	104
5.2 Detailed description of the new model	109
5.2.1 Component one	110
5.2.2 Component two	111
5.2.3 Component three.....	113
5.2.4 Component four.....	114
5.2.5 Component five	116
5.3 Summary of chapter 5	118
 Chapter 6: Initial research direction	 119
6.1 Archival study of AAC aids.....	119
6.1.1 Method.....	120
<i>Results</i>	<i>121</i>
6.2 Reflections on change of direction.....	129
 Chapter 7: Empirical studies	 132
7.1 Focus Groups	132
7.1.1 Method.....	133
<i>Participants</i>	<i>133</i>
<i>Materials</i>	<i>134</i>
<i>Procedure</i>	<i>134</i>
<i>Results and discussion</i>	<i>135</i>
7.1.2 Implications for AAC	143
7.2 Observations.....	145
7.2.1 Method.....	146
<i>Participants</i>	<i>146</i>
<i>Materials</i>	<i>148</i>
<i>Design.....</i>	<i>150</i>
<i>Procedure</i>	<i>152</i>
<i>Data analysis</i>	<i>153</i>
7.2.2 Results and discussion.....	153
7.2.3 Discussion of results.....	171
7.2.4 Summary of observations.....	173
7.3 Parent interviews	175
7.3.1 Method.....	175
<i>Participants</i>	<i>175</i>

<i>Materials</i>	176
<i>Procedure</i>	176
<i>Results and discussion</i>	177
7.3.2 Summary of parent interviews	181
7.4 Staff interviews	185
7.4.1 Method.....	185
<i>Participants</i>	185
<i>Materials</i>	186
<i>Procedure</i>	187
<i>Results and discussion</i>	187
7.4.2 Summary of staff interview	191
Chapter 8: General Discussion and Conclusion	193
8.1 Summary of main findings.....	193
8.2 Theoretical implications.....	197
8.3 Future work	197
Bibliography.....	200
Appendices	A
Appendix 1: Ethics clearance.....	A
Ethics final report.....	A
Ethics modifications and extensions.....	B
Appendix 2: Project information statement and consent.....	C
Project Information Statement	C
Consent form: Focus groups	E
Variations to consent according to study	F
<i>Observations (For neurotypical participants)</i>	F
<i>Observations (On behalf of clients by Centre Director)</i>	F
<i>Parent/staff interviews</i>	F
Appendix 3: Staff interview protocol	G
Protocol for staff	G
Additional questions in protocol for centre management.....	H
Appendix 4: Change of thesis title.....	I
Appendix 5: Further documentation of the IMM physical prototype	J

List of Figures

Figure 1: Diagram of the disability day centre.	8
Figure 2: Means to represent the idea of the noun: bed.	21
Figure 3: Means to select the representation of the idea.	21
Figure 4: Means to transmit the representation.....	22
Figure 5: Linear model (Adaption of the original Transmission Model).	68
Figure 6: Adaption of the Interactional Model.....	69
Figure 7: Adaption of the Transactional Model.....	70
Figure 8: Adaption of the Encoding Decoding Model.	72
Figure 9: Adaption of the Closed Cycle Control System for Speech Model.	75
Figure 10: Adaption of the Components of Communication Model.	77
Figure 11: Adaption of the Communication Cycle Model.	78
Figure 12: Adaption of the AAC Communication Model.....	80
Figure 13: Notes about basic design for the model's shape.....	105
Figure 14: Notes about information contained in the model.....	105
Figure 15: Design of model features, including interaction.	106
Figure 16: Paper prototypes of the model.	107
Figure 17: Laser-cut and other prototypes.	108
Figure 18: The Integrity of Message Model.....	109
Figure 19: IMM component one.	110
Figure 20: IMM component two.....	112
Figure 21: IMM component three.	113
Figure 22: IMM component four.	115
Figure 23: IMM component four: possible results.	116
Figure 24: IMM component five: hidden and engaged AAC bypass.	117
Figure 25: Toilet signage at the centre.....	123
Figure 26: Public-safety signage at the centre.	123

Figure 27: Centre-made signage showing the weather each day.	124
Figure 28: Centre-made picture-based signage, used in the kitchen.	124
Figure 29: Commercial, illustrated PCS picture cards stored at the centre.	124
Figure 30: Commercial, photographic, food picture cards stored at centre.	125
Figure 31: Centre-made, photographic, activity picture cards stored at centre.	125
Figure 32: Example of a section of text-based daily timetable.	126
Figure 33: Example of a text and image-based daily timetable.	127
Figure 34: Example of an IMM result for archival study data.	128
Figure 35: Data from the communication <i>TO</i> clients category.	136
Figure 36: Data from the communication <i>FROM</i> clients category.	137
Figure 37: Categories added for communication among staff and clients.	138
Figure 38: Follow up poster, presented to participants.	139
Figure 39: Example of an IMM result for focus groups data.	143
Figure 40: First iteration of observation protocol sheet.	149
Figure 41: Second iteration of observation protocol sheet.	154
Figure 42: Percentage breakdown of staff-initiated exchanges by category.	156
Figure 43: Percentage breakdown of client-initiated exchanges by category.	157
Figure 44: Total number of on-site communication exchanges per session.	159
Figure 45: Comparison of on-site staff/client-initiated communication.	161
Figure 46: Total number of off-site communication exchanges per session.	165
Figure 47: Comparison of off-site staff/client-initiated communication.	167
Figure 48: Comparison: number of staff-initiated exchanges between locations. ...	169
Figure 49: Example of an IMM result for observation study data.	174
Figure 50: Example of an IMM result for parent interview data.	182
Figure 51: Example of an IMM result for staff interview data.	192
Figure 52: Summary of IMM result examples from empirical research chapter.	196

List of Tables

Table 1: Summary of causes of CCN by impairment.	17
Table 2: Basic AAC process.	20
Table 3: Barriers and supports to positive AAC outcomes.	33
Table 4: Philosophy summary.	41
Table 5: Cultural distinctions.	43
Table 6: A timeline of selected disability groups.	48
Table 7: Three models of disability.	51
Table 8: The process of ‘wounding’	55
Table 9: Social models of disablement.	57
Table 10: Social barriers of disability.	60
Table 11: Summary of Communication models.	83
Table 12: Summary of criteria for evaluating communication theory.	88
Table 13: Co-cultural Communicative Practises summary.	97
Table 14: Summary of Communication theory.	99
Table 15: Summary of features in the Integrity of Message Model (IMM).	118
Table 16: Types and number of AAC identified at the centre.	122
Table 17: General breakdown of staff ages and experience.	147
Table 18: Diagnoses for the 27 clients observed.	148
Table 19: Communication challenges and solution strategies.	183
Table 20: Breakdown of staff participants.	186
Table 21: Participant explanations for lack of AAC use at centre.	189

List of Abbreviations

AAC	Augmentative and Alternative Communication
ABI	Acquired Brain Injury
ALS	Aided-language Stimulation
ASD	Autism Spectrum Disorder
CCN	Complex Communication Needs
CMC	Computer Mediated Communication
CP	Cerebral Palsy
DRM	Disability Rights Movement
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBP	Evidence Based Practice
ES	Empathising/Systemising theory
ICF	The International Classification of Functioning, Disability, and Health
ID	Intellectual Disability
LAMP	Language Acquisition through Motor Planning
NECAS	Non-Electronic Communication Aids Scheme
NDIS	National Disability Insurance Scheme
OPCS	Office of Population Censuses & Surveys
PCS	Picture Communication Symbols
SGD	Speech-Generating Device
SRV	Social Role Valorization
UCD	User Centred Design
UN	United Nations
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organization

Chapter 1: Introduction

1.1 CCN and AAC

Between 1.2 and 1.5% of individuals in Australia, Canada, the UK, and the US have significant challenges in their daily lives because of their lack of verbal communication skill (Beukelman & Mirenda, 2013). These individuals have what is known as Complex Communication Needs (CCN). Therapeutic methods, called Augmentative and Alternative Communication (AAC), are available to help these people to communicate, and there is consensus that these techniques and devices can be beneficial (Beukelman & Mirenda, 2013). Nonetheless, there are challenges to AAC use by people with CCN, including a possible reliance on a variety of other people, as well as organisations for their communication, and a lack of current research about adult AAC users. It is important, therefore, to gather contemporary, and contextual evidence about the communication challenges of these adults, and the environment in which they communicate.

The initial aim of this research was to design new AAC aids for adults with CCN, but with the results of the first study suggesting that very little AAC was used by participants, I changed the aim of the thesis to focus instead on the identification of communication breakdowns among adults with CCN given that lack of use. Thus, two questions were raised that subsequent research sought to answer. Firstly, why are AAC aids and techniques seldom used by participants in the research, and secondly, what communication interference or, noise, exists in this vacuum of use? After an exploration of these topics, a further question was posed: Can an interactive, physical tool be designed and used to identify and present visually the communication breakdowns in these complex environments?

This research addresses these issues by providing data from clients and staff who frequent a disability day centre, a government-funded facility available for the therapy, employment, and entertainment of adults with impairments. The research in this thesis is presented in written form, but also as the physically-designed artefact. The artefact serves as a logical and useful progression of existing research, embodying and extending the data, in the form of an interactive, diagnostic communication model.

1.2 Impairment and Disability

Throughout this thesis, impairment and disability will be discussed at length. While conceptions that “fall under the category of ‘disability’ vary” (Chouinard, 2009, p. 242), especially in mass media (Zhang & Haller, 2013), I will continue to use the two distinct terms wherever possible, with impairment typically referring to the illness, or internal medical condition of a person, and disability typically referring to the external cultural and social factors of disablement.

The use of the term, disability, will intermittently deviate from the binary distinction stated above, where contemporary organisations, fields of study, and procedures use the term in different ways. Examples of this difference in use include ‘disability studies’, ‘disability rights’, ‘disability workers’, and instances where impaired people are periodically called ‘disabled people’ by individuals in these fields of study or organisations. I will therefore use disability in this thesis according to context, and follow the standard use of the terms by medical and other professionals where relevant.

1.3 Thesis structure

In this chapter, I describe the research participants that took part in the studies, as well as the physical location where the research took place. Typically put near the empirical method chapters in theses, these descriptions are presented here in this thesis because I enlisted the cooperation of these participants and the disability day centre early in my research development. This positioning enabled me to focus and refine the subsequent literature review on the health, and communication environment of individuals similar to the clients, staff, and parents involved in this research. This chapter also introduces the design theory used in the development of the new communication model presented in this thesis, with chapter 5 discussing this design process in greater detail.

Chapter 2 presents background information to the two topics noted above: health and communication. The first is an overview of the typical health conditions of adults with CCN. Here I describe the developmental and acquired impairments that affect a person’s speech, and discuss the implications of these in relation to their lack of communication skills. The second is a discussion of available AAC therapeutic

methods. In this latter section, I provide a description of the complex AAC process, including the development, supply, and use of these methods, and assessment and training of AAC users.

Chapters 3 and 4 extend the two topics presented in chapter 2. In chapter 3, I expand upon the discussion about health, by describing external challenges that may affect an individual's communication skills and abilities beyond their impairment. This chapter describes the historical, and current cultural environment that these adults live within, and presents the ways in which these issues are debated and presented. In chapter 4, I describe the processes of communication, highlighting the importance of such for the individual and society. Here I present eight existing communication models that visually and textually represent the act of message exchange.

At the end of chapter 4, a range of communication theories is presented. Some of these investigate the effects of various types of communication on message exchange. This is relevant here given the unique nature of AAC, that often employs different techniques external to an adult user to enable communication. Other theories critically analyse the role of communication in social relationships, especially those that feature a group that is marginalised in some way by another. Adults with CCN typically rely on a network of individuals and organisations for their communication needs, and this can set up challenging power imbalances, potentially resulting in their marginalisation, or disablement.

The discussions here tie in information from previous chapters, presenting a selection of relevant theories that show the relationship between impairment, disability, and communication. The overview of adults with CCN, and their communication challenges, assistance and environment, is completed by the end of this chapter.

In chapter 5, I present the design process, and the features of the Integrity of Message Model (IMM) prototype. This novel, physical, diagnostic tool is a synthesis and extension of the existing communication-theoretical literature, particularly the communication models outlined in chapter 4. Developed using design theory, my knowledge of design, and insight gained during the processes of producing this thesis, the model can be used to identify noise in communication. At the end of each

research chapter, I present an example of an IMM result based on the data analysis to that point in the thesis.

The next chapters outline the studies employed within this research. The initial archival study, conducted to determine the types of aided AAC then stored at the centre, is presented in Chapter 6. As discussed, the original intention was to design refined AAC aids for use at the disability day centre, and the implication from the archival data was that additional, refined AAC would not be used, if the centre environment was not conducive to the use of current aids. Here, I also outline and justify the change of research direction, and suggest some possible reasons for the lack of AAC use in the centre. I also describe the selected methods used in the remainder of the research, used to investigate this limited AAC use, and the blockages to communication in the disability day centre given that limitation.

In chapter 7, I present the six empirical studies necessitated by this change of direction. These include two focus groups with staff participants, two observational studies with staff and clients, one set of interviews with parents, and one group staff interview. The justification for, and the preparation as well as the execution of studies, data analysis, data transcription, interpretation, and reporting of these is outlined accordingly.

In the empirical studies chapter, the two focus groups with staff participants are presented. These were conducted in order to gather opinion-based data about communication challenges in the centre from their perspective. The discussions in these groups were transcribed verbatim, thus enabling contextual quotes to be used as illustrative examples of the topics covered. The participants in these groups noted many challenges in their communication with clients and with each other. As part of this study, I also produced a poster inviting the staff to add or amend any information I might have missed or misunderstood in the focus groups.

Next, the two observation studies I conducted in the centre are reported. These studies, one using an ethological method, and one conducted as a participant observer, were designed to identify and understand challenges from a client, as well as a staff perspective, and to note performance data of the message exchanges among participants. Some statistical information, about the patterns noted in the observed communication, is displayed in this chapter, with the data analysis revealing that staff participants initiated the majority of communication. This study

also supported earlier data, that aided and unaided AAC were seldom used during centre activities.

To further the information gathered from various types of participants, I conducted telephone interviews with two parents of centre clients. These parents played an important role in helping to highlight the communication challenges from a different perspective, in the lives of their dependents away from the centre, earlier in the client's lives or in the evenings after their time at the centre. Parents noted that AAC use was extremely important. I present this study after the discussion about observations, noting contextual quotes from participants.

The final study presented in chapter 7 is the staff group interview. In this method, staff members were asked to complete a written questionnaire asking their opinions about AAC use at the centre, and their thoughts about the analysed data in this thesis to that point.

Following the empirical studies chapter, in chapter 8 I present a general discussion and conclusion comprising a summary of main findings, including IMM results from the research, the theoretical implication of those findings, and some suggested future work for development of the information and the artefact presented in the research.

1.4 Use of design in this thesis

Along with the illustrations presented within the written component of the thesis, I designed the physical IMM tool, the latter a physical manifestation of the understandings I developed from the empirical research, and the literature review (what Matthews and Wensveen, 2014, call a research archetype: see chapter 5). This design development followed a User-Centred Design (UCD) approach (Norman, 2002), and explored the adoption of emerging consumer-level laser-cutting, and innovative digital-printing technology. The prototype was then used to evaluate, formalise, and gain additional insight into the collected, and analysed data.

The UCD approach is, primarily, focused on the understanding of users, and the collection of data from and about them, before a product or service is iteratively designed for them. An exploration of this process was originally intended to inform the development of AAC aids, as outlined in chapter 6, but, when the direction of the

thesis changed, used to develop the IMM instead. The physical design outcome for this thesis, thus, changed from a therapeutic communication tool, to a diagnostic tool used to describe the communication of people with impairments. As impaired adults have a range of abilities, and therapeutic needs, a designer's access to these powerful, and rapid-fabrication techniques, as described in chapter 5, is useful for the timely revision, and customisation of these tools.

1.5 Organisation, location, and participants

With the original focus on the development of new AAC, a suitable location needed to be found to gather contextual information from participants about current AAC design and use. With this aim in mind, I telephoned and emailed five disability organisations to enquire about the types of facilities that were suitable for this research, and whether any centres would be interested in working with me on this thesis. Facilities that were considered included family homes and shared accommodation, where people with impairments lived, and day centres where they spent their days learning vocational and other life skills, while receiving daily, in-house support from professional disability workers.

After liaising with staff from the different disability organisations, one disability day centre indicated their interest in my proposal, and we organised meetings to work through the logistics of such a partnership. An arrangement was subsequently organised, where I was free to conduct research at the centre. As it is a busy organisation, few staff could be spared to help me with my research there, and I was also encouraged by centre management to develop efficient ways to gather evidence at the centre, so as to keep my disruptions to centre routine, with busy staff, and vulnerable client participants, to a minimum. Despite these limitations, the arrangement with the centre was suitable to my needs. They also saw the benefits of my investigation of AAC for their staff and clients.

As discussed, at the completion of the archival study (presented in chapter 6), suggesting that very little AAC was used at the centre, I changed the aim of the research. The centre was very accommodating during and after this change, understood why it took place, and understood what could be accomplished given the new direction. The centre staff could also see potential advantages in obtaining such information, which would be shared with them as a matter of course.

The next section in this chapter describes the disability day centre's facilities, staff and clients, with the sections thereafter describing in more detail some of the mental and physical impairments of the clients, and the communication assistance available for them.

1.6 The disability day care centre

The empirical studies reported later in this thesis were undertaken at one disability day centre in a suburb of Melbourne, Victoria, Australia. By choosing to partner with the centre frequented by AAC users, the data collection and analysis in the research was considerably more efficient and feasible than employing methods for individual participants, in various individual settings, in a number of personal home situations, for example.

Conducting a study within a centre provided administrative and ethical support, as centre management could help with participant recruitment, and a centre director could provide consent as a proxy for groups of centre clients for some methods. The participants in the studies generated in this thesis are adults with an impairment, professional staff who care for them, and parents or family caregivers who drop off and pick up clients each day.

1.6.1 The centre

The centre provides daily care for adults with an impairment, as well as offering opportunities for education and employment. As shown in Figure 1, the centre has three general activity rooms (sensory, craft, and computer rooms), cooking and eating areas, toilets and staff offices. Outdoor areas include a garden.

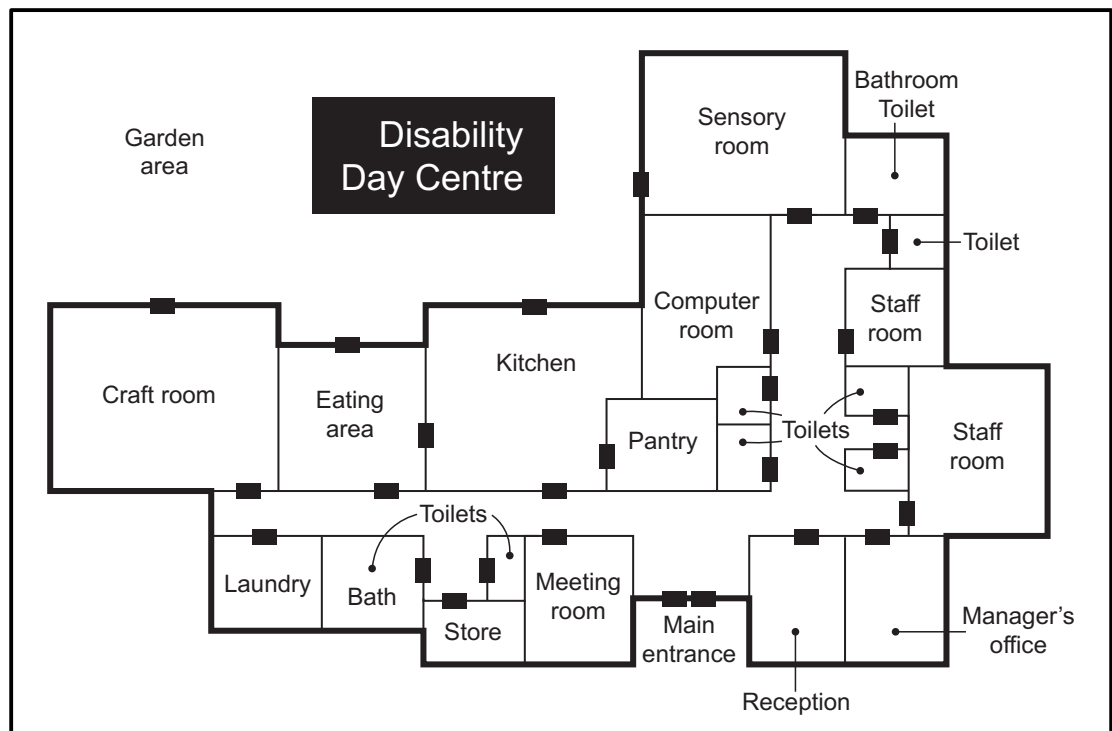


Figure 1: Diagram of the disability day centre.

1.6.2 The staff

The centre has 19 permanent and five casual staff. Staff members have a broad range of relevant experience, ranging from one to 15 years of working in the disability sector. They also have a range of formal training backgrounds. A typical staff member, for example, will hold a CHC40308 Certificate Four in Disability Studies (Australian Government, 2012). This certificate is available to Australian citizens who have successfully completed a Year 12 Victorian Certificate of Education (VCE) or equivalent, or to mature-age individuals who have relevant industry or vocational experience. The qualification allows workers to be employed in entry-level positions in residential and support centres, including disability day centres. Typically, these workers will report to service managers.

In the course of their duties, staff members at the centre are responsible for the care of one or two key clients, but they are also expected to ensure that all clients are cared for in any group activities they supervise. A staff member is selected as a key worker for a particular client based on past experience with, or specific training for, clients who have a particular impairment, their experience with a particular client, or a skill set that matches an activity the client engages in regularly.

1.6.3 The clients

A typical day at the centre includes day-long group activities for various groups of clients. In travel training, for example, clients are taken on public transport to practise independent travel skills, and in cooking sessions, the clients cook, serve and eat food. In household tasks and fleet cleaning, clients and staff clean the centre's transport (mini-vans) and the centre's rooms, and in sensory sessions, clients interact with objects chosen for particular attributes such as an object's texture, or the sound they make when played with or squeezed. Finally, personal development sessions are designed to help clients learn to advocate for themselves and be assertive.

Clients take part in a particular activity according to their perceived or expressed preferences, because staff feel particular clients would benefit from some training or experience, or to vary the stimuli or experiences of a particular client throughout a week. Staff are also careful to separate clients who present with problem behaviour when in close proximity with other particular clients.

Clients come to the centre to take part in these group activities, as well as in certain organised educational activities associated with basic courses off-site at nearby vocational tertiary institutions. Sessions such as cooking are held on most days, while activities away from the centre, such as travel training, or bowling, occur once each week.

Each of the 75 clients frequenting the centre has typically been diagnosed with more than one impairment, although all have some form and degree of intellectual disability (see chapter 2). The many mental impairments affecting clients include Autism, Cerebral Palsy, and Down Syndrome.

Many of the clients also have additional physical impairments, including Epilepsy, various forms of blindness, Diabetes, and Progressive Spastic Paralysis. Diabetes is a condition where the body cannot maintain healthy levels of glucose in the blood, which is the main source of energy for the body. Unhealthy levels of glucose can lead to long- and short-term health complications (Healey, 2007). Progressive Spastic Paralysis is a condition where nerve damage or dysfunction causes stiffness and gradual tightening and permanent bending of the lower limbs (Parker & Parker, 2002).

Conditions that affect clients physically and intellectually include Cornelia de Land syndrome, Fragile X Syndrome, Dyspraxia, and Prader Willi Syndrome. Cornelia de Land syndrome is a genetic condition that causes severe physical and intellectual anomalies (Lacassie, Bobadilla, & Cambias, 1997). Fragile X Syndrome is associated with behavioural and learning challenges, and various intellectual and physical abnormalities (Harris, 2005, p. 232). Dyspraxia is an intellectual impairment that makes it difficult for a person to plan and coordinate their physical movement (Colley, 2006). Prader Willi Syndrome is associated with intellectual challenges, behavioural problems, and obesity (Harris, 2005, p. 225). These conditions affect the clients in many different ways, so that a broad range of abilities is distributed among clients throughout the centre, individuals ranging from non-ambulatory, non-verbal people to verbal people with a moderate intellectual condition.

With a general understanding of the participants at the centre, in the next chapter I outline Complex Communication Needs (CCN) by describing some of the related impairments of the clients, as well as describing the methods and aids employed in AAC. This next chapter is relevant to both the original and the revised directions in this research. The centre's client participants are the same in both cases, and an understanding of AAC is also appropriate regardless of the research focus and the current use of AAC at the centre. That is, descriptions of the existence and engagement with AAC at the centre would, in any case, be important.

Chapter 2: CCN and AAC

Before solutions to the problems presented in this research can be effectively discussed, the fundamental terms used in related literature need to be outlined. The next three chapters will present this information, with this chapter detailing two main topics, and the subsequent two chapters extending this information in various ways.

Here, I outline CCN and AAC, the former a term used to describe a lack of verbal communication skill, and the latter a series of methods used to help individuals with CCN to communicate. I discuss some causes, as well as the implications of CCN, and outline many aspects of the design and use of AAC interventions. This chapter also serves to explain why this thesis has a focus on AAC used by *adults* with an *impairment*.

2.1 Complex Communication Needs (CCN)

CCN is a widely used term describing the inability of an individual to meet their daily communication needs by using speech alone (International Society for Augmentative and Alternative Communication, 2012). The term typically refers to an individual's impairment, or mental and physical condition affecting their own verbal communication. The ways in which these impairments affect speech are discussed later in this chapter.

There are also many ways in which the various features of an external environment can influence communication effectiveness, and this concept of disablement, discussed in later chapters, is central to this research. While some studies do suggest that there is a “parallel between ‘ordinary’ people operating in an ‘extraordinary’ environment (for example, high work load, adverse noise or lighting conditions), and an ‘extra-ordinary’ (impaired) person operating in an ordinary environment” (Newell & Gregor, 2000, p. 18), this thesis will focus on *impaired individuals* and their communication challenges with regard to their impairments, in addition to the further, debilitating effects of external pressures on that communication.

Individuals with CCN are sometimes described as being non-verbal or verbal. The former term is typically used to suggest a lack of any ability to make noises or use spoken word to communicate. The latter is used to denote any “vocalisations that are communicative in nature”, which could include:

...voluntary vocalizations, such as yawning, laughing, crying, moaning, yelling, and belching, that often signify physical or emotional states. Some individuals are also able to produce vocalizations that substitute for speech, such as “uh-huh” for yes or “uh-uh” for *no*. Such vocalizations may be idiosyncratic and may require interpretation by people who are familiar with these individuals’ repertoires of vocal signals (Beukelman & Mirenda, 2005, p. 41).

Some individuals with CCN have more advanced verbal skills, but their spoken words, or their contextual meaning, may be difficult to understand by unfamiliar communication partners.

To continue with a look at impairment affecting speech: published prevalence reports from various nations show that between 1.2 and 1.5% of individuals (Australian Bureau of Statistics, 2015; Perry, Reilly, Cotton, Bloomberg, & Johnson, 2004) have CCN. This lack of or interference with vocal ability can be temporary or permanent, due to acquired impairments (from surgery or physical trauma) or developmental impairments (such as an impairment affecting them from birth) (Speech Pathology Australia, 2013).

As discussed, individuals with CCN may have comorbidities, or “associated conditions” (Baron-Cohen, 2008b, p. 99). That is, they have more than one of these physical or mental impairments. Note also the subsequent application of the word, neurotypical, in this thesis, a shortening of the phrase, neurologically typical, used to describe people who do not have an impairment and are, typically able, or, ordinary (Sinclair, 1998).

A small selection of these impairments is described next, in order to show a variety of CCN causes, presenting some developmental and acquired conditions, with mental and physical challenges. A summary of these then follows, with a discussion about the implications of CCN, before AAC methods are described.

2.1.1 Developmental impairments

Intellectual Disability

Intellectual Disability (ID) is a blanket term used to describe “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development” (World Health Organization, 2016. para. 1). The term ID describes individuals:

...who have intellectual impairments. It also encompasses (individuals) who have been placed in institutions because of perceived disabilities or family rejection and who consequently acquire developmental delays and psychological problems (World Health Organization, 2016. para. 3).

Other developmental and acquired impairments, with physical and mental challenges, are presented next.

Autism Spectrum Disorder

One of the causes of CCN is Autism Spectrum Disorder (ASD, or Autism), a developmental impairment that occurs in 1% of the population and results from atypical neurodevelopment (or irregularity in brain formation) (Baron-Cohen, 2008b). Since 2013, with changes to what constitutes Autism in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013), the spectrum now includes Asperger Syndrome, as well as Classic Autism. As suggested with the use of the word, spectrum, there is a large range of abilities of those with Autism. With Classic Autism (or low-functioning Autism), IQ can vary, but there is generally a language delay in early life. With Asperger Syndrome (or high-functioning Autism), there is average or above-average IQ with no language delay and often above-average language development. Both have the same diagnosis because they share difficulties in:

- Social functioning, as they typically lack empathy for other people.
- Communication, where low-functioning Autistics may have little or no spoken word skill or comprehension, and high-functioning Autistics may have difficulty interpreting lateral-type communication, such as the use of sarcasm and metaphors.
- Sensory input, where certain textures or noises can be disruptive and unpleasant for them.
- Coping with change, as in a disruption to their daily routine.

Individuals with Classic Autism and Aspergers also have unusually narrow interests, from repetitive behaviour, such as rocking or uttering the same sound repeatedly at the lower-functioning end of the impairment (with Classic Autism), to speaking about one topic at length in great detail at the higher-functioning end of the impairment (with Aspergers) (Baron-Cohen, 2008a).

Both of these spectrum extremes are relevant when describing individuals with CCN. While those with Classic Autism can have little or no spoken word skills, and an inability to comprehend verbal communication fully, individuals with Aspergers may still need AAC help with their communication because of their challenges with social skills and comprehension. Indeed, two features of ASD have been described as potentially advantageous when using AAC. First, the narrow-focus, systemising aspect of the condition is seen as positive in one theory, called Empathising/Systemising theory (Baron-Cohen, 2008a), where ASD is described as an impairment with regards to a person's lack of empathy, but a talent when referring to their strong organisational ability. Second, other researchers describe autistic people as being strong visual learners (Grandin, 2006; Schuler & Baldwin, 1981). Consequently, AAC interventions can cater to these strengths, with aids designed for these and other individual needs and abilities. Before I discuss this further, I highlight in the next section some of the physical challenges those with CCN face.

2.1.2 Developmental and acquired impairments

Cerebral Palsy

While the communication challenges of individuals with ASD come from their cognitive conditions, those with Cerebral Palsy (CP) are challenged with physical limitations. CP is a variety of impairments that affect an individual's movement, balance, and posture. These individuals may not be able to speak because they lack control of necessary mouth and jaw muscles. CP is seen as either a developmental impairment or acquired brain injury, depending on when brain damage occurs in the person's life, as an individual can be affected before or after birth, by genetic predisposition, or by external forces such as a physical accident (Ballin & Balandin, 2007).

While CP is not seen as being a progressive condition, secondary problems such as muscle tightness and other internal issues can bring on early arthritis and speed the ageing process. This onset of various physical challenges (including the lack of muscle control) can affect their medical care, with some doctors and medical procedures requiring a patient to sit still during many types of treatment (McNaughton & Beukelman, 2010, p. 183). Furthermore, individuals with CP may lack the necessary physical skills to operate some of the AAC aids (described later in this chapter), intended to help them communicate.

Further to the discussion of early ageing interfering with communication, the gradual, natural ageing of an individual can also bring on CCN. Having discussed a range of mental and physical issues arising from developmental factors, in the following section I briefly extend the discussion about ageing and other acquired impairments, with an outline of Acquired Brain Injury.

2.1.3 Acquired impairments

Acquired Brain Injury

Including some types of CP, many other acquired conditions can occur from different types of brain damage. While individuals with ASD and CP may have their whole lives to adjust to their communication limitations, people with Acquired Brain Injury (ABI) deal with these limitations in other ways, with sudden trauma causing

potentially immediate impairments such as Aphasia or Brain-Stem Impairment, or a gradual onset of an ageing disease causing conditions such as Dementia, that typically occur later in a person's life. While these conditions and those discussed earlier in the chapter occur because of development or accident, the latter also has more profound implications to the study of CCN and AAC, discussed below.

Aphasia and Brain-Stem Impairment

Aphasia is an impairment that results from damage to the part of the brain that controls language, interrupting the sequence of the neurological steps required to communicate. This interruption can cause a person to struggle with various parts of the communication process, from using to understanding verbal speech. Typically, a Cerebral Vascular Accident (CVA), or stroke, causes this condition (Beukelman & Mirenda, 2005). Another immediate-onset condition, similar to aspects of CP, is Brain-Stem Impairment, which is caused by accidents that disrupt the circulation serving the lower brain-stem, so the nerves and muscles of the face, mouth, larynx and other controls necessary for verbal communication are affected (Beukelman, Ball, & Fager, 2008).

Dementia

Unlike immediate-onset conditions, Dementia is a disease typically categorised by a gradual loss of function, in this case with memory loss. Individuals with Dementia have difficulty with communication because of the challenge of keeping track of conversation and retrieving mental information during the process. This disease, associated with ageing, in particular, will have profound effects on society in the years to come, because the percentage of ageing people is growing rapidly, with the number of people in Australia 64–84 years set to “grow by an average 3.5% per year...to 4.0 million in 2022” (Australian Bureau of Statistics, 2009b, para. 13).

2.1.4 Summary of impairments causing CCN

In summary, Table 1 outlines a cross-section of some of the typical causes of CCN by impairment. This is followed by a discussion about the implications of CCN.

Table 1: Summary of causes of CCN by impairment.

Impairment	Developmental?	Acquired?	Characteristics	Effect on communication
Intellectual Disability	yes	yes	Language loss: Mental challenges	Difficulty understanding and using speech
Autism	yes		Language loss: Mental challenges	Difficulty understanding and using speech
Cerebral Palsy	yes	yes	Language loss: Physical challenges	Difficulty using speech
Aphasia		yes	Language loss: Mental challenges	Difficulty understanding and using speech
Brain-stem Impairment		yes	Language loss: Physical challenges	Difficulty using speech
Dementia		yes	Memory loss	Difficulty following conversation

2.1.5 Implications of CCN

Having outlined some of the ways in which individuals develop or acquire CCN, (but before I present AAC methods, intended to help them with these challenges) I will discuss the implications of CCN on the individual and society. As described below, there are indications of the level of importance given to effective communication, with studies that outline the large percentage of time people spend communicating, others that present ways in which it is essential to daily life, and the inclusion of communication as a topic in government census questions, international health statistics and human rights documents.

Donne's famous statement, "No man is an island" (Fetzer, 2010), Freud's insistence of our need for interpersonal contact (Moser, 2006), and Maslow including "love and belongingness" in his Hierarchy of Needs (Block, 2011, p. 914), all support the idea that the intimate nature of communication has historically been discussed as important. Additionally, a study of business relationships, describes some 80% of a person's time at work is spent communicating with colleagues and clients (Nellermoe, Weirich, & Reinstein, 1999). Other studies outline the myriad reasons that people communicate; that the communication act takes place in an attempt to

get physical, identity, social and practical needs met (Adler, Rosenfeld, & Proctor II, 2001, p. 7); or as a need for affiliation, achievement, control; or the reduction of anxiety or uncertainty (Griffin, 2012, p. 474).

The essential act of communication is also discussed. Two academics (Baumeister & Leary, 1995), present the idea that:

...first, there is a need for frequent, affectively pleasant interactions with a few other people, and, second, these interactions must take place in the context of a temporally stable and enduring framework of affective concern for each other's welfare (p. 497).

Further research suggests that effective communication skills are essential to a person's ability to take part in society, to "obtain appropriate housing, engage in ongoing meaningful activities, receive a reliable income and needed services, and gain access to opportunities for social interaction" (McNaughton & Beukelman, 2010, p. 12). Indeed, four ways in which various international organisations collect or present information about this topic, highlight this essential nature of effective communication.

Firstly, government census documents present questions about communication challenges, in Australia (Australian Bureau of Statistics, 2009a), and in the United States (Center for Disease Control and Prevention, 2015). Secondly, The United Nations (UN), states in Article 19 of the *Universal Declaration of Human Rights*, that "everybody has the right to freedom of opinion and expression" (United Nations, 1948). Thirdly, the UN states, in Article 21 of the *Convention of the Rights of Persons with Disabilities* (United Nations, 2014), that those with a disability have the freedom to "seek, receive, and impart information and ideas on an equal basis with others and through all forms of communication of their choice". Finally, chapter three of *The International Classification of Functioning, Disability, and Health* (ICF), from the World Health Organization (World Health Organization, 2001), outlines voice and speech functions as one of eight main body structures that determines a person's level of health and ability (p.71).

Studies also describe the implications of a lack of effective individual communication skill as being a common cause for relational breakups (Mirenda & Iacono, 2009, p. 443), loneliness in older people (Ballin & Balandin, 2007), and even physical illness

(McDaniel & Johnson, 1975). Some individuals with a mental illness may also use “challenging behaviours, such as spitting, vomiting, biting, hitting, breaking objects, running away and tearing clothes”, as examples of how “various behaviors are calculated to achieve their desired ends. Moreover, the behaviors described appear to be finely tuned to convey not only wants and needs, but also ideas” (Olney, 2001, p. 89).

There is also the social and financial cost of supporting individuals with CCN, who may find it difficult to work, or who need support for depression and other conditions resulting from isolation and exclusion from society (International Society for Augmentative and Alternative Communication, 2014). The National Disability Insurance Scheme (NDIS), for example, is “expected to support approximately 460,000 people and cost \$22.2 billion per annum’, when it is ‘fully-rolled out’ in 2019 and 2020” (Windholz, 2014, p. 89).

With the importance of effective communication supported by individual studies and international focus, and the implications of CCN described above, in the next section, AAC, I will present the therapeutic methods available to assist those with CCN to communicate.

2.2 Augmentative & Alternative Communication (AAC)

In presenting AAC, I will segment this section into three; firstly, with a description of AAC; secondly, with an overview of AAC assessment, selection, and training; and finally, with an outline of some of the barriers to and supports for effective AAC.

2.2.1 Description of AAC

AAC is an alternative means of communication for people who cannot use spoken language effectively. Speech Pathology Australia (2013), outlines the various forms of AAC below as:

... any type of communication strategy for people with a range of conditions who have significant difficulties speaking. There are two main types of AAC: aided AAC and unaided AAC. Aided AAC is any external item used to aid communication (e.g. object symbols, communication boards, books, key-ring mini-cards, wallets, speech generating devices, computers, mobile phones,

tablets). Aided AAC includes both high technology systems and low/light technology systems. Unaided AAC refers to communication techniques that do not require the use of an external aid. That is, the person uses whatever is available to them, generally their own body. Examples of unaided AAC include using eye contact, facial expression, body-language, gestures and manual sign (p. 1).

A clear explanation of this range of alternative communication methods extends the aided/unaided delineation beyond the description in the quote above. This explanation, presented in Table 2, splits the AAC process into three, as a list of ways in which an idea can be represented, the representation selected, and the representation transmitted to another person, with each category split into aided and unaided means.

Table 2: Basic AAC process.

(Lloyd, Quist, & Windsor, 1990, p. 178; Soto & Merrell, 1995).

Means to represent idea		Means to Select Representation		Means to Transmit representation	
Aided	Unaided	Aided	Unaided	Aided	Unaided
Tangible (real) objects	Gestures	Mechanical pointers	Blinking	Communication boards	Direct Transmission
Drawn pictures	Sign Language	Switches	Body movements	Communication charts	
Photographs	Finger spelling	Mechanical indicating devices	Eye gaze	Communication cards & books	
Graphic symbols	Eyeblink alphabet codes	Electronic indicating devices	Gesturing	Adapted/dedicated computers	
Visual languages	Pantomime		Pointing (with body part)	Specialist AAC computers	
Written words	Spoken language		Speech	Paper and pen	
Braille/tactile languages			Vocalisation		
Synthetic Speech			Writing		

To illustrate these categories, some examples of means to represent an idea (Figure 2), select the representation (Figure 3), and transmit the representation (Figure 4), are presented below.

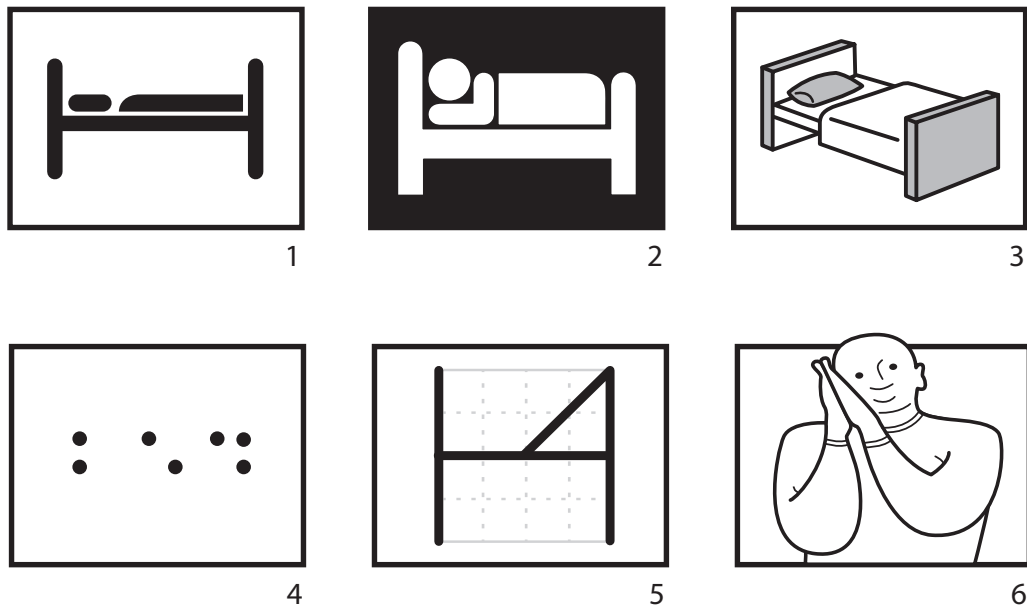


Figure 2: Means to represent the idea of the noun: bed.

Graphic symbols (1 & 2), isometric pictogram (3), and diagrams showing Braille (4), a Bliss-symbol (5), and manual sign language (6).



Figure 3: Means to select the representation of the idea.

Unaided finger pointing (1), aided head-pointer (2) and aided mechanical switch (3).

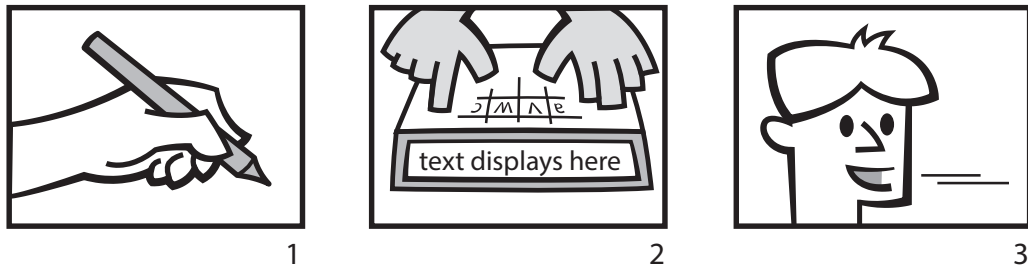


Figure 4: Means to transmit the representation.

Aided pencil & paper (1), aided specialist type-to-text computer (2), and unaided direct transmission with speech (3).

If a person wanted to use a picture to represent the word, bed, for example, and selected its picture representation using an assistive head-pointing device, then transmitted the picture through a computer email program, each of these three means would be aided. This method may also indicate that this person would be familiar with picture-symbol sets, and has motor-skill issues because of the need to use the prosthesis (and not their hands), to select and then electronically send the picture. Alternatively, if a person were able to use spoken language to represent, bed, and the spoken word to select and transmit the idea directly to someone else, then the whole process would be unaided. Note that with the focus of this thesis being about impairment/disablement and communication, AAC that is controlled externally to a user is relevant to this study, because of the effect this can have on a user's independence. This includes aided AAC, but also forms of unaided AAC, where users rely on their own body, but may need external support to learn a technique such as sign language.

As suggested in Figures 2, 3, and 4, components of the AAC process can be used in various ways. Two dimensional images, for instance, can be used:

- As separate ideas, by selecting or exchanging a printed graphic symbol representing an object to request or receive the real version of the object (Sulzer-Azaroff, Hoffman, Horton, Bondy, & Frost, 2009).
- As phrases, by arranging many printed or electronically displayed symbols in a row to represent a sentence visually (Patel, Schooley, & Wilner, 2007).
- As a graphic language, by arranging lines or images in patterns that represent language (Locos Language; Bliss-symbols; Icon Language; hieroglyphics), in much the same way as written words (Mizuko, 1987).

- As a tactile language, where geometric images are arranged in patterns, then embossed so as to provide a raised surface that can be interpreted by a blind person's fingers (Burns, 2015).
- To promote a personal interest in a user's communication, by using photographs (of family members, environments or activities) in print, in a communication-book, or in an electronic device application, such as Proloquo-to-Go (Sennott & Bowker, 2009).

In addition to the use of graphic imagery, there is a variety of ways in which other audio and visual communication is possible on electronic devices. These devices are called assistive technology, or assistive devices, and are "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (US Government, 1998, Section 3 (3)). Communication assistive devices (Robitaille, 2010) include:

- In-ear Devices, designed to help those with limited or altered verbal skills (speech impediments). Some play a live recording of the user's voice in their ear to help them speak more effectively.
- Speech Generating Devices. The display screens on these devices are designed to let users select words, phrases or pictures to be spoken aloud by the device. For younger users, this limited number of pre-selected phrases can be triggered by pressing the equivalent symbol on a screen. For older users, synthesized speech can say whatever is entered into the device (with a variety of means to select the representation).
- Hand-held devices, including pens that scan and read written text, then speak or show the verbal or written equivalent, or software that displays visual schedules, or arranges typed information in various visual formats.
- Augmented or specialised computers, smartphones and tablets. These are either specifically made for AAC use or contain AAC applications that mimic AAC methods (using images, text, or animation) on small devices.
- Augmented home telephones that include features converting text-to-speech for non-verbal users or speech-to-text so deaf users can receive communication.

- Devices containing social media applications, with texting, live chat, and video conferencing.

Note here that AAC is ideally multi-modal, with a variety of aids and techniques in use by one person, depending on what is needed at a particular moment, or the contextual nature of the environment. A bulky, paper-based system may be inappropriate in a cramped environment, and an electronic device that generates artificial speech unsuitable in a noisy street environment, for example.

Given this overview of AAC type, and the breakdown of the basic alternative and augmentative process, in the next section I describe how a person's functional and communication skills (before and after AAC use) can be assessed, and how this can facilitate the matching of AAC aids to users. An outline of AAC training techniques, and barriers and supports to effective use then follow.

2.2.2 AAC assessment, selection and training

Despite the availability of a large number of AAC aids and techniques, and because users have developmental or acquired impairments, with physical and mental limitations, these individuals may not be able to source or set up AAC for themselves, and may require assistance in a variety of ways. Some of the experts a person with CCN typically rely on for assistance could include immediate or extended family, paid or voluntary carers, teachers and teacher's aids, speech-language pathologist, physician, occupational therapist, physiotherapist, social worker, educational therapist, psychologist, rehabilitation engineer, and vision specialist (Family and Community Services, 2016, p. 26).

All of the individuals above can provide evidence for the abilities and needs of a person with CCN, with this evidence-based practice increasingly seen as vital to the effective individual assessment, and the assignment and use of AAC for a user:

An evidence-based practice (EBP) approach to clinical practice emphasizes the importance of integrating sound research evidence into the decision-making process" (Schlosser, 2004, p. 1).

For example, immediate family members, such as parents, sometimes tasked with caring for their impaired children throughout adulthood, typically have useful and

intimate knowledge of their dependant's needs. A physician could provide information about a person's physical or mental challenges, such as the onset of Dementia, while a speech pathologist could give some insight into the expressive (ability to use communication) and receptive (ability to understand communication) abilities of a person.

As well as using anecdotal family and professional medical information to determine the suitability of AAC methods for users, specific AAC assessment techniques have been developed. These techniques fall into two categories: those that identify a person's abilities; and those that assess a person's functional skills as they relate to AAC use. Techniques from both categories are now briefly discussed.

Assessment of abilities

Ahead of AAC use, a person's abilities can be assessed in many ways. Questionnaires and checklists can be employed, completed by a potential AAC user or a professional observing a user's daily activities. The ICF Framework (Simeonsson et al., 2003), can be used to define a person's level of functioning, associated with their health, cultural, and personal factors. Questions from the ICF health care and mobility question section include, "Do you use any assistive device such as glasses, hearing aid, wheelchair, etc.?", and, "Do you have any person assisting you with your self care, shopping or other daily activities?" (World Health Organization, 2003, p. 10).

Other methods, such as the Triple-C Checklist (Iacono, West, Bloomberg, & Johnson, 2009), the Communication Matrix (Rowland, 2011), and the Profile of Functional Impairment (Linscott, Knight, & Godfrey, 1996), specifically assess abilities related to various forms of communication. Some of the statements on the Triple C checklist, for example, include determining whether a person with an impairment "gives or shows an object to a person to obtain an action", or "uses photos, pictures or signs for choice making" (p. 53).

Assessment of functioning with AAC

Various measures exist to determine the functional skills of a person as they relate to AAC. These include those that critique an AAC user's participation in social interaction, such as the Participation Model (Light, Roberts, Dimarco, & Greiner,

1998), and those that assess a user's performance and satisfaction with an AAC aid (Demers, Monette, Descent, Jutai, & Wolfson, 2002).

Additionally, four communication competencies can be measured in a user's experience with AAC (Light & McNaughton, 2014). These include Linguistic (use of means to represent an idea), Operational (technical use of the AAC device), Pragmatic/Social (taking turns, initiating, maintaining and terminating conversations), and Strategic competencies (use of control communication, such as, slow down, and, I don't understand).

As well as family members and professionals using various measures to collect information about the abilities of AAC users, and their AAC use, there are considerations when selecting appropriate AAC aids.

AAC Selection

With information from the assessment of a person's abilities and functionality, techniques such as Feature Matching (International Society for Augmentative and Alternative Communication, 2012) can then take place, to determine a person's abilities, and their need for AAC tools and methods. For example, a person's motor skills would determine what controls an electronic-based device would include, and their preferences for and understanding of different types of means to represent ideas, would determine their use of symbols sets.

One project that attempts to match the abilities of impaired users with appropriate AAC is the Non-Electronic Communication Aids Scheme (NECAS) (Iacono, Lyon, Johnson, & West, 2013). This is a government-funded scheme in Australia, intended to provide low-technology aids to individuals with CCN.

AAC training

With potential tools selected, then matched to a user, there is a number of ways in which professionals help people to use AAC. These include helping a user identify the meaning of various means to represent ideas, matching a person's physical abilities to a communication method, and establishing a core vocabulary to use in their communication. A selection of these types of methods is now described.

Aided-language Stimulation (ALS) (Jonsson, Kristoffersson, Ferm, & Thunberg, 2011) is a process where a therapist or teacher uses verbal speech in conjunction with an alternative idea-representation (Figure 2) to teach the correlation between the two (for example, speaking the word, bed, while indicating the picture or written text for the same idea). This combination teaches symbol meaning and models language skills, with some methods complete when a user becomes familiar with the symbol meanings, when the verbal component may be longer needed. The ways in which some symbol sets are set up, help to reinforce this educational use of linkage, by including the written text representing an idea above the drawn image of the same idea, colour coding different images to group similar concepts together, and, as discussed earlier, using photographs familiar to a user to promote a personal interest in developing their AAC skills (Mirenda & Iacono, 2009).

Motor planning is a technique intended to teach a series of repeatable motor tasks that can achieve predictable results. As discussed earlier in this chapter, individuals with Autism, who typically dislike change, and who possess narrow fields of interest, can benefit from this technique. Once steps have been learned, this method is intended to give a user the independence to form their own communication. The Language Acquisition through Motor Planning (LAMP) method, for instance (Bedwani, Bruck, & Costley, 2015), takes users through repeated physical steps, manipulating the controls of a Speech-Generating Device in a particular sequence, to access and use familiar words or sentences stored on the unit.

Core Vocabulary methods (Clendon, Sturm, & Cali, 2013) are intended to develop the use of a small number of frequently occurring words or ideas for effective social and needs-based communication. These are used by therapists repeatedly with users in an attempt to ensure a manageable, useful set of ideas or words become familiar to them. Lists vary according to the age and abilities of the user, and the environment in which communication is expected to take place.

With an explanation of CCN, and various aspects of AAC, in the final section of this chapter I discuss the barriers to, and supports for effective AAC use for adults with CCN. This will conclude the initial overview of the clients in the disability centre, and current methods that exist to help them communicate. With this thesis exploring the nature of impairment/disability and communication, the next two chapters will continue to explore the challenging nature of AAC, in relation to the relationship

between impairment and disability (see chapter 3), through communication theory (see chapter 4).

2.2.3 Barriers to and supports for effective AAC

As discussed above, AAC is a sophisticated process, and users with different physical and mental impairments, abilities, and needs typically require the assistance of a number of people to be able to communicate effectively. As well as this, a person's conditions, abilities and needs change over the course of their lives, or in different situations. The final section of this chapter will present barriers and supports in four ways: the first including gaps in current AAC research; the second including issues with AAC design; the third including challenges in the use of AAC; and the fourth including AAC barriers and supports.

Gaps in current research

With the variety of individuals with CCN, and types of therapeutic AAC aids available to them, there is no one study that can provide overarching information relevant to all users (Howlin, Goode, Hutton, & Rutter, 2004; Schlosser & Raghavendra, 2004). This means there are a myriad of studies researching a wide range of different areas in this field. While there is general consensus that well-matched AAC intervention can be beneficial (Light & McNaughton, 2014), there are research gaps (Dawe, 2006), and one in particular shapes the subsequent information in this thesis, described below.

As outlined briefly in the introduction to the thesis, effective AAC use can require the assistance of different people and organisations, and those people who have access to those resources benefit, with professionals existing in those environments. Consequently, there is more research about children (who frequent compulsory education environments as part of primary and secondary school) than there is about adults, who have typically left those support networks.

While these adults exist in a world with sophisticated neurotypical expectations (with assumptions about seeking employment, tertiary education, and participation in social activities), the limited adult research has mainly focused instead on techniques to control some of this group's problem behaviour, outlined earlier in this section (Iacono, Johnson, & Forster, 2009, p. 454). With this in mind, this thesis

contributes to the research about adults with an impairment, who have CCN and who use, or could benefit from using AAC. The remaining sections are particularly relevant to adult use. With adult expectations of AAC users, the effective design, use, and support of AAC aids is important.

Design

With a focus on adult AAC users, the nature of adult communication can bring about many challenges in the design of therapeutic aids. The negative aspects of AAC design, for instance, can include:

- A lack of age-appropriate means to represent an idea. This could be as a graphic style, in the inappropriate use of juvenile-styled drawn pictures, or as content, as the lack of appropriate means-to-represent adult concepts needed to report crime, participate in employment or further education, or communicate sexual and personal information (Bryen, 2008). While the design of simple images is typically intended to match a user's cognitive level, not all users want or benefit from the use of child-like image sets to represent their communication.
- The exclusion of creative professionals in the design of AAC, including graphic design professionals who understand the use of space and colour and interface experts who understand usability (Patel et al., 2007).
- The inappropriate design of devices. Therapeutic devices "must be aesthetically pleasing, age appropriate, fashionable, and culturally and socially acceptable. Devices that look 'handicapped' are not adopted" (Francis, Firth, & Mellor, 2005, p. 1).
- The lack of evidence-based practice in some AAC design, with financial gain or a preoccupation with certain forms of technology replacing sound assessment and support techniques (Schlosser & Raghavendra, 2004).

Notwithstanding the appropriate design of AAC aids, the ways in which the aids are used can still be challenging. A small selection of these issues is discussed next.

Use of AAC

Adults with CCN not only need appropriately designed aids to perform adult tasks, but they also need to communicate in a society full of neurotypical speakers, who are familiar with a daily use of rapid, sophisticated verbal language, with typical motor skills and abilities, and infrastructure that primarily caters to this latter group. Use of an alternative or augmentative communication system in this environment can be problematic, and two of the issues in this case are:

- The slow rate of aided-AAC use, as the “conversational speaking rate of natural speakers who do not have disabilities vary from 150 words per minute to 250 words per minute” (Beukelman & Mirenda, 2005, p. 67). Additionally, natural speakers can employ other skills in their communication, including context, timing, and other sophisticated means to infer meaning in even the most poorly-worded exchanges. Alternatively, “the AAC rates of those who use aided symbols were reported to be less than 15 words per minute under most circumstances. In many cases, the rates are much less – often two to eight words per minute” (Beukelman & Mirenda, 2005, p. 67).
- The difficulty in inferring meaning from certain types of graphic symbols. Some alternative representations of an idea are easier to understand than others. For example, “symbols for nouns are easily learned given that they are concrete and therefore easier to depict visually...In contrast, verbs, which contain a high level of abstract semantic information, tend to yield symbols that appear more visually complex and less iconic” (Patel et al., 2007, p. 63). Additionally, “verbs may be more complex to depict because of the difficulty of rendering a dynamic event using static images” (p. 63).

Such issues are made more challenging when other communicators fail to give appropriate attention or fail to understand an AAC user’s attempt at communication. The role of support staff and family members is important, as is the patience and tolerance of members of society for different modes of communication. Some of these AAC support challenges are described next.

Barriers and support

As discussed in the AAC assessment, selection and training section, effective AAC may require the support of many professional carers and family members. The logistics of organising this group of people can be challenging, and just one of the barriers to effective AAC use. Three other barriers are presented below.

Firstly, the variation in the motivations and skills of the support group. Australian census data indicate, for example, that approximately 45% of primary family carers cited, “emotional obligation”, and between 20 and 30% cited, “had no other choice” or, “no other care arrangements available”, for their reasons to look after family members with an impairment (Australian Bureau of Statistics, 2015, para. 15). There is also a “practical challenge that comes with finding the time to develop and implement the aids” (Trembath, Iacono, Lyon, West, & Johnson, 2014, p. 898), and challenges as parents reach older ages and struggle with their own abilities. Furthermore, disability support workers’ reports showed that:

...frequent turnover of staff, inadequate training and inadequate support had a clear bearing on the extent to which the adults with ASD in this study were supported to use AAC, leading to inconsistent support and, at times, abandonment of AAC. However, their reports also indicate that the individual attitudes of those in a position to support their use of AAC also played a key role in determining the level of support provided. The results also suggested that even as individuals, the support workers we interviewed were at times inconsistent in their views and support towards AAC. That is, while some expressed strong support for one mode of AAC, they were reluctant to consider other possible modes for the adult with ASD they supported due to their personal views and judgements (Trembath et al., 2014, p. 898).

Secondly, the overall lack of support from professional services. A report about speech, language and communication impairments reports a number of issues, such as a lack of trained specialists, lack of publicly-funded support services, long waiting lists for that support, and uncoordinated services (International Society for Augmentative and Alternative Communication, 2014). Another overview describes the experiences of impaired adults as “characterised by broken connections, limited and changing social networks, and limited and changing support systems” (Mirenda & Iacono, 2009, p. 443). They are also “likely to have experienced limited

communication support, (and) limited opportunities for self-determination...” (p. 444).

Finally, the use of controversial methods with little evidence support. These include methods such as Facilitated Communication (Lilienfeld, Marshall, Todd, & Shane, 2014), in which a helper guides an AAC user’s hand to write or select symbols during communication. Reactions to this approach suggest that the method “is ineffective” and “works only when facilitators know the answers”, as it takes advantage of “the propensity of (support) people’s thoughts to influence their movements without their awareness” (p. 69).

To complete a look at the supports, as well as the discussed barriers to effective AAC use, the following comparison (Lund & Light, 2007, p. 326) is presented in Table 3.

Table 3: Barriers and supports to positive AAC outcomes.
(Lund & Light, 2007, p. 326).

Barriers to positive AAC outcomes	Attitude barriers	Negative attitudes of professionals
		Low expectations of family members
		Negative attitudes of non-disabled peers
		Negative attitudes of society
	Cultural differences	Difficulties developing communication systems for multiple languages
		Professionals' lack of understanding of cultural issues
	Technological barriers	Limitations in technology
		Difficulty accessing technology
		Technical breakdowns
	Service delivery limitations	Lack of availability of services
		Limited knowledge of professionals
		Lack of collaboration between professionals
		Limited focus of goals
Supports to positive AAC outcomes	Social Support	Supportive, inclusive community
		Strong parental advocacy
		Expectations of success
		Family involvement in interaction
	Personal characteristics	Patience
		Persistence/determination
		High expectations
		Social nature
	Services	Competent and knowledgeable professionals
		Training for families, facilitators & teachers
		Effective communication between professionals, family, school

2.3 Summary of chapter 2

In summary, a number of adults in our society have CCN, a lack of functional verbal communication skills, and rely on or could benefit from the use of ACC methods, therapeutic aids designed to assist them with these challenges. There are various causes of CCN, including developmental or acquired impairment, and different types of AAC, including unaided AAC (use of sign language, gestures, or eye-blinking), and aided AAC (use of various external means to represent ideas, and select, and transmit the representations).

The act of communication is important for individuals and society, and there are implications for a lack of verbal skill, including health, and financial issues. Methods exist to help adults use AAC, including assessment, selection, and training techniques. Even so, while there is consensus that well-matched aid-use is beneficial, there are challenges to effective AAC use, including gaps in research in some areas, and issues with design, use and support. As well as the focus on client impairments and communication, this chapter also served to explain the limit in scope of this thesis to adult AAC users, who have CCN, and rely on the use of a form of therapeutic communication support.

This concludes the initial outline of the clients at the centre, along with techniques available to help them, with the next two chapters extending some of the presented topics in different ways. In the next chapter, I will explore the nature of disability, as distinct from impairment, and as it relates to barriers to effective communication and support, and in chapter 4, I will present the act of communication in greater detail.

Chapter 3: Impairment and disability

In this chapter, I further the discussion about impairment, with a presentation of the factors beyond diagnosis that influence the ability and opportunities of those with CCN. Introduced with a philosophical and historical look at the marginalisation of people with an impairment, the chapter discusses the meaning of culture for this group of people, some models used to determine and classify disability, the formation and aims of the Disability Rights Movement, and the separation of the terms, impairment, and, disability. A summary of the chapter then follows, which will complete the overview of those with an impairment and a disability, before a discussion about communication is presented in chapter 4.

Where chapter 2 discussed the medical diagnosis, or impairment of a person, this chapter presents additional cultural and social factors that affect an impaired person's ability, activity, and subsequent inclusion in society. These additional factors have been described by some as, disability, as distinct from, impairment, (Union of the Physically Impaired Against Segregation, 1975). Academics note this complexity of terms, suggesting that disability "is a slippery category" (Olney & Kim, 2001, p. 563), a "complex, scalar, multi-dimensional phenomenon" (Shakespeare, 2008, p. 11), and "an issue, a label, a statistic, an experience, and a complex space" (Goggin & Newell, 2003, p. xiii).

Because of the idea that disability, as distinct from impairment, "is so obviously shaped by cultural and social norms and expectations" (Meyer, 2010, p. 167), and "is a cultural level adversity" (Luborsky, 1994, p. 240), a look at these external factors is necessary to build an understanding of individuals with CCN. The next section begins with a historical, and philosophical introduction to disability.

3.1 Disability: philosophy and history

Philosophers historically addressed the concept of disability in different ways (Nietzsche, 2013; Smith, 2005), but the work of two noted philosophers, Marx (1954) and Foucault (1982), is particularly relevant to this research because insights from both have been influential in the development of the Disability Rights Movement, and in Disability Studies (Oliver, 1999; Shakespeare, 2008; Slorach, 2011). The work of Foucault, in particular, is relevant as a statement about communication.

3.1.1 Marx

Marx (1954) wrote about society, economics and politics, and his works are collectively described as Marxism. Marxism outlines the ways in which human societies develop through class struggle, and describes the dominant class (the bourgeoisie) as controlling both the means of production (manufacture and economics) and the individuals making the products (the working class, or proletariat). His work is relevant to this thesis because of his critical description of the Industrial Revolution and the subsequent rise of Capitalism, that has been seen as having a significant, and disabling effect on the individual (Russell & Malhotra, 2002; Slorach, 2011; Stack, 2007, p. 706).

According to Marx, there were various ways in which the proletariat was affected during the Industrial Revolution. He states that employment environments changed, as more people moved from shared community labour to centralised factory employment. While farms, for instance, were set-up as communities (to care for children and the elderly, so people with various abilities could contribute their labour to the group in flexible ways), the factory imposed an environment where only people with typical motor and intellectual abilities could contribute.

Marx describes this shift in employment as the “alienation of man”, as the divorce of a person’s free-will to one of “estranged labour”. This is brought about by “degrading spontaneous activity”, as it “estranges man’s own body from him, as it does external nature and his spiritual essence, his human being”. This also “means that one man is estranged from the other...” (Marx, 2012, p. 91). Furthermore, fewer people were left to care for dependents on the farms, and women became dependent on the money men made. Women not only provided this labour for free, but also their ability to make more workers: “Labour produces not only commodities: it produces itself and the worker as a commodity” (p. 82). This implies a number of issues:

- A person’s only value in the manufacturing industry was as a worker in the factory, with the repetitive process making irrelevant any other wants and needs of the dominated worker. Marx noted that the worker was “crippled by life-long repetition of one and the same trivial operation, and thus reduced to a mere fragment of a man” (Marx, 1954, p. 488). He also suggested that “in its blind, unbridled drive, in its werewolf greed for surplus labour, capital oversteps not only the moral restrictions upon the working-day but also its

physical limitations. It usurps the time needed for the growth, development and healthy maintenance of the body. It steals the time needed for fresh air and the light of the sun” (p. 265).

- The manufacturing process injured people, and made them impaired, as “the victims of industry, whose number increases with the growth of dangerous machinery, of mines, chemical works, etc.” (Marx, 2007, p. 707). Furthermore, Marx described ongoing health complications, by presenting workers as “a degenerated population, both physically and morally. They are, as a rule, stunted in growth, ill-shaped, and frequently ill-formed in the chest; they become prematurely old, and are certainly short-lived...” (Marx, 1954, p. 245)
- People were dominated (and made more compliant to use for cheap labour) with this classification of those who were not useful, as “the demoralized and the ragged”, on their “incapacity for adaption, due to the division of labour”, as “people who have passed the normal age of the labourers”, and “the mutilated, the sickly, the widows, etc.” (Marx, 2007, p. 707).

3.1.2 Discussion: Marx and CCN

In spite of the many ways in which employment has changed over the years since the Industrial Revolution, with legally-binding workplace safety and equal-opportunity arrangements in place (Feldacker & Hayes, 2014), Marxist theory does offer those with CCN some explanation for their challenges. The set-up of the modern-day factory, or the contemporary physical and organisational work environment, is still a place where neurotypical forms of rapid speech, physical access, and physical and mental ability are primarily catered for. Those with CCN are seen by some in society as a drain of resources (Crowe, 2015), they are still injured or embarrassed by environments that do not cater to their various abilities (Australian Broadcasting Corporation, 2016), and the use of demeaning labels for their impairments still exist within the media and in employment situations (Gillman & Collman, 2015).

Today, academics (Nirje, 1969; Oliver, 2009; Wolfensberger, 2011), as well as socialist bloggers (Slorach, 2011; Stack, 2007), still see society as perpetuating much of the same subjugation:

(The) root of our oppression is the fact that capitalism sees everything in terms of profit and profitability - and this colours how capitalists view disabled workers. Most employers see disabled employees as a “problem” - something difficult, something different, something that will cost them more to employ. That isn’t to say that capitalists are incapable of realising that disabled people can be a source of cheap labour. So the oppression of disabled people is a reflection of the way in which capitalism reduces everything to profit - effectively, capitalism says disabled people are surplus to requirements. (Stack, 2007 Profitability section, para. 1).

While Marx suggests that society has a negative, direct effect on impaired people, Foucault (1982) suggests that power imbalances and the marginalisation of people is more insidious, and universal. A Marxist version of power can be described as regarding scarcity, where people fight for a finite number of resources, fear exclusion from finite employment, and ultimately death. A Foucauldian version of power is about plenty, where subjectification is present throughout all aspects of life (Hartley, 2002). Foucault’s philosophy is described in more detail next.

3.1.3 Foucault

The work of French philosopher Foucault (1951–1984) is of particular relevance as a focus on the contextual and changing meaning of disability, and the idea that knowledge and power are interlinked in the everyday lives of these and other people. One of Foucault’s objectives was to “create a history of the different modes by which, in our culture, human beings are made subjects” (Foucault, 1982, p. 777).

According to Foucault, there is power inherent in the use of language, the latter controlled by religion in the past, and practices such as science in the present. These paradigms of language he calls “discursive formations” (Rabinow, 1991, p. 10), and describes them as creating or shaping a person’s sense of Self. He suggests that “knowledge is not made for understanding; it is made for cutting” (Foucault, 1977, p. 88)

As an influential author, Foucault describes three ways in which human beings who were different were marginalised by the society in which they lived. In doing so, he implies that the power and influence in the language of that society caused this.

The first of these he calls, dividing practices, or “modes of manipulation that combine the mediation of a science (or pseudo-science) and the practice of exclusion - usually in a spatial sense, but also in a social one” (Rabinow, 1991, p. 8). Here he is describing the manipulating practice of those in authority (with religious or quasi-medical knowledge and power), excluding those who differed from the norm by separating them completely from society into prisons and institutions. These different others included prostitutes, criminals and the disabled, although the type of undesirable varied according to the laws and the attitudes of those in power at the time. In *The Birth of the Clinic* (Foucault, 2012), he describes the development of the asylum and other similar institutions, and in *Madness and Civilisation* (Foucault, 2001), he describes the contextual meaning of madness, noting that people were treated differently depending on the moment in history. His examples include times when mentally impaired people, for example, were seen as representing a kind of wisdom in the Renaissance period, as undesirables who chose madness in the classical ages, and as objects to study and fix in more modern times.

The second, scientific classification, is where humans were objectified with descriptions of their maladies, in the execution of dehumanising practices brought about by experts with psychological and other medical knowledge. Here, Foucault suggests, the ailments of a person were dealt with while excluding the personal care of the person themselves, in a practice he calls the Medical Gaze (Foucault, 2012). Just as those in religious and other positions of authority had power in relation to the mad, those with scientific knowledge had power in relation to the mentally and physically ill in the former’s mastery of that knowledge. Using language to classify and determine the attributes of a subject’s illness, Foucault suggested, meant that the subject could be controlled.

The third, with what Foucault called, subjectification, is the process where human beings take up certain subjectivities. The suggestion is that if practices are set up where people are being watched or judged, they will control themselves, whether they are being watched or not. Foucault describes the workings of the Panopticon, a type of prison, as an example of this phenomenon, where one guard can see into

each cell, but those inside each cell cannot tell whether they are being watched at any moment (Foucault, 1995). In this instance, inmates police their own behaviour and conform with dictated personas if they think they are being watched, even if they are not at that time. A more modern equivalent of this is seen in the use of surveillance cameras in today's urban environments. Subjectification also describes a wider phenomenon of potential self-control, in which a subject conforms to social rules based on the avoidance of embarrassment (following fashions and trends), ridicule (looking different), or scrutiny (conforming with rules such as those that govern financial tax, or road traffic arrangements).

As well as the ways in which people are subjectified, Foucault also writes about resistance, suggesting that "in order to understand what power relations are about, perhaps we should investigate the forms of resistance and attempts made to dissociate these relations" (Foucault, 1982, p. 780). Just as he describes power as diffuse, or spread through society, so he describes resistance, and writes that one could not exist without the other.

3.1.4 Discussion: Foucault and CCN

Foucault presents ideas that are relevant to those with CCN. First, his concept of powerful language is important in an understanding of the treatment of impaired people in modern society, and it is this concept that is embodied in the physical artefact presented later in this thesis. This artefact can be used to identify noise, or interference, in communication, caused by language and other contextual factors in the user's environment.

Second, Foucault's contextual description of disability shows the ephemeral nature of social attitudes and scientific thought, and the negative, cautionary factors in declaring current opinion as fact. This reflects some of the discussions in chapter 2, where AAC practices may not be supported by evidence-based practice.

Third, his thoughts on dividing practices mirror the difficulty with which some adults with CCN can participate in society, or navigate and negotiate some of the barriers in modern built environments and services. Some of these barriers are described in more detail, below, in the Disability Rights Movement section.

Fourth, Foucault's concept of the Medical Gaze is similar to some of the negative aspects of the communication-aid design processes, where financial or technological goals alone can drive AAC design and use, rather than the personal support for, and an understanding of the person who will use the aid.

Fifth, his description of self-correction, or subjectification, describes the potential ways in which people with impairments adjust their behaviour to fit in or look normal in society. This process is discussed more in chapter 4, where Co-Cultural Theory is presented.

Finally, Foucault's description of resistance in society can be seen in the structuring of disability as a culture, described in the next section, and the subsequent formation of the Disability Rights Movement, discussed thereafter. To complete this section, and before disability culture is discussed, a summary of Marx and Foucault theory is presented in Table 4, including the historic and modern implications of their theories for those with CCN.

Table 4: Philosophy summary.

Philosopher	Historic implications of theory	Modern implications of theory
Marx	Estranged labour: Limited labour opportunities for impaired people	Work environment predominantly set up for neurotypical participation
	Employment value: Of value as factory worker only	Value in ability to earn a wage or to contribute to society
	Injury and illness caused by dangerous machinery and poor factory conditions	Non inclusive employment conditions denying employment participation. Mental and physical illnesses caused by inappropriate environments.
	Classification of person: According to usefulness to factory	Negative stereotypes and labels for impaired people in and out of the workforce
Foucault	Dividing practices: Segregation of people in institutions and away from society	Difficulty of inclusion for disabled people, because of environment or attitude of others
	Classification: By medical professionals	Assignment of communication aids based on assumptions or profit, instead of evidence about each individual
	Surveillance: By authorities. Perpetuated by self to conform to socially defined normal standards	Disabled may attempt to fit-in when faced with unrealistic social attitudes about normality, or minimise look of their impairment to others

3.2 Culture and disability

In this section I will discuss the meaning of the term, culture, and outline ways in which some individuals with a disability and others have used similarity of experience and ability to encourage relationships with like-minded others. The general features of a culture are outlined, as well as the implications of relationships within the same or across different cultures.

3.2.1 Cultures

Culture, is defined in various ways (Martin & Nakayama, 1999; Martin, 2012; Orbe, 1998), but it may be taken as “that set of values, beliefs, norms, customs, rules, and codes that socially define groups of people, giving them a sense of commonality” (Trenholm & Jensen, 2000, p. 363). One description (Adler et al., 2001), suggests that culture is a:

...matter of perception and definition. When you identify yourself as a member of a culture, you must not only share certain characteristics, but you must also recognise yourself and others like you as possessing these features and see others who don't possess them as members of different categories (p. 35).

Just as there are different definitions of culture, there is a number of types of cultures suggested, including descriptions of:

- Cultures seen as Individualistic (where the individual is valued more than the group), or Collectivist (where the group is valued more than individual). The former typically describes western society (US, UK and Australia); the latter describes eastern society (Asia) (Hofstede, 2001).
- Low- and high-context cultures. This refers to the way in which a culture typically communicates, with Low-Context referring to direct and logical communication (intended to clearly express thoughts and feelings in the words spoken), and High-Context referring to communication that uses contextual clues in messages (in a process that values harmony over directness). An example of the former culture is Australian society, and the latter Japanese culture (Martin & Nakayama, 1999).

Other distinctions made between cultures include the identification of In-groups and Out-groups (Samovar, 2013), referring to the dominance of a particular culture within society, power-distance (the way in which a culture reacts to authority), and uncertainty avoidance (a culture's tolerance for difference) (Adler et al., 2001). A summary of these different cultural distinctions is presented in Table 5.

Table 5: Cultural distinctions.

Type of culture	Description	Example
Individualistic	Individual valued more than group	USA
Collectivist	Group valued more than individual	China
In-group	A dominant group within society	A neurotypical group
Out-group	A marginalised group within society	A disabled group
Power distance	The way in which a culture reacts to authority	Large distance: Japan
		Small distance: Australia
Uncertainty avoidance	A culture's tolerance for differences	High: Middle East
		Low: Scandinavia

3.2.2 Disability culture

As discussed previously, some challenges to inclusion and acceptance for disabled people include the ways in which society treats and labels individuals who are different. There are positive as well as negative aspects to the categorisation of disability as a culture by its members and from other people. For example, one suggestion is that:

...socially dominant culture shapes the way in which disability and impairment are viewed, and has contributed to the oppression of disabled people. At the same time disabled people have forged their own cultures as acts of resistance. Culture, therefore, is both a source of oppression and of liberation for disabled people, and is therefore central to the politics of disability (Riddell & Watson, 2003, p. 1).

Concurrent with the segregation of disabled people in society, was the classification of the group as a different culture, but it was not until the 1960s that disabled individuals started publicly identifying a disability culture, in a bid not only to unite to resist oppression, but also to share experiences and help one another. As one impaired researcher (Gill, 1995) describes:

...the most compelling evidence of a disability culture is the vitality and universality of these (latter) elements despite generations of crushing poverty, social isolation, lack of education, silencing, imposed immobility, and relentless instruction in hating ourselves and each other (para. 10).

Gill (1995, p. 10), continues by offering a list of the core values of a disability culture, including:

- An acceptance of human differences (e.g., physical, functional, racial, intellectual, economic/class).
- A matter-of-fact orientation toward helping; an acceptance of human vulnerability and interdependence as part of life.
- A tolerance for lack of resolution, for dealing with the unpredictable and living with unknowns or less-than-desired outcomes.
- Skill in managing multiple problems, systems, technology and assistants.

The positive aspects of disability culture as presented here are central, for example, to the development of events such as the Paralympics, an international sporting competition exclusively available for the participation of disabled athletes. Para, refers to the games as being, alongside, the able-bodied Olympics, as, para, is Greek for, beside, or, alongside (International Paralympic Committee, 2016), and this refers to the idea that each event is as important as the other. Furthermore, the stated vision of the event is “to enable Para athletes to achieve sporting excellence and inspire and excite the world” (para. 12). This equal comparison of disabled and neurotypical activity highlights a defining element in the modern beginnings of the Disability Rights Movement, with the use of a process called Normalization, an approach presented in more detail later in this chapter.

To continue the discussion about culture and disability, but before the outline of the Disability Rights Movement, I will make points about the potential impact of cultural

distinctions that may affect the experiences of impaired people in different environments. A discussion of disability culture, as it relates to ID and CCN, is also given.

3.2.3 Discussion: culture

As discussed, culture is described as the commonality of a group of similar types of people, who unite for many reasons; in the case of disabled individuals, for a sharing of experience, feeling of belonging, or uniting for resistance. Their experiences as individuals of different international cultures have been known to change, depending on the type of environment they live in. For example, a study that compared disability experiences in the US (an Individualistic culture) with Japan (a Collectivist culture) found that there were differences in the way individuals were supported by government policy and neurotypical attitudes (Heyer, 2000), where:

Japanese legislation has emphasized different needs over equal rights, especially in the areas of education and employment policy, and the emphasis on difference and special needs has resulted in well-equipped but nonetheless separate facilities. Disability groups have traditionally adopted their demands accordingly and have focused their energies on improving the quality and quantity of services rather than demanding full integration (p. 20).

These differences highlight the approaches of different countries in international environments, for integration, assimilation, and separation. For example, while an Individualistic culture (such as Australia) may have poorly-designed, non-inclusive public transport systems, minimal public pictorial language, but progressive and inclusive equal-rights policies, a Collectivist culture (Japan) can have excellent inclusive public transport and an abundance of alternative pictorial language systems, but poor integration policies for disabled people. Some of these barriers and differences are discussed later in this chapter.

Another difference highlighted in the discussion above is the experiences of the physically and mentally impaired. For example, the benefits of belonging to a culture often come about by identifying as a member of that culture (Gill, 1995) which can be a problem for a person with a mental impairment, when that person may have little concept of their own existence (see chapter 2). Indeed, many of the concepts and features of the disability culture as discussed above are dependent on a

member's intellectual knowledge of one's own environment and social positioning. Furthermore, the ability of a person to communicate their membership or identity in that culture is challenging too if one has CCN, with all the communication difficulties this entails. Such issues are also discussed in the next section, about the development of the Disability Rights Movement, which began exclusively as a movement for the physically disabled.

3.3 Disability rights, models, and barriers

The Disability Rights Movement (DRM), a global collective of disability organisations and disabled people, can be seen as an extension of parts of disability culture, for the purposes of resistance and empowerment, in an attempt to improve the lives of impaired people. One of the most powerful concepts championed by the Movement was the introduction of the influential Social Model of disability, a model that governments and organisations have adopted to various degrees (Nirje, 1969). A phrase adopted by the Movement, "Nothing about us, without us", exemplifies their aims (Charlton, 1998, p. 3).

In this section, I will begin by discussing the development of the DRM, followed by the models of disability the Movement embrace or reject, and the myriad of external barriers they identify as problems in their lives. A discussion of these topics will then follow.

3.3.1 The Disability Rights Movement

In *Ramp Up*, an influential Australian disability website edited by the late activist Stella Young (Tracey, 2014), a history of the DRM is outlined:

Disability rights began in earnest in the late 1960s inspired by the civil rights movement in America and the gay rights movement. But, a foundation had been laid for this work long before. Groups for blind and deaf advocacy arose in the early part of the twentieth century; as early as WW1, injured veterans were lobbying for pensions and better access to employment and housing (Barton, 2013).

This lead-up to the development of the DRM was exemplified by this grouping of disabled people, either with individuals forming groups, or with organisations

collecting these people together. As discussed earlier in the culture section, some disabled individuals gathered to share similarity of experience and companionship, and this led to some forming resistance groups. This resistance was not only a reaction to what they thought was domination or marginalisation by a government, but also to the additional control of some institutions seeking to care for these individuals. In the former case, injured veterans and other disabled people fought for equal rights, and in the latter, the autonomy to control their own lives, instead of care organisations making decisions for them (International Society for Augmentative and Alternative Communication, 2014). Some of these organisations gather information about these individuals to study them (Australian Bureau of Statistics, 2009a), and disabled people have been physically gathered together by organisations who wish them harm (Mostert, 2002), as well as treat their illnesses (Department for Communities and Social Inclusion, 2016).

The DRM sought to take control of their own lives and to control the ways in which some of these disability groups made decisions about them. Modern policies outline a minimum number of impaired persons on a committee or disability board, for instance, and a growing number of decisions are made with information provided by disabled people, not on behalf of them (Bagshaw, 2016). Table 6 shows a selective history of the development of some of these disability groups, as well as some significant changes in the operation, organisation, or aims of these groups. Note the older and potentially negative, descriptive terminology used (dumb, asylum), employed in more modern times as insults or descriptions of a degree of suffering or a frightening place (Zhang & Haller, 2013).

Table 6: A timeline of selected disability groups.

Year	Organisation or Individual	Decision makers	Description
1760	Braidwood school	Thomas Braidwood	School for the deaf in Edinburgh, Scotland. Taught British Sign Language, rather than Oralism (spoken language) (Houghton-Mifflin, 2015)
1817	Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons	Medical staff	Start of development of American Sign Language. Based on work at Braidwood school & Royal Institution for the Deaf in Paris (Crowley, 2016)
1824	Blackwells Island	Medical staff	An island in New York dedicated to segregation of the impaired. Many buildings and uses. Horrific conditions uncovered in 1887 by Pulitzer prize-winning journalist (Bly, 1887)
1898	Alexander Graham Bell	Alexander Graham Bell	Inventor of the telephone argues that sign language should not be widely used (Bell, 2005), and promotes the idea of Oralism (Baynton, 1998)
1908	Invalid pension established	Australian Government	Invalid and other pensions paid to disabled people from 1908. (Australian Bureau of Statistics, 1988)
1970	Chronically Sick and Disabled Persons Bill	UK Government	This Act of Parliament was passed without input from impaired people (Close, 2011)
1972	The Union of the Physically Impaired Against Segregation (UPIAS)	UPIAS members	A rights group formed in the UK by physically impaired people (Union of the Physically Impaired Against Segregation, 1975). Instrumental in the promotion of social role in disability
1980	Rehabilitation international	Conference organisers	Impaired people can attend this conference but cannot present (People With Disability, 2016)
2008	UN Convention for the Rights of Persons with Disabilities	UN panel	Ratified in Australia 2008, Sweden 2008, UK 2009, EU 2010, Japan 2014. USA still to ratify (United Nations, 2006)

With a description of the DRM, and the establishment of relevant organisations and policies, the next section presents some of the ways in which disability has been defined, classified and positioned within society, with models of disability. The DRM has rejected many descriptions of disability proposed by the first three (medical, charity, and economic), and embraced the fourth (social) model in many ways.

3.3.2 Models of Disability

Various models and approaches have been used to describe disability (Dartington, Miller, & Gwynne, 1981; Finkelstein, 1996; Oliver, 2009), including the medical, charity, economic and social models. All seek to describe the nature of impairment in society, and the characteristics of what is normal:

The construct of what is 'normal' is deeply imbedded in our thinking, as well as in the paradigms and activities of schools, hospitals and other institutions. The constructed dichotomy between able and disabled people has broad implications for the person who is considered disabled. In western society, ability and productivity are linked to the perception of a person as fully adult, while differences in behaviour, communication, emotion or thinking diminish the status of the individual (Luborsky, 1994, p. 25).

Brief descriptions of the medical, charity, and economic models are presented next, followed by a discussion, then the social model is discussed at length, along with the social barriers associated with the latter.

The Medical Model

The medical model has historically been the most dominant, used to describe, classify, and care for or cure those with an impairment and disability. This model assumes limitations in a disabled person come from their physical and mental illness, "places the source of the problem within a single impaired person, and concludes that solutions are found by focusing on the individual" (Michigan Disability Rights Coalition, 2016, Definition 1). This model presents assumptions that disabled people are sick, and typically need a cure to make them more normal. As well as this, if a person cannot be cured, then a person can be labelled abnormal, with intervention needed, and this may limit the life-choices the disabled person may have. While the medical model has been described as a dominating service provision (Oliver, 2009), the scientific method of therapy and investigation does give a medical understanding of a person's condition (Shakespeare, 2008), even if there are concerns about the power inherent in the opinions of medically-trained experts (Oliver, 1990).

The Charity Model

The charity model implies that disabled people are tragic people worthy of pity, and victims of circumstance. While resources supplied by charities can be beneficial (Gammy, 2016), some of their language describing, and emotive images of suffering victims used as a means to gather money is problematic, by "creating distance and inequality between the giver and the receiver" (Swain, French, & Cameron, 2003, p. 91). Swain et al. continue:

Charity advertising provokes emotions of fear, pity and guilt, ostensibly to raise resources on behalf of disabled people. The images and language have built upon and promoted stereotypes of disabled people as dependent and tragic (p. 91).

There are examples of this in advertising, including the televised depiction of a woman with Multiple Sclerosis, trapped in an icy box (Foster, 2014), and a print advertisement showing a child's toy bear with no eyes or ears (Kerridge, Kerridge, Brown, & Nicholas, 2013), used to depict deafness and blindness. Some media reports of disabled actors working in these campaigns describe their negative treatment during and after their employment (Findlay, 2015).

The Economic Model

The economic model describes disability in relation to employment, and an ability to earn money. This model is used by governments to investigate welfare needs and organise disability policy. Disability welfare payments can highlight the inability of a person to work, and differences in ability and condition vary greatly, complicating decisions about the amount of money needed to compensate each individual appropriately. Marxist and Foucauldian theory, about the control of individuals through money, employment and classification is relevant here, with one academic (Oliver, 2009) suggesting a controversial, materialist view of disability, in which:

...the production of the category 'disability' is no different from the production of motor cars and hamburgers... Each has an industry that has a vested interest in producing their product in particular ways and in exerting as much control over the process of production as possible (p. 90).

The rollout of the National Disability Insurance Scheme (NDIS) in Australia by 2020 (Australian Department of Human Services, 2017), highlights some of the economic issues for individuals and organisations, with an Australian newspaper, the *Financial Review*, suggesting in 2016 that:

As newly empowered consumers with control of their own funding – and with overall funding levels due to double under the NDIS – some 460,000 disabled Australians, along with family carers, will in future wield significant economic power, free to choose exactly where, when and from whom they purchase essential services and supports. And in many cases, that is unlikely to be from any of those existing charities or other providers notorious among people with disabilities and families for excessive administrative charges, rundown and understaffed group homes, shoddy services and historically apathetic response to evidence of physical, emotional or sexual abuse of their disabled clients (O'Reilly, 2016).

Before a discussion of the DRM, and the group's reaction to the first three models of disability, a summary of the models is presented in Table 7. The fourth, the social model, along with the social barriers the model encapsulates, is then presented.

Table 7: Three models of disability.

Model	Aim	Positive impact	Negative impact
Medical model	Classification	Cure or assistance	Impersonal treatment
Charity model	Support	Financial support	Labelling as dependent
Economic model	Support	Financial support	Labelling as statistic or burden

3.3.3 Discussion of the DRM, and resistance to models

The medical, charity, and economic models have been part of a neurotypical approach to disability for many years, used by professionals in many industries to classify, control, or study impaired people, and to placate, include, or identify with them (Michigan Disability Rights Coalition, 2016). As has been briefly discussed, there are positive and negative associations for each of them. While the early

development of the DRM necessitated a strong rejection of these models by disability activists, more recent descriptions of the role of charities and medical professionals do acknowledge the importance of some help for impaired people:

Despite the deficiencies of medical sociology and medical ethics, it would be foolish to ignore the many valuable contributions to understanding disability made from these perspectives. Moreover, it is not medicine, but inappropriate medicalisation which is the root of the problem (Shakespeare, 2008, p. 11).

Furthermore:

Although we should not reject out-of-hand its therapeutic aspects which may cure or alleviate the physical and mental condition of many disabled people, it does not offer a realistic perspective from the viewpoint of disabled people themselves. To begin with, most would reject the concept of being "abnormal". Also, the model imposes a paternalistic approach to problem solving which, although well intentioned, concentrates on "care" and ultimately provides justification for institutionalization and segregation. This restricts disabled people's opportunities to make choices, control their lives and develop their potential (Michigan Disability Rights Coalition, 2016, definition 1. para. 8).

Whatever recent acknowledgement of the positive role of the helpers described in the medical, charity, and economic models, the DRM was instrumental in suggesting a fourth social model, as a reaction to what they felt was the control and condescension of neurotypical experts and groups. Social models of disablement were suggested by disability advocates, and these now form a part of government and organisational disability policy (Race, Boxall, & Carson, 2005). The idea that disability is formed externally to a person, and can therefore be lessened or removed, has been a powerful, influential contribution by the DRM. The next sections discuss these social descriptions of disability, first with an outline of three socially-related models, and then with examples of the social, external barriers the DRM describe.

3.3.4 Social Models of disablement

While the three models previously described reflect predominantly neurotypical approaches to descriptions of disability, socially-themed models have been developed or embraced by the DRM to explain their challenges. These influential approaches include the *Normalization* model from Sweden (1969), the *Social Role Valorization* from the US (1983), and the *Social Model of Disability* from the UK (1983). Because of their similar descriptions, note here that I use different terms to describe this next group of three (social models of *disablement*), and another for one individual model within this group (*the social model of disability*). These are now presented.

Normalization

In 1969, the term, Normalization, was coined, a principle developed and implemented in Scandinavian countries as:

...a means of making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society (Nirje, 1969, p. 18).

The principle sought to integrate disabled people physically and socially into neurotypical environments, to give disabled people the opportunity to live in as normal a way as possible. This included the normal routine of wake and sleep hours, opportunities to live in a house and work in an alternative place, and opportunities for education and relationships available to others in society. The approach also “underlies demands for standards, facilities and programs” (Nirje, 1969, p. 19) for the inclusion of disabled people into society.

Despite the use of the term, retarded, currently seen as an extremely negative term for, impaired, the principle at the time was considered by disability advocates (Neufeldt, 2001; Wolfensberger, 2011) as a desirable outcome for disability and neurotypical culture. The deinstitutionalisation of care for the disabled, from segregated facilities to community and family care began with the introduction of the Normalization principle. Proponents of this approach emphasised that this was not an attempt to force this group into typical and possibly unfamiliar and uncomfortable activities, rather to typify the way in which society viewed disability, and to give

disabled people equal opportunities (Wolfensberger, 2011). Opponents note that a better solution would be to promote the importance of different lifestyles and needs, rather than attempting to instil a normal way to live (Oliver, 2009). The Normalization principle has been instrumental in influencing another model, Social Role Valorization, discussed next.

Social Role Valorization (SRV)

Social Role Valorization (SRV) (Wolfensberger 1983), heavily influenced by Normalization, is a process intended to analyse, report, and influence the way in which disabled people are valued in society. Just as normalization was influential in the promotion of the social integration of disabled people into normal society, SRV seeks to improve the lives of those disabled people as part of society.

SRV is described as having three main goals. First, to enable disabled people to “obtain the good things in life” (Race et al., 2005, p. 512), in the same way that many neurotypical people can. These good things include good health, employment opportunities, and a home. Second, the “facilitation, support, and defence of valued social roles” (p. 512) for these people. In this way, these people are seen as important and worthy members of society. Third, the “maximization of both social image and personal competency” (p. 512). This goal is related to two concepts emphasised in SRV: the common experiences (or wounds) of disabled people and the channels through which their social standing is assumed. By reducing the negative experiences of a disabled person, and by taking note of the channels, or ways in which the person is seen as devalued, SRV seeks to maximise their social image and competence.

Table 8 summarises aspects of the process of wounding (Race et al., 2005), associated with negative common experiences. These include the ways role messages and expectancies are portrayed, such as the way impaired people are treated in a physical environment, during activities, or the way they present themselves.

Table 8: The process of ‘wounding’.

Impairment: Leading to →	Low social status	Rejection by family or others	Cast into devalued roles such as: Menace, waste, sick
Results in →	Stigmatisation	Segregation	False assumptions
Commonly accompanied by →	Loss of control	Deindividualisation	Exclusion and poverty
Give rise to the following feelings →	Awareness of source of anguish	Awareness of being an alien	Resentment of privilege

SRV is seen as having a focus on the individual, and as such, has been criticised as ignoring those aspects of society that limit the activities and experiences of impaired people (Oliver, 2009). The next section will detail the Social Model of Disability, which is seen as focused on social changes for disabled people.

Social model of disability

The social model of disability was so named by Oliver (2009), an impaired researcher, lecturer, and disability advocate in the UK. This model was influential in presenting a definition of disability that differed from some of the previous, generalised, medical descriptions of the term. Oliver noted that the work of a Disability Rights Group, the Union of the Physically Impaired Against Segregation (UPIAS), was integral to an understanding of the social influences on his own, and other disabled people’s lives. UPIAS formed in the UK in 1972, and the concerns voiced by the group echoed Foucault’s: objections to the earlier separation of the impaired from other neurotypical members of society, the dominance of medical and other professionals in decision-making in their lives, and the negative and closed-minded language of the public that potentially affected the self-esteem and facilitated the self-editing behaviour of some individuals to fit in with this dominant society.

The UPIAS group's aims were to have:

...facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives (Union of the Physically Impaired Against Segregation, 1975, para. 1).

They also commented that it was not:

...impairments that were the main cause of our problems as disabled people, but that it was the way society responded to us as an oppressed minority. The group reject also the whole idea of "experts" and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the "psychology" of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to — far better than any able-bodied expert (Union of the Physically Impaired Against Segregation, 1975, para. 15).

UPIAS made the distinction between the illness of a person, and the way in which they are limited by social barriers. The term, impairment, was adopted, and the term, disability, took on new meaning, with impairment described as the diagnosed condition of a person (such as Autism, Cerebral Palsy), and disability as the way in which a person's ability and activity is restricted by external forces. A description of this separation of terms notes that "disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 2004, p. 73).

This notion, that limitations with impaired people do not completely reside within them, and can be affected by external barriers, has been debated and discussed since its introduction, but adopted over time to various degrees by government and community groups. For example, one of the questions posed in the UK 1986 Office

of Population Censuses and Surveys (OPCS) questionnaire is, “Can you tell me what is wrong with you?” (Oliver, 1990, p. 7). A question from a similar questionnaire in the 2009 National Disability Strategy Consultation Report in Australia asks, “what are the greatest barriers that people with a disability face to participating fully within the community and what specific local or national actions could be taken to overcome these barriers?” (National Disability Strategy, 2012, p. 75).

With the three social models of disablement presented, and summarised in Table 9, the section thereafter describes some of the external barriers suggested by these approaches and integral to the description of that external disablement by the DRM. Following this is a discussion of the Movement and their adoption of social models of disablement, and social barriers, before a summary of the chapter is presented.

Table 9: Social models of disablement.

Model	Focus	Main aim	Adoption	Criticisms
Normalization	Individual	For disabled people to have normal routines, and opportunities	Sweden	What is normal? Not appreciating differences.
SRV	Individual	Promote valued social roles for disabled people	Disability services Sweden	Perpetuates barriers – conditions, environs and values
Social model of disability	Society	Enable person to take full control of their lives by providing support and removing barriers	Disabled individuals UK	Ignores the experiences of individuals with learning difficulties – the abilities of ‘competency impaired people’ needing help with decision making

3.3.5 Social Barriers: Disability

Researchers discuss the disabling impact of social factors on impaired adults (Olney & Kim, 2001; Stoner et al., 2006; Thomas, 2004), and suggest that “the extent to which one is disabled is the result less of factors residing in the individual and more on the interaction between the individual and the environment” (Renty & Roeyers, 2006, p. 521). For example, descriptions of three main barriers that challenge the impaired, and thus disable them, include:

Attitudinal barriers.

These include negative attitudes about and stereotypes of the disabled, perpetuated by individuals and the mass media. Individual attitudes can include low expectations of disabled people, assumptions about cognitive ability based on physical attributes, and incidents of bullying and other abuse (Perkins, 2016). Additionally, media representations of what is considered healthy, attractive, and of value rarely include images or descriptions of people with a disability (Riddell & Watson, 2003).

Furthermore, the differences in media reports about tragedies involving neurotypical and impaired individuals may differ (Findlay, 2016), with one disability advocate (Young, 2014) suggesting that:

...when we hear of a crime like this, we quite rightly recoil in horror. And yet, when we hear that a murdered wife is also a woman with a disability, we can find ourselves a little bit less horrified. As though her status as a disabled woman gives us a little more empathy towards the perpetrator of violence. It's victim blaming at its very worst (para. 6).

Environmental barriers

These barriers include built environments that fail to cater to those with an impairment, and prevent the inclusion and participation of those with special needs. Physical barriers include the presence of stairs but not ramps for wheelchairs users, and heavy doors, and other buttons, controls and entrances that people with motor-skill issues cannot operate independently. The absence or inappropriate installation of tactile signage on train stations, and audio signalling on pedestrian crossings can affect those who are blind and deaf. Barriers that affect those with cognitive

impairments include the predominance of text-heavy or complicated way-finding and other signage, with no pictures or simple information to help those with CCN.

There can be other negative influences, even when inclusive access is considered, with the addition of disability-access to inadequate current, or new built environments adding expense and complications for neurotypical builders and owners. Some features of inclusive access require more space than other solutions. Ramps need a minimal slope and distance for ease of wheelchair access, for example (International Organization for Standardization, 2015a).

The ways in which people use these alternative features can also be seen as different, and possibly troublesome. For example, trains in Melbourne, Australia, do not line up their access points to the station platforms, and need a person in a wheelchair to telephone ahead of time, and go to the front of the train, where the driver can exit and physically line up a ramp for them to board through the doors. This is clearly seen by other commuters, and adds to the time the train stops at the station. Furthermore, “because the only place that people with wheelchairs in Melbourne can board a train is at the front, only two can be on the train at any one time” (Kerridge, Kerridge, Brown, & Nicholas, 2016, para. 4).

Institutional barriers

These include laws, or practices that discriminate against people with impairments, or the lack of adherence to inclusive rules. For example:

- For inclusive education, a “shortfall between the educational reality that children experience around the world and what governments have promised and committed to through human rights treaties” (HRW, 2016, para. 5). This includes “weak government monitoring mechanisms, lack of zero-discrimination policies, lack of accountability for children who drop out of education, and unchecked power wielded by school officials as to who goes to school” (para. 11).
- Laws denying deaf people the right to take part in law proceedings, because of the fear that an interpreter may influence a deaf person’s judgement and the proceedings. An instance of this was when a person was denied approval to “sit on a jury with an interpreter present (because) the interpreter became a 13th jury person” (Kerridge et al., 2016, Para. 17).

- Insurance policies that discriminate against those with an impairment. For example, a person was denied a Long-Term Disability pension, because social media photographs “appear to be a young woman who is engaged in life activities”, who is “awake, smiling and alert”, and “do not appear to depict an individual who looks chronically ill” (Davidson, 2016, para. 1).

Before a discussion of the DRM and their adoption of social models and barriers, a summary of the social barriers of disablement is presented in Table 10.

Table 10: Social barriers of disability.

Barrier	Description	Impact	Examples
Attitudinal	Opinions and stereotypes	Low self-esteem and restriction of opportunity	Impaired seen as less important than neurotypical people
Environmental	Physical obstacles	Denial of access	Stairs for wheelchair users
Institutional	Laws, policies, procedures	Restriction of rights	Laws restricting inclusion for education and insurance protection

I will now present a discussion of disability rights, models and barriers, particularly in relation to those with CCN.

3.3.6 Discussion of the DRM, and adoption of social models

The social approaches have been critiqued and debated since their inception, and proponents of the SRV and the Social Model typically disagree with each other about the aims of their respective approaches (Oliver, 2009; Wolfensberger, 2011). There are suggestions, however, that the two models share many positive features, that their “support of oppressed people are inevitably influenced by values, worldviews and political positions”, and “the fact of oppression, as we have noted, is not in dispute between adherents of the Social Model and SRV” (Race et al., 2005, p. 519). Further suggestions note that SRV has influenced more than just the individual, notably the social environment around them, and the social model has not ignored those with an intellectual impairment, but has grounds for their inclusion, as discussed later in this chapter.

Advocacy of the social models of disablement by the DRM has meant that change has taken place with respect to government policy, and the organisation of disability services to some extent. The three social models of disablement have been adopted in different ways. Normalization and SRV, for instance, have been credited with “achieving considerable favourable change in learning disability services in a number of countries ... and consequent improvement in the lives of individual people with learning difficulties” (Race et al., 2005, p. 507). The social model of disability, on the other hand, “although enthusiastically embraced by many people with physical and sensory impairments, has been less readily adopted by learning disability services” (p. 507).

The concept of this external disablement has been acknowledged by society to some degree. There is discussion that impaired people should have some inclusion in corporate and government disability decision-making (Woodley, 2016); some accommodation has been made to develop inclusive urban environments (Coleman, Clarkson, Dong, & Cassim, 2007); and there has been some effort to represent these people in popular culture, however challenging this may be (Goggin & Newell, 2003).

Three approaches have been presented, that describe the way in which models have been adopted by society (Oliver, 2009). First, the humanitarian approach, which assumes that “services were provided out of goodwill and the desire to help individuals and groups perceived as less fortunate” (p. 53). This approach is an “all pervasive” example of the medical model, the disabled person is seen as “the problem”, and users are “expected to be grateful” (p. 53). Second, the compliance approach is described as a stated set of initiatives and legislation where “producers have typically seen their role as doing the minimum amount required complying with the law or government regulations”, with this approach categorised by “conflict, a denial of entitlements and expectations, inadequate services and low levels of user satisfaction” (p. 53). Finally, the citizenship approach, regarded as the desired application of the social models, is where “disabled people are regarded as equal citizens with full rights and responsibilities” (p. 54). This includes the economic view that disabled people are seen “as both workers and valued customers” (p. 54), the political view that they are recognised as empowered individuals, and the moral view that they are citizens with rights and responsibilities.

Changes brought about by the adoption or acknowledgment of the social model of disability have come about because of physically-disabled individuals and protest groups, clearly communicating their critical views of their treatment, so that change could take place. Alternatively, the implications for those with communication difficulties means that their needs and wants are more challenging to illustrate to others, which again highlights the importance of effective AAC, because:

...increased inclusion in society and participation in activities of daily life will remain elusive goals for adults with developmental disabilities who are nonspeaking unless they have a lifelong method of communicating that is understood and honored by others (Stoner et al., 2006).

There have been attempts by rights organisations to include the needs of those with intellectual challenges. In 1976, for example, UPIAS widened the aims of their organisation from the inclusion of members “lacking part or all of a limb, or having a defective limb, organism or mechanism of the body” (Union of the Physically Impaired Against Segregation, 1975, p. 14), to including individuals with other impairments, “so that any impairment (including sensory and intellectual examples) falls within the potential scope of disability” (Barnes, 1999, p. 28).

Furthermore, for those with challenged communication and/or intellectual abilities, the nature and definition of choice has been discussed (Brisenden, 1986). As noted previously, one criticism of the social model of disability has been that those with an intellectual disability have been excluded from the aims of and benefits associated with the use of the model. This is because the model associates external, controlling factors, such as the support given by care organisations to the impaired, as negative. The reality is that those with CCN, and many others, need this external support to help with a variety of tasks (including communication: see chapter 2.2.2) their impairments may prevent them from completing. So external influences can be seen as problematic, or as essential services controlled by a person with CCN.

Some intellectual-disability advocates, for example, suggest that:

We do not use the term 'independent' to mean someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led. It cannot be applied to someone living in an institutional setting, therefore, because the routine of their life will

be pre-determined, to a greater or lesser extent, by the needs of the professionals in charge of the institution. However, it can be applied to the most severely disabled person who lives in the community and organises all the help or 'care' they need as part of a freely chosen lifestyle. The most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine. The degree of disability does not determine the amount of independence achieved (Brisenden, 1986, p. 178).

There are other challenges with social barriers for those individuals with an ID and CCN. For example, attitudinal barriers can present when insufficient time is given to allow for a slow AAC exchange, or people lack the patience to decipher the slurred natural or listen to the unique artificial speech used by an impaired person. Studies have found that those with developmental impairments need help to confirm their worth, and potential, and that their exposure to negative messages about disability affects them greatly (Olney & Kim, 2001); that their "disability is often portrayed by in the media, as well as by family members and friends, as a problem to surmount, rather than as an experience to be understood and appreciated" (p. 582).

Environmental barriers can cause adults with CCN not only to struggle with information to help them move independently around a city, but may also influence their decision to leave their home. The challenges with struggling with public information, and with their independence further challenged by the need to ask for help (to open doors, or explain complicated pricing or instructions) can make them more susceptible to obesity, and other medical conditions caused by a sedentary lifestyle. As discussed in chapter 2, their lack of participation in society, can give rise to other issues, including depression.

Some methods do exist that can facilitate the physical independence of individuals with a broad range of ability (Norman, 2002). One such method is called Inclusive Design (Coleman et al., 2007), a more recent form of User-Centred Design (UCD), the latter previously discussed in the thesis introduction. Inclusive Design is the process where the greatest number of users are catered for in a design process. For instance, in the train-access example described earlier in this section, an Inclusive Design solution would be to enable the train and the station to always line up, so that independent access with any means of locomotion (walking, wheelchair or

other) is always possible. Some excellent examples of this type of design is seen in the Mass Transit Railway (MTR) train system in Hong Kong and other locations around the world (Atkins, 2010; Gaudion, Hall, Myerson, & Pellicano, 2015; Timlin & Rysenbry, 2010). Nevertheless, while Inclusive Design approaches are beneficial, voluntary targets by some organisations, notably Australia's construction industry, often fail to build benefits such as wider doors, ramps and other inclusive features into existing residential homes (Bleby, 2016).

Institutional barriers for people with CCN occur when current research using evidence-based practice (EBP) has not been adopted by governments and associations, and outdated modes of thinking perpetuate in policy and bureaucracy. As discussed in chapter 2, this may mean inadequate provision for the development, supply, and support of communication aids, and the lack of public education about the unique needs, abilities and communication methods employed by those with CCN. In the same way that environmental barriers could be redesigned to allow for access regardless of ability, the use of an Inclusive Design process could extend the use of current pictorial signage (International Organization for Standardization, 2015b), to include a greater focus on public AAC image display.

While the DRM's adoption of the social models of disablement has highlighted the plight of those with an impairment, academics have since noted many issues with the binary, impairment or disability, divide (Shakespeare & Watson, 2001; Thomas, 2004). For example, some suggest that both disability advocates and sociological medical approaches have been useful, saying that "people are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial" (Shakespeare & Watson, 2001, p. 17). Others note that "impairment and illness have direct disabling effects by limiting activity" (Thomas, 2004, p. 578), and that social models "attempt to 'write the body out' completely from the biology/society equation" (Williams, 1999, p. 803). While there is consensus that the initial adoption of social models of disablement have had positive influence on many aspects of society, there is also consensus that a more balanced approach can be of even more benefit to those with an impairment, moving forward (Shakespeare, 2008).

I will now present a summary of this chapter.

3.4 Summary of chapter 3

To summarise this chapter, some academics and activists have noted that there are external (disabling) factors, beyond an individual's medical condition (or impairment), that affect their ability, activity, and inclusion within society. Historical and philosophical views of these issues, from Marx and Foucault, offer insights to the ways in which individuals have been treated, impaired, and disabled. Foucault's theories also have relevance for the study of communication in this thesis, and in the presentation of the physical artefact shown later, that embodies his work.

More modern studies show that disabled people have gathered as a culture to share experiences and to fight for their rights, and that an outcome of these gatherings has been the development of the global DRM. The Movement's aims, as exemplified in the adopted phrase, "Nothing about us, without us", describe their opposition to neurotypical individuals, organisations and environments controlling their lives to various degrees. This rights group has championed social models of disablement, suggesting that external factors have negatively impacted their lives. This has been a departure from other, earlier models, such as the medical, charity, and economic models, that the group saw as negative forms of this neurotypical control. The social models highlight external barriers that disable individuals, including institutional, environmental, and attitudinal barriers.

With chapter 2 describing those with CCN in relation to their medically described impairment, chapter 3 has now completed the description of these individuals with the possibly additional, external, social factors of their disablement. Chapter 4 will now continue the other discussion presented in chapter 2, by furthering the information about AAC, describing communication processes, along with communication models, types and theories.

Chapter 4: Communication

Having discussed the typical users and types of AAC in chapter 2, this chapter focuses on the communication act itself, firstly, by presenting a consensus of the basic processes of communication, and then by describing a series of communication models, types and theories as they relate to the process of neurotypical, as well as AAC exchange. This information is then used, with information from previous chapters, in the development of a refined AAC Communication model, presented in the next chapter.

4.1 Processes of communication

The Latin root of communication (*communicare*), means to be in a relationship with, or, to share, and has links in English with the words, common, commune, and, community (Schulz & Cobley, 2013). This would suggest an act of bringing together (Rosengren, 2000).

Researchers describe the act of communication in various ways, as the shared process of exchanging meaningful messages; as a “relational process of creating and interpreting messages that elicit a response” (Griffin, 2012, p. 6); as a “social process in which individuals employ symbols to establish and interpret meaning” (West & Turner, 2010, p. 5). Sharing messages, at least for neurotypical communicators, involve “talking and listening, writing and reading, performing and witnessing, or, more generally, doing anything that involves ‘messages’ in any medium or situation” (Craig & Muller, 2007, p. 39). As previously discussed in chapter 2, an individual’s AAC messaging is typically more limited in scope.

Attempts to formalise and illustrate this sharing of messages have been presented over various forms, in these models, types, and theories. Communication models are presented next, in increasing degrees of sophistication, all offering important insights to our understanding of communication. I have divided this next section into thirds, as three of the models describe general, neurotypical communication, one describes the nature of power in message exchange, and a fourth details a path to a model specifically depicting AAC. These latter models include additional information about cognitive actions and multiple methods of communication delivery.

4.2 Models of Communication

Models represent the visual simplification of a process, “a simplified picture of a part of the real world...characteristics of reality” (Schulz & Cobley, 2013, p. 7). In relation to AAC users, the advantage of a model is that it “provides the teacher or rehabilitation specialist with the basis for understanding the communication problems associated with (the impairment), and it offers a rationale for the intervention procedures we develop” (Sanders, 1982, p. 16). The first models presented here continue the explanation of communication processes by describing general, neurotypical communication.

4.2.1 General communication models

Early models attempting to describe communication processes contain shared elements, namely a sender and receiver, a sent message, a channel to send the message through, and noise that can potentially affect the sending or meaning of the message. These models became increasingly descriptive and sophisticated, as one was built on the other. This section includes the following:

- Linear model, initially the Transmission model (Shannon & Weaver, 1949).
- Interactional model (Schramm, 1954).
- Transactional model (Barnlund, 2011).

Linear Model

The Transmission Model (Shannon & Weaver, 1949), was the first linear representation of communication, and describes a signal being sent through a channel, then received. As the signal travels from sender to receiver, noise, may interfere with the communication process. Here the term, noise, was a generalisation of degrading influences on the signal, and did not necessarily refer to a communication infused with meaning. The channel, in this case, referred to a wire or radio channel; the original model intended to describe purely technical, cybernetic signalling from one place to another.

Since the model was introduced, descriptions of this linear form of communication model have evolved to attribute meaning to the signals, and those signals as messages sent and received by humans (Rothwell, 2000). These refined linear

interpretations describe noise in four ways: semantic, which introduces contextual challenges in the use of specialised language such as slang and jargon; physical, including audio noise and other external distractions; physiological, including internal biological factors such as illness; and psychological, which includes internal factors influencing the integrity of the message, such as a negative reaction to an abusive message. These types of noise have the potential to lessen the effectiveness of human communication.

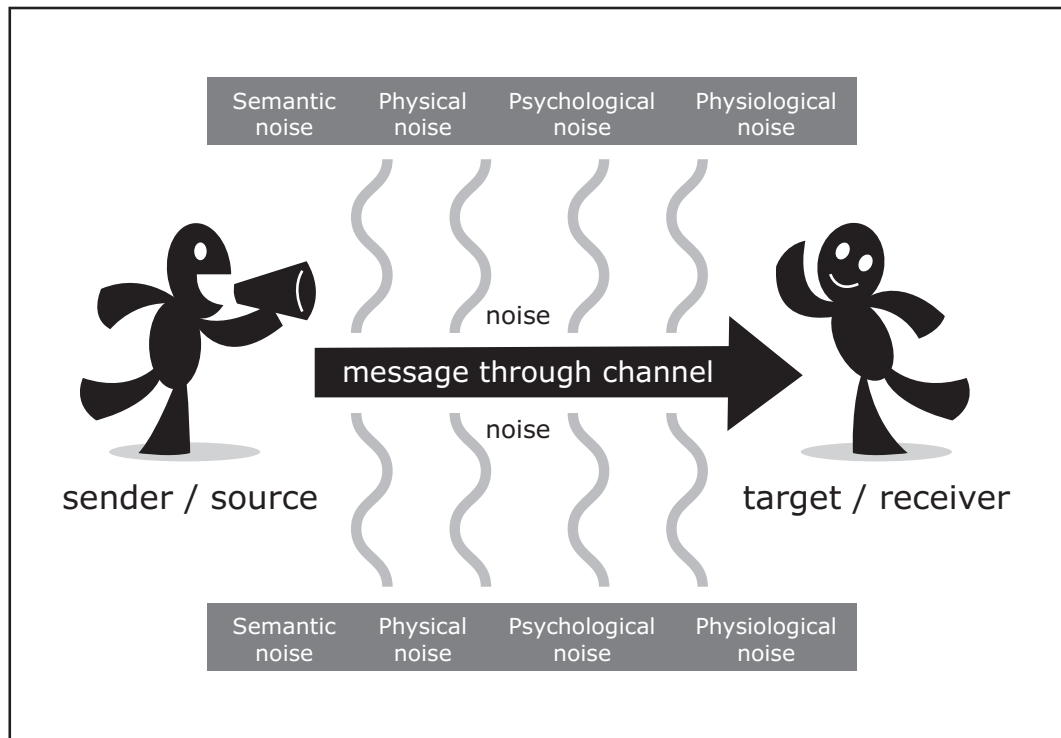


Figure 5: Linear model (Adaption of the original Transmission Model). (Shannon & Weaver, 1949)

The linear model describes communication as one message going one way. Two components, channel and noise, are useful components of communication, and these have been retained in subsequent models, such as the Interactional Model discussed next.

Interactional model

The Interactional Model (Schramm, 1954), builds on the linear model, with communication now seen as a two-way process (Figure 6). The model is circular, suggesting that not all communication is intentional or deliberately given meaning,

and introduces the concept of receiver feedback. Messages are now seen as both intentional and unintentional behaviour, which includes communication such as blushing and other non-verbal cues that are messages sent in reaction, or as feedback to a received message. The model also displays individual environment fields around each sender that overlap. These environments represent the personal experiences and cultural background of each sender. Note that while a small portion of each environment overlaps, the majority of each field does not, and it is this feature that represents different experiences that potentially can cause miscommunication.

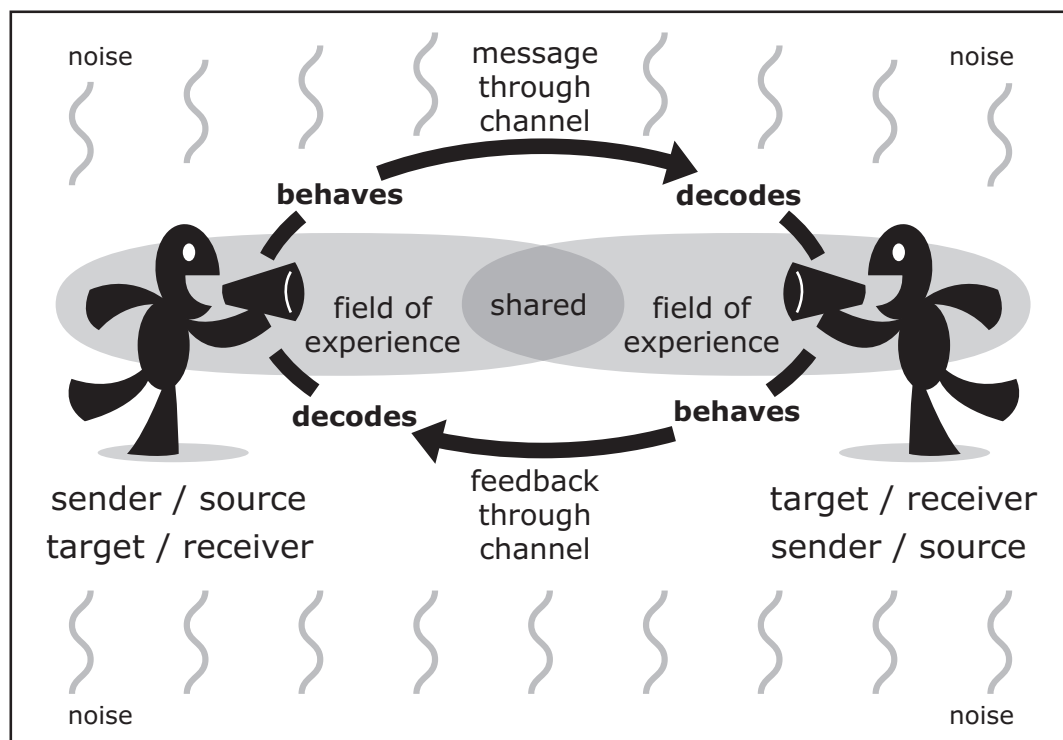


Figure 6: Adaption of the Interactional Model.
(Schramm, 1954)

While the Interactional model adds insightful features, communication is still seen as something that occurs in discrete parcels, with a definite start and end to each message, and a sender who is only sending or receiving at a given moment. Overlapping environment fields (or shared experiences) are also not seen as changing over time. The next, Transactional Model, addresses some of these issues.

Transactional model

The Transactional Model (Barnlund, 2011), attempts to outline what happens in most neurotypical communication, by describing the process as the simultaneous sending and receiving of messages (Figure 7). Thus, the terms, sender and receiver, have been replaced with the term, communicator, to suggest that effective communication is not done to someone, but with them. Communication in this model is described as continual, simultaneous interaction, rather than a linear or circular path of sending and receiving messages. The fields of environment and feedback have been used again, as well as the channel and noise terms used across all three models. While the Interactional model stopped at describing the environmental fields as being mostly separate with some shared experience, the transactional model presents the fields of experience growing together into one field as more shared communication occurs.

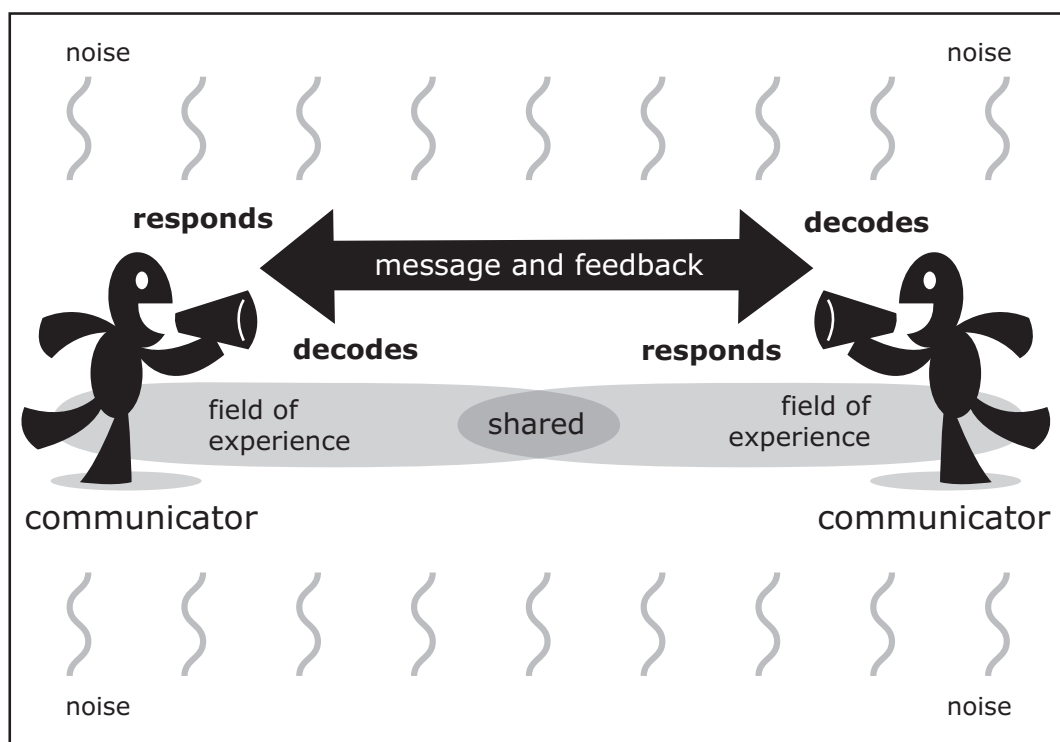


Figure 7: Adaption of the Transactional Model.
(Barnlund, 2011)

4.2.2 Discussion of general communication models for AAC users

The descriptions and models above offer an insight into the unique nature of AAC use, and highlight some of the differences between this and neurotypical communication. Indeed, two aspects of the communication process are altered with the use of AAC devices. Firstly, the potential to share through message exchange can be limited by the sometimes impersonal nature of Aided AAC use, and secondly, the types of messages are limited as well, depending on the capabilities of an AAC device.

General communication models also offer important insights to the AAC process. For instance, the channel, for adults with CCN, *is* the message, if users rely on Aided AAC for their communication. The channel, in this case, does not only affect the nuance of the meaning in the message. Without a channel, in this case extended to an alternative to, or augmentation of speech, AAC users cannot effectively communicate. This is an important point to consider, and is discussed later in this chapter, and in other parts of this thesis.

The concept of noise is of importance as well, and offers a unique set of challenges for AAC users. These users deal with many types of noise that challenge their communication effectiveness: the physiological noise of their condition (impairment health issues affecting their ability to listen, write and understand), the psychological noise brought about by their differences (dealing with social attitudes about their appearance, use of AAC, and abilities), the semantic noise from communicating in a unique language (and decoding rapid neurotypical speech); and the physical audio noise around them (typically being surrounded by many carers, staff and other adults with impairments). Discussions by Foucault about the negative and powerful use of language are relevant here.

With the three models providing explanations of general communication processes, the model in the next section expands upon the concept of meaning in communication (and theories of Foucault), to further discuss the idea that there is power infused in language.

4.2.3 Encoding Decoding Model: power relations

The Encoding Decoding Model (Hall, 1980) emphasises power as being an important element in the sending and receiving of messages, where encoding is the infusion of meaning in the production of a message by a sender, and decoding is the process of a receiver translating and extracting meaning out of a received message (Figure 8). Primarily focused on mass media communication, this model is relevant to this research for its depiction of the communication act as being about power relations, as a “complex structure in dominance” (Hall, 1980, p. 163). As discussed, when adults with an impairment and CCN rely on external assistance, such as the dynamic allocation of resources for their communication effectiveness, power can be an important part of communication.

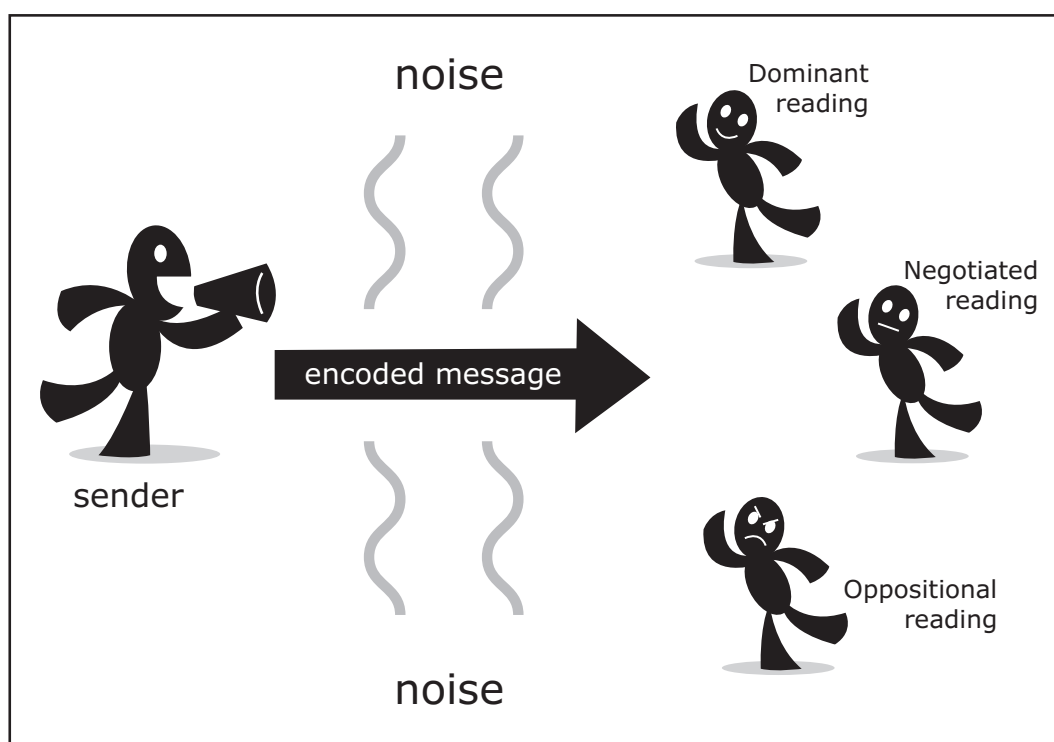


Figure 8: Adaption of the Encoding Decoding Model.
(Hall, 1980)

This model presents mass media, for example, as maintaining the “dominance of those already in positions of power” (Griffin, 2012, p. 344) by encoding messages reflecting that dominance, and suggests three different interpretations of a message by a decoder or message receiver:

- The dominant reading is one where a decoder reads or interprets the message in the encoded form as intended. In its purest form, this is known as transparent communication.
- The negotiated reading is one where a decoder agrees with the meaning in the message, but opposes certain aspects of the message in a personal, contextual way.
- The oppositional reading is where a decoder disagrees with the meaning of the message entirely.

For example, if a government agency produces a message about the adequacy of its disability support funding and support systems, a person with an impairment who relies on that support could read the message by:

- Agreeing with that information. This reading is inside the dominant code. The audience reading coincides with the government's preferred reading.
- Agreeing generally with the dominant ideology, but opposing the idea in specific areas. If this person thought overall support was adequate, but not for their specific impairment, for instance, this would be applying a negotiable code to the decoding of the message.
- Rejecting the message. If this person did not agree with the communication, and saw it as a biased message that was not true, then the reader would be substituting an oppositional code.

4.2.4 Discussion of the Encoding Decoding model

Note that while the Encoding Decoding model specifically presents power imbalances in communication, the models presented earlier in this chapter represent power in their general design. As discussed, the linear model shows a communication one way, suggesting that the sender holds power. Subsequent circular models, such as the interactional, and transactional, present communicators as meeting potentially as equals (Griffin, 2012).

The suggestion in this Encoding Decoding model, that dominance of one group can potentially be maintained through communication, is particularly relevant for AAC users. While this fourth model introduces possible responses to a message, and

suggests that power plays a role in these exchanges, the possible frustration for AAC users is twofold: that their ability to select and use these responses effectively is limited by their AAC device, and their ability to communicate anything at all is dependent on an even greater power imbalance, as other people are typically responsible for the supply and support of their AAC.

This power imbalance suggests a fifth type of noise be added to these models to describe the challenges to AAC use for communication: bureaucratic noise. This would serve to highlight the control that government allocation of resources, and neurotypical communication partners, have over the ultimate quality of communication for AAC users. This type of noise, a form of institutional barrier, as described in the previous chapter, affects the quality of communication for these users in a unique way that neurotypical people may not experience.

With the presentation of the three general models, and an insight to the potential power relations within communication, the final models in this next section show development toward a model for AAC. This will then complete this section, before communication types are discussed.

4.2.5 AAC and related models

I will now present four models that serve “as a bridge from the more general models of communication to a specific model for AAC” (Lloyd et al., 1990, p. 182). Note that while the first two models in this next section have selected features that are applicable, the final two were specifically designed to describe communicators with CCN. As with the previous models presented, each of these four influenced the development of subsequent models. Unlike the previous models, these new ones add information about the internal processes of communicators, including their possible thoughts and other cognition during message exchange.

Those described here include the models:

- Closed Cycle Control System for Speech (Fairbanks, 1954).
- Components of Communication (Berko, Wolvin, Wolvin, & Aitken, 1977).
- Communication Cycle (Sanders, 1982).
- AAC Communication (Lloyd et al., 1990).

Closed Cycle Control System for Speech

While this model (Figure 9) only refers to the act of speaking, or the sending of a verbal message, it does expand upon aspects of the Interactional model by describing the feedback process in more detail. Fairbanks suggests that to gather feedback, the sender is able to see changes in their own facial features, hear their voice, and feel their mouth as they speak:

Speech, or any communication output, is self-corrective in most senders.

This is possible because the sender is able to constantly monitor the output via various forms of feedback (auditory, visual, and tactile) and adjust such output according to a preconceived standard based on previous experience (Lloyd et al., 1990, p. 182)

Fairbanks (1954) describes this set-up as providing feed forward, with the significance of the data about the past used for a prediction of the future.

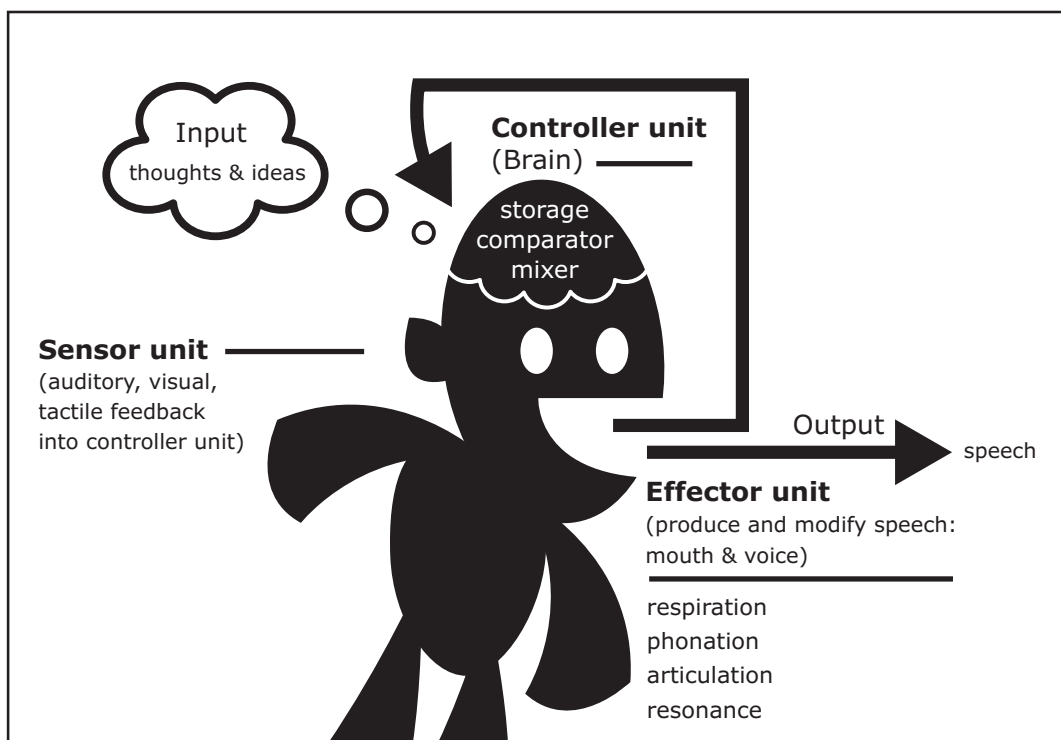


Figure 9: Adaption of the Closed Cycle Control System for Speech Model. (Fairbanks, 1954).

Integral to the model is the symbolic depiction of three main systems:

- The Controller unit (or human brain) that contains storage for message information, the comparator that compares the current message to information gleaned from previous messages, and the mixer that combines information from previous and current messages to enable a person's desired communication.
- The Effector unit (or mouth and related features) that includes the production and modification of speech. This contains features that affect breathing, and the shaping and execution of verbal communication.
- The Sensor unit (or human senses) that includes the three main senses used to gather feedback during the sending of a message, such as sight, hearing and touch. Touch here refers to the term, proprioception, or the ability of a person to control or be aware of their muscles and body.

While internal feedback, and feed forward in this model is shown as important to control the quality of speech production, the next model expands upon this concept to include external feedback and an explanation of environmental influences.

Components of Communication

This model (Berko et al., 1977) shows feedback as coming from two sources, as intrasender (internal) and intersender (external) feedback (Figure 10). Internal, intrasender feedback is described here as using a servosystem, a label that references the term, servomotor, a mechanical feature used in quality control during product manufacture. The implication here is that the quality of a message can be guided with the use of a feedback mechanism. External feedback, also used here to determine the integrity and effects of a communication, is described as being gathered from the reactions of a person receiving the message, in much the same way as earlier models.

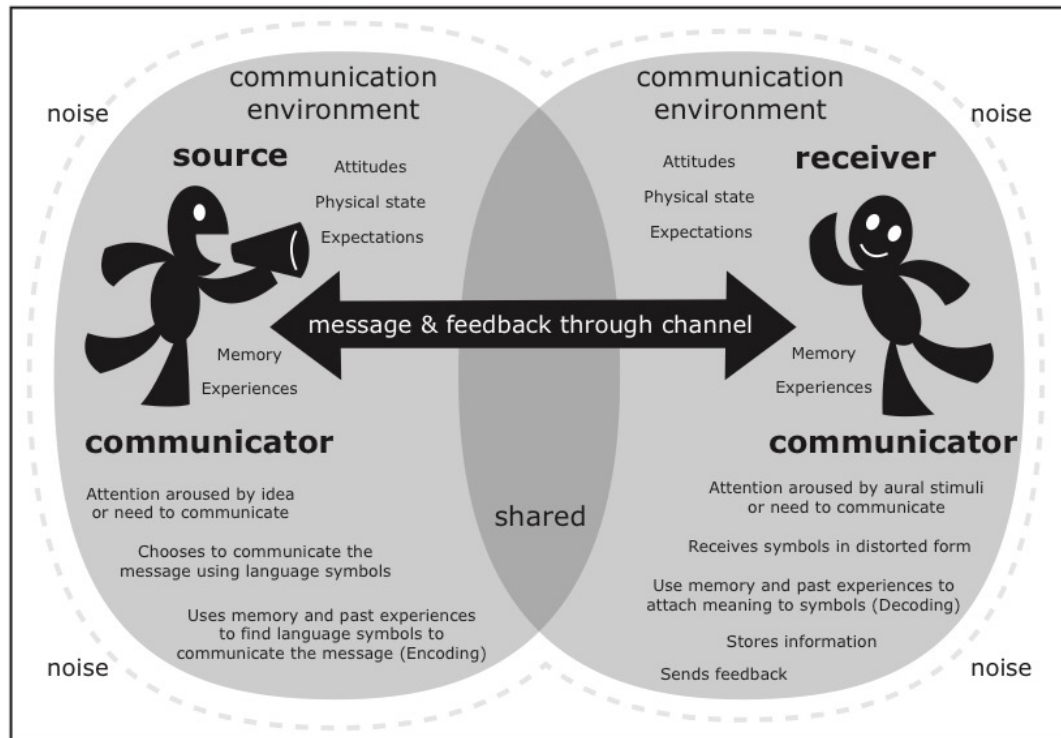


Figure 10: Adaption of the Components of Communication Model.
(Berko et al., 1977).

This external feedback also emphasises the importance of the environment in message exchange. Expanding upon the growing shared experiences described in the Transactional model, this one attempts to consider many of the variables of a communicative act. In contrast to the earlier models, this model attempts to include aspects such as experiences, attitude, and physical state. As illustrated, this environment also includes the memories and expectations of communicators, and lists a number of points considered by a sender and receiver during the act of communication.

While the first two models above in this section contain features that are relevant to communication by AAC users, the following two were designed specifically with these users in mind.

Communication Cycle Model

Sanders (1982) (Figure 11) advances a model that describes the communication act as using more than just speech, through a variety of channels. Originally conceived to offer an explanation of deaf people's communication challenges, this model

outlines the role of human body parts and channels in the sending and the receiving of messages. For instance, using the hand and arms, messages initiated by writing and gesturing move through the visual channel, and can be seen by a receiver's eyes, and potentially understood using the receiver's visual cortex part of the brain.

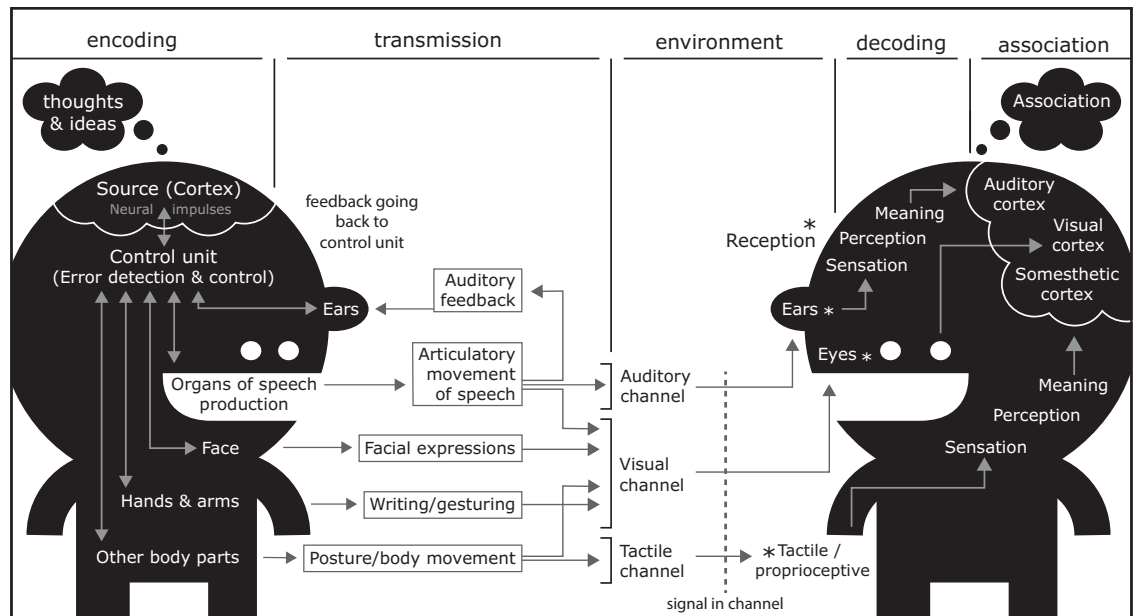


Figure 11: Adaption of the Communication Cycle Model.
(Sanders, 1982).

Writing, gesturing, posture, body movement, and facial expressions are now also included as part of the sending process, and the three senses used in Fairbanks' model (auditory, visual, tactile), are now used here to describe the receipt of a message or to provide feedback to the sender.

Sanders describes the receipt of a message exchange in great detail, with a series of stages from the reception of the message through sensation, perception, and meaning to an association (or contextual understanding) of the communication in the brain (cortex) of the receiver.

Sanders (1982) also discusses the concept of, redundancy, which he describes as "that part of a message that can be eliminated without significant loss of information" (p. 27). Here, he outlines the role of, constraints (p. 22–26), limitations that can be used by a person to help interpret a distorted or incomplete message. These constraints include contextual information gathered from a surrounding environment (situational constraints), or the known rules of a language, (phonemic and structural

constraints), that could give additional clues to a message's meaning. An example of a useful limitation, is when a person could understand the meaning of an incomplete word, because they know that there are only two possible words it may be, given their knowledge of the language, then only one because of the context of its use in a sentence or environment. Sanders notes that "if the listener is highly familiar with the (communication) code and its rules, there is a greater chance of overriding the deleterious effects of any noise" (p. 183).

The term, redundancy, then, outlines the advantages of communicators' shared experience, language and context to streamline conversation, where the sender and receiver can rely on this knowledge to, potentially, use abbreviated forms of communication. Note here that the use of redundancy does not replace effective communication, but that this familiarity may make simpler communication more understandable.

While Sanders' model was intended to describe alternative means of communication by those with a hearing impairment, the final model in this section was designed specifically to describe the unaided and aided communication of typical AAC users. A slight change to Sanders' model, this next one presents all of the human senses as involved in the process, and attempts to show the barriers and interfaces set up between a sender and receiver in the use of alternative or augmented forms of communication.

AAC Communication Model

Figure 12 shows the AAC Communication model (Lloyd et al., 1990).

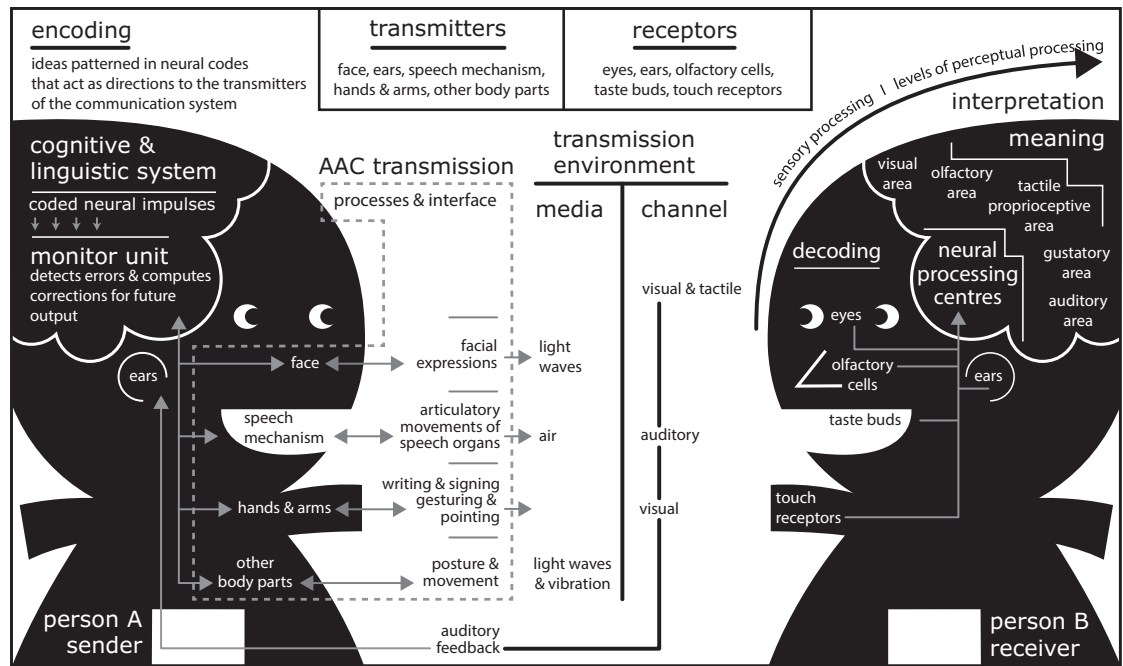


Figure 12: Adaption of the AAC Communication Model.
(Lloyd et al., 1990)

This model presents the work of Sanders with some modification:

First, we have made a distinction between a broader communication environment, which includes people and context, and a transmission environment, which may also be called a propagating medium or signal environment. What we call the transmission environment is what Sanders simply called environment. This is the environment through which a common boundary with the receiver is achieved. Second, we have superimposed AAC transmission processes and an AAC interface. The third modification is the simplification of the 'neural processing' centers portion of the schematic representation of the model...The neuroprocessors are essentially the same for any communicator (sender or receiver), except for any impairments that may be present (Lloyd et al., 1990, p. 175).

While Sanders described the direct sense-related path of a message, for instance, from hands, through a visual channel, to a visual cortex, Lloyd et al. (1990) make a distinction between the human portion of the communication, and the external portion, through a channel to another person's receptors. Writing and gesturing (the AAC), for instance, now move from the hands and arms (human processes),

through light waves (media), as a visual channel through the eyes and visual-perception area in the neural processing centre of a receiver (human receptors) to enable meaning.

This model also shows a lined barrier around the transmitters developing the communication, as a means to depict the use of AAC process as the interface between sender and receiver.

4.2.6 Discussion of AAC and related models

The additional models described in this section highlight a number of issues for AAC users, including the complexity of neurotypical communication, and the many tools verbal speakers can rely on to facilitate effective message exchange. From the models shown in Figures 9 and 10, the effective use of feedback is something that AAC users may struggle to use appropriately, as noise may prevent those with CCN from either collecting the information (because of hearing or visual loss), or interpreting the information (because of intellectual disability). Furthermore, elements of the environment described in the Components of Communication Model (Figure 10), are problematic for these users, because the experiences of individuals with CCN may be limited, they may have memory loss, and the attitudes and expectations of neurotypical people they communicate with may not be conducive to the slower communication during AAC use.

The Communication Cycle Model (Figure 11), tailored to individuals with hearing loss, expands the process to include non-verbal communication, and while this does reflect the multi-modal nature of AAC exchange, it also assumes that the message exchanges are unaided. Sanders does, however, discuss the concept of redundancy in his work (Sanders, 1982), which is an important concept for AAC users in two ways. Firstly, given the myriad of challenges with the use of AAC aids, a way in which those with CCN can communicate effectively with others, without or with little use of aids, would be beneficial. In such instances, familiar communication partners could use contextual clues to help extract some meaning from each other's messages. Secondly, while situations between those with shared experiences have the potential for this understanding, that situation may not be typical for an individual with CCN. Relying on the limited advantages of redundancy, and limiting the training

and use of AAC, could leave them less able to communicate with a wider range of unfamiliar communication partners, and reduce their independence and vocabulary.

In the AAC Communication Model (Figure 12), the depiction of the distinction between the communication and the transmission environments is important. Adding this element, the concept of the interface in AAC exchange is presented. That is, the idea that for people with CCN, a direct communication path from a sender to a receiver is not always possible; an AAC aid or technique is typically needed. Using much of Sanders' model, but simplifying aspects such as the neural processing centre and some of the terminology (for example, somesthetic cortex), the model presents a coherent look at augmented and alternative communication processes through various human senses and external media.

With eight communication models now outlined, various aspects of the communication act, between a sender and receiver have now been diagrammatically represented. As discussed, each model offers something different to an understanding of AAC exchange. The explanations and discussions presented in these models, and in previous chapters, are also used as the framework for a new, refined communication model, presented in chapter 5.

4.2.7 Summary of Communication models

Before the next section, communication types (or environments), are described, a summary of models is presented (Table 11).

Table 11: Summary of Communication models.

Year	Model	Author	Figure	Important introduced features
1949	Transmission	(Shannon & Weaver, 1949)	5	Noise and channel
1954	Interactional	(Schramm, 1954)	6	External feedback
1954	Closed Cycle Control System	(Fairbanks, 1954)	9	Internal feedback
1970	Transaction	(Barnlund, 2011)	7	Shared environments
1977	Components of Communication	(Berko et al., 1977)	10	Details of environment
1980	Encoding Decoding	(Hall, 1980)	8	Power imbalances
1982	Communication cycle	(Sanders, 1982)	11	More than just speech
1990	AAC Communication	(Lloyd et al., 1990)	12	AAC specific

4.3 Types of Communication

In this section, I discuss communication types. While descriptions of processes and models elaborate on the act of message exchange, types of communication outline various environments in which these acts take place.

Types of communication are grouped into style of delivery or number of participants: intrapersonal (within one person: imagining, dreaming, thinking); interpersonal

(between two people); small group (three or more people); organisational (with and among large companies or environments); public/rhetorical (to large groups); mass mediated (to large groups through a mediated channel); and intercultural (between and among groups of different cultures) (Adler et al., 2001). In typical face-to-face conversation, AAC users employ interpersonal communication in their message exchange, but their means of message delivery is mediated. AAC users can also be described as communicating intercultural, as discussed in chapter 3. These three types of communication (interpersonal, mediated, and intercultural) are now briefly outlined, ahead of a more in-depth discussion of related communication theories.

4.3.1 Interpersonal communication

Interpersonal communication is traditionally described as face-to-face information exchange between two communicators, with a two-person group described as a dyad (Adler et al., 2001). It is noted as the earliest form of communication that is experienced, and typically is the most common form used in a person's life. Unlike group or other types of communication, "dyads are complete and cannot be subdivided" (Adler et al., 2001, p. 15), with each side having to negotiate with the other in order to get their needs met.

Interpersonal, sometimes called, dyadic communication, is not only defined in relation to style or quantity of participants, but as a range of exchange quality. The extreme, low-quality, impersonal nature of some face-to-face interpersonal communication is described as impersonal communication, with the high-quality extreme described as personal communication. Features such as uniqueness (the contextual way in which we communicate with different people), irreplaceability (the importance of different exchanges), interdependence (how exchanges make each other feel), and disclosure (shared personal thought and feelings) are seen as measures of quality in this range (Redmond, 1995). In one book, Adler et al. (2001) suggest that:

...most of us don't have the time or energy to create personal relationships with everyone we encounter. Most relationships aren't either personal or impersonal. Rather they fall somewhere between the two extremes (p. 17).

While some neurotypical communicators have the ability to guide this level of intimacy in a conversation with their interpersonal skills, AAC users are guided by

different constraints. As discussed in chapter 2, the communication abilities of adults with CCN vary greatly, according to their impairment and disability. Furthermore, the availability and effectiveness of the AAC to which they have access determines the personal level of their exchanges, because they communicate through an external, mediated channel, discussed next.

4.3.2 Mediated communication

While interpersonal communication has typically been categorised as involving the physical closeness of communicators in face-to-face communication (Knapp & Daly, 2011), early descriptions of mediated communication were presented as a very different form of communication, as an exchange through external means, such as print (books, written notes, and newspapers) and electronic forms (television, telephone), between people in different physical locations from each other. The term, cues-filtered-out (Culnan & Markus, 1987), was first coined to describe the perceived lack of personal, subtle information available in these mediated exchanges, including tone-of-voice or subtle meaning in printed text or written letters, or facial cues and other non-verbal communication in telephone calls.

With the development of more sophisticated, simulated aspects of face-to-face exchange in mediated communication, including the ability to receive instant feedback (live-chat, text messages), and to see another person (pictures on social media, video telephony), more current research such as Computer Mediated Communication (CMC) (Liang & Walther, 2015), extends interpersonal communication to include forms of this mediated type. Other theories, described in more detail in the next section, explain the similarities and differences between two forms of interpersonal communication: face-to-face communication, between people in the same, immediate, physical area, and mediated communication, with people physically away from each other.

While the similarities and differences of real and simulated interpersonal communication types are debated, some of the processes of face-to-face AAC still do not fit neatly into either of the current descriptions of these two types (the close physical proximity of face to face, or the geographically-distant, mediated categories), because AAC communicators can use both at the same time. That is,

even when communicating in the same physical area with other communicators, aided AAC users exchange messages through a mediated, external channel.

This unique type of interpersonal communication further highlights the differences between this group and neurotypical groups, so communication between members of this and with other groups can also be defined as intercultural communication, discussed next.

4.3.3 Intercultural communication

Further to the discussion about culture and disability in the previous chapter, intercultural communication refers to situations in which individuals from different cultures exchange messages in a way that is shaped by their different cultural ideals (Samovar, 2013). Sometimes seen as challenging, members of each culture typically need an understanding of the other, or at least empathy on the part of each communicator, for effective communication to take place.

As with the range of personal exchange in interpersonal communication, there are also degrees of cultural significance in intercultural communication: “At the ‘most intercultural’ end are situations where differences between the backgrounds and beliefs of communicators are high” (Adler et al., 2001, p. 37). The differences between neurotypical and AAC-using groups are typically high, when the latter’s physical appearance, behaviour, and method of communication can be markedly different from the former group. Furthermore, the former group’s propensity for attributional variations (perpetuation of stereotypes), and uncertainty avoidance (tolerance for differences) (see Table 5), can contribute to the differences between them and AAC users.

AAC users face challenges when cultural differences contribute to assumptions about their ability even before they communicate. These factors, as well as the other implications of their unique type of communication, are discussed next, before communication theories are presented.

4.3.4 Summary of communication types for AAC users

As with communication processes and models, the segmented, neurotypical view of communication types presented above needs some refinement to describe AAC

exchange adequately. The delineation of the two types of interpersonal communication (the physically close face-to-face and the physically separated mediated), still does not sufficiently describe the AAC processes, because both types can be used at the same time. Furthermore, mediated means of communication, and stereotypical assumptions can affect the personal nature and effectiveness of message exchange, as well as the degree of cultural difference between neurotypical and AAC groups.

The next section presents communication theories, and this information, along with specific aspects of processes, models and types of communication, are brought together in the form of a refined model, outlined in chapter 5.

4.4 Communication Theory

To complete the overview of communication, in this section I begin by describing the term, communication theory, and then presenting two overviews of the field: the first a pair of opposite, academic approaches to communication study; the second a more nuanced, meta-theory of traditions in the field. This is in order to highlight this complexity of study about communication beyond this range of research styles. As AAC users employ a unique form of communication, this is followed by a breakdown of each facet of that uniqueness, as described by relevant communication theories. These include the range of theories about mediated communication, and those that discuss power relationships among individuals and cultures. As discussed, pertinent aspects of each of these theories, plus those from models and types, will then be combined to form a refined communication model.

4.4.1 Two overviews of communication theory

Communication theory is an “umbrella term for all careful, systematic, and self-conscious discussion and analysis of communication phenomena” (Bormann, 1989, p. 25). Under that umbrella we find hundreds of communication theories. To narrow the selection to appropriate communication theories, I look at two existing meta-analyses of the field.

Firstly, communication theory can be broadly categorised into styles ranging from purely objective to purely interpretive approaches, with objective approaches seeking explanation through scientific, quantitative forms of testing, and interpretive

approaches searching for qualitative meaning and value. Table 12 outlines a comparative summary of criteria for evaluating communication theory.

Table 12: Summary of criteria for evaluating communication theory.
(Griffin, 2012, p. 13).

Objective (Scientific) Theory	Interpretive Theory
Explanation of Data	Understanding of People
Prediction of Future	Clarification of Values
Relative Simplicity	Aesthetic Appeal
Testable Hypothesis	Community of Agreement
Practical Utility	Reform of Society
Quantitative Research	Qualitative Research

Secondly, communication theory is made more complex by the range of traditions that it draws upon. One researcher (Craig & Muller, 2007), suggests that this range moves across seven traditions in the field (p. xv): Rhetorical, Semiotic, Phenomenological, Cybernetic, Socio-psychological, Socio-cultural, and Critical forms of theory:

- Rhetorical forms include those that explore propaganda, influence and persuasion in communication, usually in communication addressing groups of people.
- Semiotic forms study the use and meaning of signs and symbols in communicated messages.
- Phenomenological forms centre on individual perception, or communication from an individual's or other's point of view.
- Cybernetic forms study the systems and networks of processing and exchanging information.

- Socio-psychological forms use objective, observable methods to seek knowledge in communication exchanges.
- Socio-cultural forms explore the idea that communication builds culture.
- Critical forms challenge empirical forms of theory and explore the role of communication as perpetuating power imbalances and repression.

Each of the traditions are not “levied off from each other” (Craig & Muller, 2007, p. xv), rather each tradition usually connects, in some way, “to ideas from one or more other traditions as well” (p. xv). This is an important point, because the uniqueness of AAC cannot be adequately described by theories focused on any one tradition. For example, in the next sections, mediated communication is represented as being across the cybernetic and rhetorical, and power relations in communication is represented as being across the critical and socio-cultural traditions.

To begin the process of looking at communication theory as it relates to AAC use, a focus on the media used for communication is of particular importance. Mediated communication theory is now presented.

4.4.2 Mediated-communication theories

As introduced earlier in this chapter, mediated communications are messages delivered through a channel external to the human body. Generally, media is a “generic term for all human-invented technologies that extend the range, speed, or channels of communication”, and medium is “a specific type of media; for example, a book, newspaper, radio, television, telephone, film, website, or email” (Griffin, 2012, p. 322).

This section is prefaced with an introduction to Media Ecology, a theory that describes the importance of the channel or medium used in communication exchange. Three opposing approaches to mediated-communication theory are then presented to highlight the ongoing debate about the nature of real and simulated face-to-face, interpersonal communication, an issue that is at the heart of AAC.

Media Ecology

The Media Ecology theory (McLuhan, 2008), is of particular relevance to this research in two ways. Firstly, the phrase “the medium is the message” (p.27), is a statement coined by McLuhan (1960), suggesting that the type of communication delivery channel is just as important as the message itself, because the channel shapes the message according to the sophistication of the channel. This idea suggests a more literal interpretation for AAC users, because typically for them, the presence of delivery medium is of primary importance, because no medium means no message at all, regardless of sophistication.

Secondly, McLuhan highlights the importance of media, suggesting that human civilisation was shaped by distinct eras in which specific media were used widely. These ages are the Tribal, Literacy, Print, and Electronic ages. McLuhan suggests that the latter Electronic age is a modern, digital version of the first tribal age, with more sophisticated technology once again providing an immediate connection to those around us. His claim that we live in a “global village” (McLuhan, 2013, p. 54) suggests that people can personally connect by using an effective artificial communication channel such as AAC. Indeed, with the proliferation of communication using mobile devices, this form of media use is now seen as typical, and welcome to AAC users (Francis et al., 2005).

The next section outlines the three approaches to mediated-communication theory. The first approach includes theories that highlight differences between mediated and face-to-face communication and argue that “systematic reductions in the nonverbal cues conveyed by different communication systems lead to impersonal orientations among users” (Walther, 2011, p. 444); The second approach involves theories that describe successful communication despite a medium’s limitations, and “reflect the ways in which communicators adapt to or exploit the cue limitations of Computer Mediated Communication (CMC) systems” (p. 445); The final approach explores similarities between face-to-face and mediated-communication, and looks at how CMC can potentially achieve the same goal as face-to-face communication.

Differences between communication forms

Early mediated-communication theories, grouped into Computer-Mediated Communication (CMC) (Walter 1996), largely look at the cues-filtered-out differences between mediated and close proximity, interpersonal communication. Social Presence Theory (Short, Williams, & Christie, 1976) suggests that text messages take away the sense that users are all involved in conversation. Media Richness Theory (Daft & Lengel, 1986), classify each type of medium according to strengths and weaknesses. This latter theory presents the idea that:

...face-to-face communication conveys highly nuanced emotions, and even double meanings. By contrast, the limited bandwidth of CMC makes it rather lean – appropriate for transacting everyday business, but not for negotiating social relations” (Griffin, 2012, p. 138).

Lack of Social Context Cues theory (Sproull & Kiesler, 1986) outlines online communication as promoting less inhibited, more self-absorbed communicators. This anonymous environment has been described as a “toxic climate for relational growth on the Internet” (Griffin, 2012, p. 138).

These theories describe the communication patterns of some CCN adults in face-to-face exchanges, where their impairment often guides their abilities. Communicators with Autism, in particular, can struggle with reading non-verbal cues and with eye contact even without mediated channels (see chapter 2). With mediated communication, the somewhat negative theoretical views of the relational capabilities of mediated communication, do seem positive for certain aspects of AAC aid use, such as the everyday business of asking for food or other items.

Successful communication despite limitations

Social Information Processing (SIP) (Walther 1992) suggests that the loss of social cues over mediated channels does not mean the loss of personal connection, but only changes the nature of the connection. Walther argues that cues are identified from the linguistic content of written or typed text (similar to the personal nature of pen-pal letter exchanges), and that personal impressions of each other can be formed, but just more slowly than direct, face-to-face communication. The SIP

acronym implies that a drink can be consumed slowly (in SIPs) or all at once (gobbled), but that all of it is consumed using either method.

Electronic Propinquity Theory (EPT) (Korzenny, 1978) looks at media choice, and finds that users given only one choice of communication medium have more propinquity with (feel psychologically closer to) other communicators, than those who are given a choice of more than one medium. Channel Expansion Theory (CET) (Carlson & Zmud, 1999) presents the idea that “as individuals gain more experience with a particular communication medium, the medium becomes richer for them” (Walther, 2011, p. 457).

As one feature of AAC is the slower communication rate of some methods (see chapter 2), the theories in this subsection suggest support for the idea that given enough time, an AAC user would not only communicate effectively, but, depending on the abilities of the user, have a richer experience.

Similarities of communication forms

As communication technology becomes more sophisticated (see for example, Skype, and Facetime), and aspects of face-to-face communication are better replicated by simulated, mediated means, other theories describe the growing similarities of real and simulated face-to-face communication. Indeed, the majority, contemporary position of interpersonal communication theory is that mediated communication, “in a variety of forms, has become integral to the initiation, development, and maintenance of interpersonal relationships” (Walther, 2011, p. 443).

The hyperpersonal view of mediated communication (Walther, 2011), “proposes a set of concurrent theoretically based processes to explain how CMC may facilitate impressions and relationships online that exceed the desirability and intimacy that occur in parallel off-line interactions” (p. 460). These include the way in which individuals can idealise a communication partner if initial impressions about a person are favourable, the way in which messages over online channels can be edited over time to shape a positive, on-line persona of a person, and the continuing feedback of conversation that magnifies these previously edited messages.

Furthermore, online channels of communication provide an opportunity for warranting (Walther & Parks, 2002), a theory that extends the positive aspects of hyperpersonal communication. This is the process of attempting to confirm a true impression of a communication partner, by looking at how individuals in their partner's social network communicate about them. This can serve as a potentially more reliable source of information about a person's characteristics than a self-edited account of the person.

There are other features of mediated communication being studied in relation to emerging forms of technology, including the concept of real presence being simulated with virtual reality (Kim & Dindia, 2011), instant video feedback over telephone (Skype and Facetime), and digital empathy being employed by medical professionals for patients over mediated channels (Terry & Cain, 2016).

4.4.3 Discussion of mediated-communication theories

As outlined in chapter 2, effective AAC use for adults with CCN depends on a number of variables, including whether the aid is suitably matched to the user (using evidence-based practice), and the abilities of the users themselves. Nevertheless, theories about the difference between forms suggest that mediated communication can get the simple jobs done, and theories that are successful despite limitations note that extra time with media could improve communication. The theories showing similarities between the two forms of communication, though, assume the geographical distance of participants as a defining feature of their studies, and not the close proximity, unique form of AAC face-to-face (but still mediated) communication. Investigating whether AAC users can in fact hide their persona behind a mediated AAC aid, while engaging in face-to-face communication, may be interesting, but is beyond the scope of this thesis. Furthermore, the positive look at emerging technologies potentially improving communication, bodes well for AAC users.

In the next section, I expand upon Foucauldian theory and McLuhan's phrase, the 'medium is the message'. Given that access to the medium is influenced or controlled by individuals and organisations other than the users of the medium, then power relations are an important factor in AAC message exchange. Communication theories discussing power imbalances are now presented.

4.4.4 Power-related communication theories

Standpoint theory

Originally a feminist theory, Standpoint theory (Harding, 1986), presents the idea that a minority group has a more developed world view than the majority group. As a critical theory, the view is that “when people speak from the opposite side of power relations, the perspective from the lives of the less powerful can provide a more objective view than the perspective from the lives of the more powerful” (p. 26).

From this standpoint, the implication is that because minority groups exist within a world designed and controlled by the majority, that minority groups become familiar with their own *and* with the dominant group. Given this presumption, the view of the majority is possibly more insular, because empathy for and a sharing of control with the minority would not typically be in the majority group’s best interests if dominance were to be maintained. Dominance here is not described solely as malicious, only that a dominant group typically enjoy that dominance and wish to remain in the elevated state of the majority.

In the world of communication, for example, neurotypical, verbal language users are the majority, and AAC users the minority. In this case, there is typically no need for verbal speakers to think about a loss of verbal language skills. For the minority, use of AAC is a constant reminder that they suddenly lack or have always lacked verbal skills. Furthermore, a large part of the successful implementation of AAC is the user’s, or communication partner’s understanding of advocacy and logistic liaison with neurotypical individuals or organisations, and an understanding of their own and other world views.

As well as theory describing a minority group as being objectively aware of their surroundings (given their ability to do this, of course (see chapter 2)), the next theory, Muted Group Theory, specifies ways in which this potential dominance focuses on language.

Muted Group theory

Muted Group theory (Ardener, 1977) describes the difficulties of a minority group attempting to communicate in the language invented and consistently used by a

majority. Suggested by two anthropologists, the theory was adopted by feminist researchers (Kramarae, 2009) to describe gender-based struggles in society. The theory suggests the group is muted by the inadequacy of a language to provide a means of expression for a minority, but also outlines another level of muteness as a majority fails to place importance on what a minority may be saying. In the theory, the word, muted, does not only mean, not speaking; the theory describes the challenges of all types of communication in this type of relationship.

AAC users do exist in a social environment full of verbal, neurotypical speakers, who communicate quickly, typically with an abundance of layered, nuanced meaning in their messaging. With AAC users, there are even more levels of muteness than the two described above, with the majority/minority division magnified. Adults with an impairment often act, and look different from what society calls, normal, and attempt to communicate in many unique ways. Evidence suggests that their communication can be dismissed even before communication can occur or be diminished (Francis et al., 2005). Furthermore, these adults have cognitive barriers to challenge their communication skills, and many AAC methods, designed to enable them to communicate, are problematic (see chapter 2).

While Standpoint theory suggests that power relations affect a group's knowledge of society, and Muted Group theory offers an explanation for challenges to language use, the final theory in this section, Co-cultural theory grew from these two theories into a study about how groups that are marginalised communicate with those that dominate. This next section also introduces communication theory as it relates to culture, also contributing to the discussion started in chapter 3.

Co-cultural theory

Co-cultural theory (Orbe, 1998) is a theoretical framework that describes how “those without societal power communicate with persons who are privileged within dominant structures” (p. 2). This theory uses the term, co-culture, to replace the terms, minority group, and, subculture, to “avoid the negative or inferior connotations of (those) past descriptions” (p. 1), and seeks to investigate communication from the marginalised groups' point of view. An extension to the work of Standpoint and Muted Group Theory, Co-cultural theory outlines six factors that influence a range of

more than 25 practices that members of marginalised groups use when communicating with members of more socially privileged groups.

These six factors (shown in italics: added) are described as being:

Situated within a particular *field of experience* that governs their *perceptions of the costs and rewards* associated with, as well their *ability* to perform, various communicative practices, co-cultural group members will adopt various communication orientations – on the basis of their *preferred outcomes* and *communication approaches* – to fit the circumstances of a specific *situation* (Orbe, 1998, p. 10).

The six factors that influence the execution of these communication processes offer a useful framework to break down the mechanics of an AAC exchange. This is particularly relevant, given that this unique form of communication requires preparation, can be slow, and involve several communication partners. An AAC user's field of experience is "likely to include ... limited communication support" and "government and educational policy changes motivated by a desire to embrace the principles of normalisation" (Mirenda & Iacono, 2009, p. 444). Their preferred outcomes may be as simple as getting their needs, such as food and shelter met, but their communication practices may be limited by their ability, and the costs and rewards potentially involve more effort than reward. As discussed, the circumstances of a specific situation are also likely to depend on the knowledge, support, and abilities of members of the dominant group as their communication partners.

Table 13 presents a selection of the Co-cultural communication practices that may be relevant to adults with CCN and an impairment.

Table 13: Co-cultural Communicative Practises summary.
(Orbe, 1998, p. 10).

Communication processes	Brief Description
Censoring self	Remaining silent when comments from dominant group members are inappropriate, indirectly insulting, or highly offensive
Avoiding	Maintaining a distance from dominant group members; refraining from activities and/or locations where interaction is likely
Mirroring	Adopting dominant group codes in attempts to make one's co-cultural identity less (or totally not) visible
Dispelling stereotypes	Myths of generalised group characteristics and behaviours are countered through the process of just being oneself
Communicating self	Interacting with dominant group members in an authentic, open, and genuine manner; used by those with strong self-concepts
Educating others	Taking the role of teacher in co-cultural interactions; enlightening dominant group members of co-cultural norms, values, and so forth
Intragroup networking	Identifying and working with other co-cultural group members who share common philosophies, convictions, and goals
Confronting	Using the necessary aggressive methods, including ones that seemingly violate the rights of others, to assert one's voice

While these communication processes may be beyond the ability of some AAC users to communicate effectively (see chapter 2), the theory does offer an insight to some patterns of communication in the power-infused, co-cultural communication of AAC exchange, highlighting even more challenges this group faces. For example, censoring self, and avoiding behaviours could mute this group even more, mirroring could magnify existing co-cultural differences, and confronting may perpetuate negative stereotypes of this already marginalised group. As well as this, the limitations of this group's communication methods could diminish the potential advantages gained with the application of the more positive processes outlined above.

4.4.5 Discussion of power-related communication theories

With Co-cultural theory offering additional insights to the potential ways that power in communication can affect different groups, the myriad of challenges to effective AAC exchange can now be more clearly presented: AAC users, with typically diminished comprehension and communication skills, exist in a world of dominant, competent verbal communicators, who use nuanced, rapid language skills to exchange messages with them and each other. AAC users also need to liaise with this neurotypical, more dominant group to enable their own effective, mediated communication, so it is advantageous to develop a more objective, more developed world view of their own and the other group. The dominant group, typically, has less understanding about AAC users (as a minority), and this latter group, when they have an effective AAC aid to communicate with, still need to use a language developed and in constant use by the dominant group.

Furthermore, a number of factors that influence the range of methods employed by AAC users to communicate with the other groups can be beyond their capabilities, or their control. This discussion exemplifies what Foucault theorised about the influential power of language being infused throughout society.

4.4.6 Summary of communication theory

Before a new Communication model is presented in the next chapter, a summary of communication theory is presented in Table 14, and a summary of this chapter is presented thereafter.

Table 14: Summary of Communication theory.

Theory	Topic	Style	Tradition
Computer Mediated Communication	Mediated	Objective	Cybernetic
Social Presence	Mediated	Objective	Cybernetic
Media Richness	Mediated	Objective	Cybernetic
Lack of Social Context	Mediated	Objective	Cybernetic
Social Information Processing	Mediated	Objective	Cybernetic
Electronic Propinquity	Mediated	Objective	Cybernetic
Channel Expansion	Mediated	Objective	Cybernetic
Hyperpersonal	Mediated	Objective	Cybernetic
Warranting	Mediated	Objective	Cybernetic
Standpoint	Power	Interpretive	Critical
Muted Group	Power	Interpretive	Critical
Co-Cultural	Power	Interpretive	Critical

4.5 Summary of chapter 4

This chapter has continued the discussion initiated in chapter 2, about Augmented and Alternative Communication, and completes the overview of relevant communication studies. The chapter includes descriptions of communication processes, models, types, and theories.

In this chapter, communication is described as a social process and the sharing of messages. Eight communication models have been presented, ranging from the

general linear model to the more sophisticated AAC Communication model. These models are visual representations of communication, with each highlighting different aspects of the processes, introducing concepts such as noise, channel, feedback, and environment. Types of communication are presented, and include intrapersonal, interpersonal, and mass-mediated forms. Interpersonal communication is described as face to face, and mediated. AAC use is described as a unique hybrid of this, as face to face, and mediated, interpersonal communication.

Theories of communication are outlined, highlighting the complex history of the field and meta analyses of the study. Different theories, including those that relate to mediated forms and power relations are discussed, and these also extend the philosophical discussions from chapter 3.

In the next chapter, a new communication model is presented, that features various attributes from earlier models, and introduces further concepts. This interactive, physical model, is a synthesis of the literature reviewed, and research conducted for this thesis.

Chapter 5: The Integrity of Message Model

In this chapter, I present a new communication model. Features from the existing communication models, as well as other information from chapters 2–4, and the empirical data, have been used to inform the development of this new model, adopting a UCD process. How and why these various features are integrated, and what other information is included in this new model, is discussed in this chapter.

The new model, called the Integrity of Message Model (IMM), serves as a diagnostic tool, designed to identify and present visually the breakdowns in communication among adults with CCN. In order to do this, the IMM has been designed to represent the sending of a message visually, from a person using AAC to initiate the communication, to a potential receiver of any ability. In the visual presentation of the communication path, the tool presents the actions taken to prepare and send a message, identifies the myriad of noise that affects the integrity of that communication, and shows the implications of shared knowledge and experiences between communication partners.

This model is used to represent visually some of the empirical data obtained and analysed for this thesis, an example of which is presented after each empirical-study section, and in the final chapter of the thesis. The simplified nature of the visual, graphic output from the model is also designed to enable people with CCN to have a greater chance of effectively using it (see chapter 2). The physical prototype, documented in this thesis, can ultimately serve as a guide to further the new model's design development in electronic or other forms.

As with the existing models, the IMM is a diagrammatic interpretation of communication, with different features that represent the act of communication. In addition to the static, two-dimensional representation of these features, this new model is interactive. That is, users can interact with it and change certain parameters intended to affect the visual look of the sent message represented therein. The model shows various degrees of a message's effectiveness, also revealing details of the type of interference affecting the message. The interactive nature of the model is versatile, useful for identification of the nuances in an individual message exchange, or as an overall representation of a group's communication patterns. Note that neurotypical people use unaided AAC, in their gesticulation and other body language (see chapter 2), so the IMM can be used to describe the interpersonal communication of more than just impaired people. In this

thesis, I use the IMM to provide an alternate, visual report on data collected from a wide range of the communication exchanges of study participants. As the model was not completed until after the empirical studies were conducted, participants did not use the device.

5.1 The IMM design process

The physical, IMM tool was designed over the final year of thesis development. As discussed earlier in the thesis, the new model was intended to describe visually the aspects of a communication environment, in this case an environment with little use of AAC. While the idea for model development was formed early, after the completion of the archival study, design and construction of the IMM prototype occurred in parallel with the writing of the thesis during that final year.

As briefly discussed in chapter 1.4, the design process of the IMM used the empirical data within a User-Centred Design (UCD) process, an approach where information about product users is of prime importance. In this case, the type of potential IMM users are study participants, and I used a specific type of UCD: Interactive Design (Preece, Sharp, & Rogers, 2015). Interactive Design involves “designing interactive products to support the way people communicate and interact in their everyday and working lives” (p. 9). The initial phase in this approach, called the user-requirements capture (Holtzblatt & Beyer, 2014), is used to “understand as much as possible about the users, their activities, and the context of that activity, so the system under development can support them in achieving their goals” (Preece et al., 2015, p. 353).

This approach includes a number of subsequent phases, beyond the systematic gathering of information about users, through stages of iterative design and manufacture, to the testing of designed products and services with users. As the IMM was designed after the empirical research had been concluded, the iterative design process used research data *about* participants, and not direct input from them, and the testing phase is therefore mentioned in the future-work section of the thesis. Further design-test-analysis iteration with target user participation is also considered future-work (see chapter 8.3). As discussed in chapter 6.2, one issue underlying the selection of empirical methods in this thesis was to gather data for use in this design research process.

To develop the initial prototype of the model, the skills I have acquired as a designer and illustrator have been useful in the IMM design process. As a designer, the development and use of a 'brief', or written document outlining what is required in a design, is important, with the brief for this model now presented.

5.1.1 The brief

Aim of project:

To develop a refined, updated communication model that can be used to describe the unique and complex nature of AAC message exchange in a simple, visual way. The model needs to contain features that enable it to be manipulated so it can display different results depending on different situations.

The model needs to show visually:

- A simplification of the AAC communication process.
- The types of communication interference or, noise, in a given situation.
- The effect of shared knowledge and experience between communication partners.

The model needs to be:

- A physical artefact, presented in this thesis as a product prototype.
- A simple, interactive, diagnostic tool.
- Constructed from inexpensive materials, and processes where possible (see disability funding challenges: chapter 2.2.3).
- Large enough so individuals with motor skill issues could potentially use the device, and small enough to fit within the thesis page size.

The model's design process needs to make use of:

- Information from the reviewed literature (chapters 2–4).
- Empirical data gathered about study participants (chapters 6 and 7).
- The user-requirements-capture phase of an Interactive Design process.

Target market:

This tool is intended for use by disability professionals, and by people who are interested to know more about AAC messaging. The features are also intended to cater to those people who struggle with purely textual, complex information.

5.1.2 Design development

The model presented as part of this thesis is an initial prototype. These objects are “physical embodiments of concepts, understandings or design spaces” (Wensveen & Matthews, 2014, p. 268). The prototype here has been used as a research archetype, and these are “principally illustrative, elaborative or ostensive” (p. 268). This archetype, in turn, could be used in future as an experimental prototype, where:

The prototype itself is the object about which design knowledge is sought through the experimental setup. Examples range from formal tests such as usability tests of the prototypes, experiential trials to assess the design attributes such as aesthetics, or cases where the prototype is treated as a physical hypothesis (p. 264).

The development of the IMM research archetype drew on what was learned through the interaction with staff and clients, and the literature review.

Focusing on designing iterations of the model based on the instructions set out in my design brief, the process involved three steps. First, written notes and drawings were produced that explored aspects of the model’s design, including preliminary ideas about its basic shape (Figure 13), what information to include in its display (Figure 14), and how to simplify, describe, and enable the features appropriately so that they could be arranged and interacted with (Figure 15). Note here that Appendix 5 presents more detail about the physical IMM prototype, than is shown in the body of this thesis. This includes photographic documentation of the materials and techniques used in the design process, and the operation of features housed within the finished model.

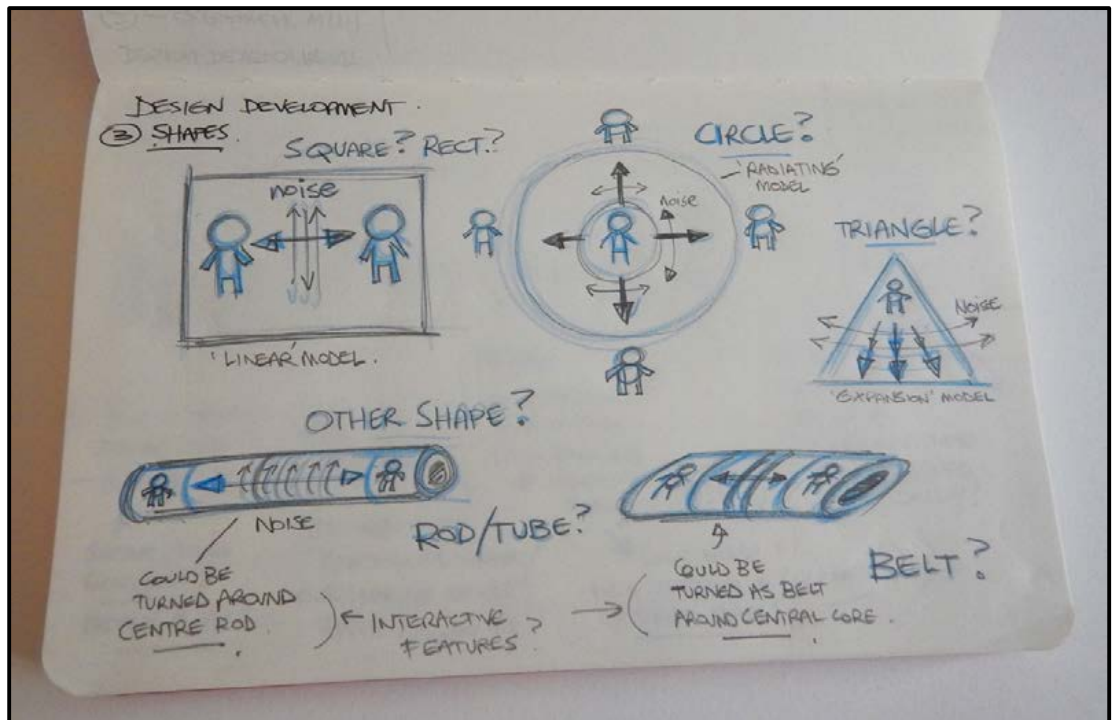


Figure 13: Notes about basic design for the model's shape.

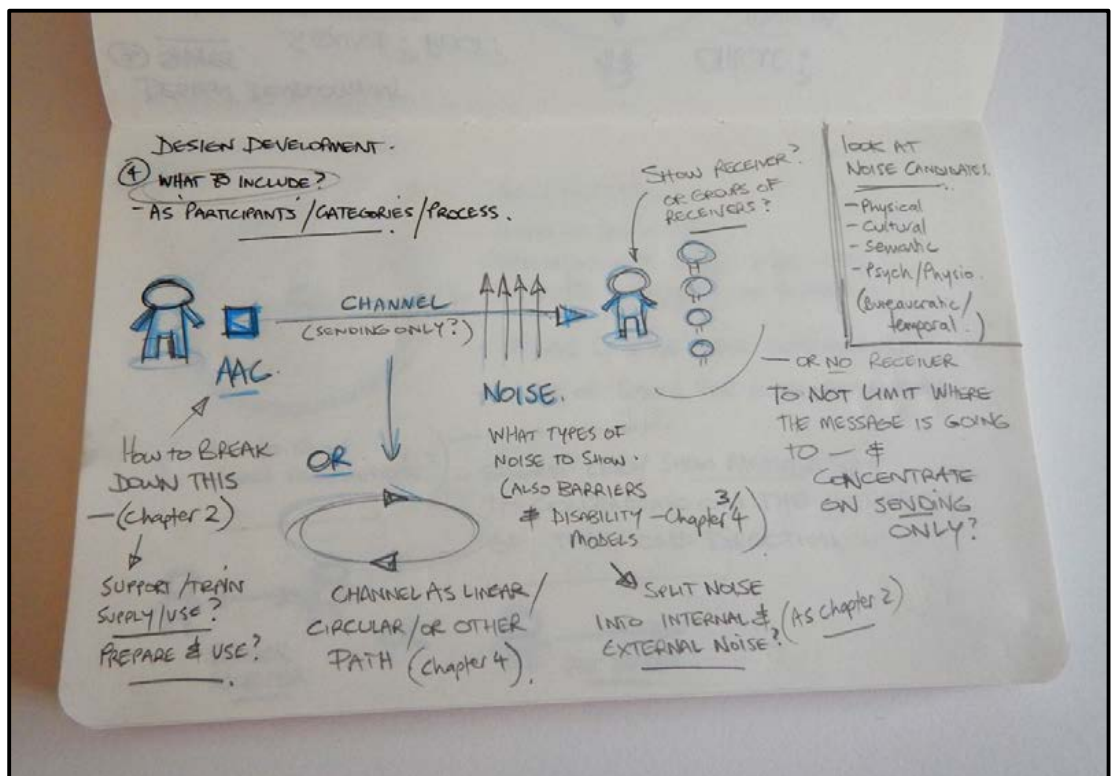


Figure 14: Notes about information contained in the model.

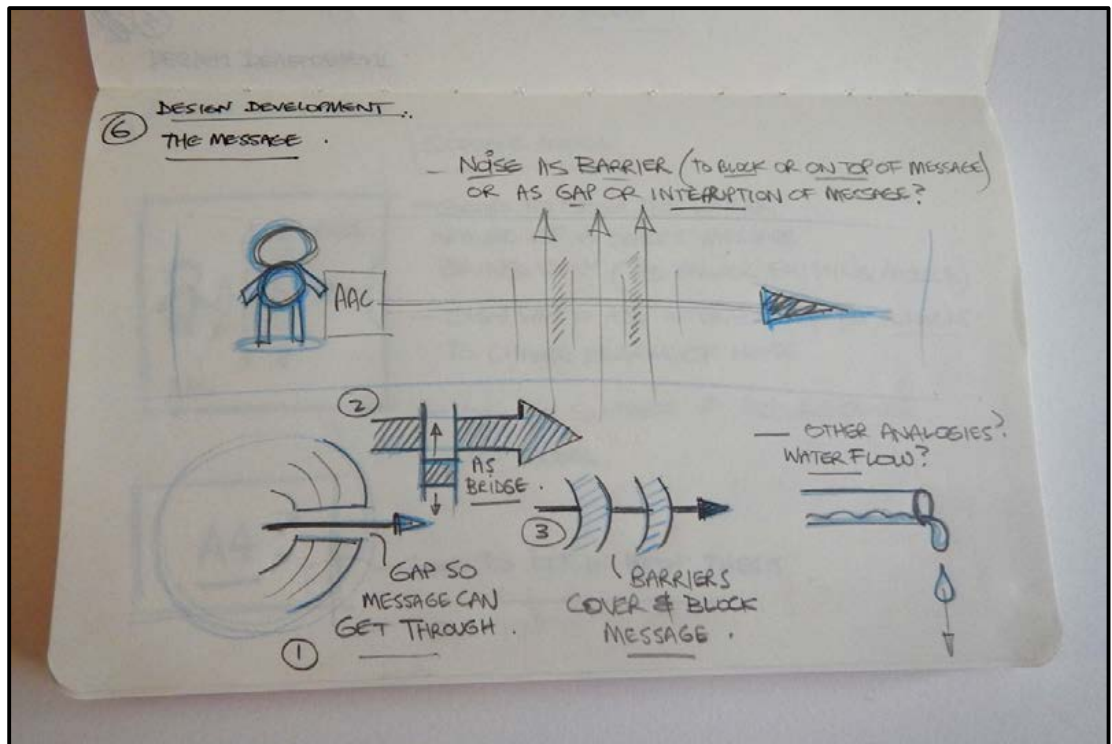


Figure 15: Design of model features, including interaction.

Second, paper prototypes of the model were designed and constructed, to test how the features worked together, and how the interactivity functioned (Figure 16). In this stage, written notes and sketches were added to the paper prototypes as a means of contextually showing variations in design. Many different shapes and configurations were iteratively designed before a circular shape was decided upon: Note, for example the rectangle-shaped variant in Figure 16.

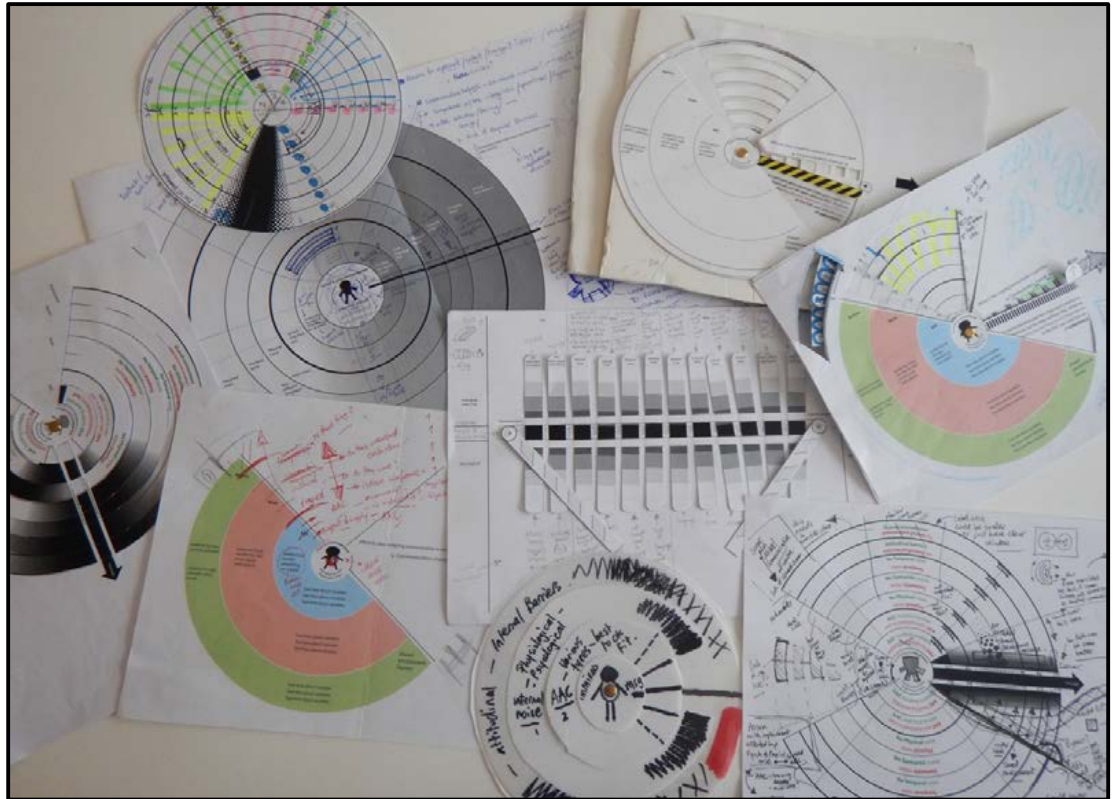


Figure 16: Paper prototypes of the model.

Third, manufacturing processes, including die- and laser-cutting techniques were used to produce further prototypes to test materials, interactivity, and other functions (Figure 17), before a final model was completed.



Figure 17: Laser-cut and other prototypes.

During the stages of design development, the features of existing communication models were studied, and considered for inclusion in the IMM. There were three features that were adapted and updated in various ways for the IMM.

First, in existing models, the concept of noise is featured. This concept has been made much more prominent and detailed in the new model presented here, because AAC communication is extremely challenging, and noise has a considerable effect on the ability of a user to send a coherent message, and on the quality of the message itself. Noise, in this model, is of prime importance, embodying the work of Foucault so as to highlight the effects of powerful language and other factors within the environment of adults with CCN.

Second, the concept of a shared environment, shown in existing models as a growing form of empathy between communicators, is refined in the IMM to show its negative, as well as positive aspects. Finally, the model displays a simplified, typographic, and visual result, allowing the results to be more easily understood by a greater number of people, including those who struggle with a comprehension of

letterforms, and more complex information. While useful, the existing, original AAC *communication model*, and others outlined in Chapter 4, are considerably more complex, text-based models, although they have been adapted and slightly simplified as illustrations for clarity in this thesis.

5.2 Detailed description of the new model

The final Integrity of Message Model, shown in Figure 18 as a graphic diagram, is composed of a series of concentric, interactive rings, described hereinafter as, layers, surrounding the visual representation of a sender, with a message shown emanating from the centre person moving to the right of the model. Layers are numbered from Layer one, with each layer numbered higher the further they are positioned from the centre of the model. For the purposes of IMM description for this thesis, the model can also be described as having five main components, these housing its features, presented next in greater detail. While instructions for use may be added to the model (perhaps on the back of the artefact), they are not present on the prototype at this stage.

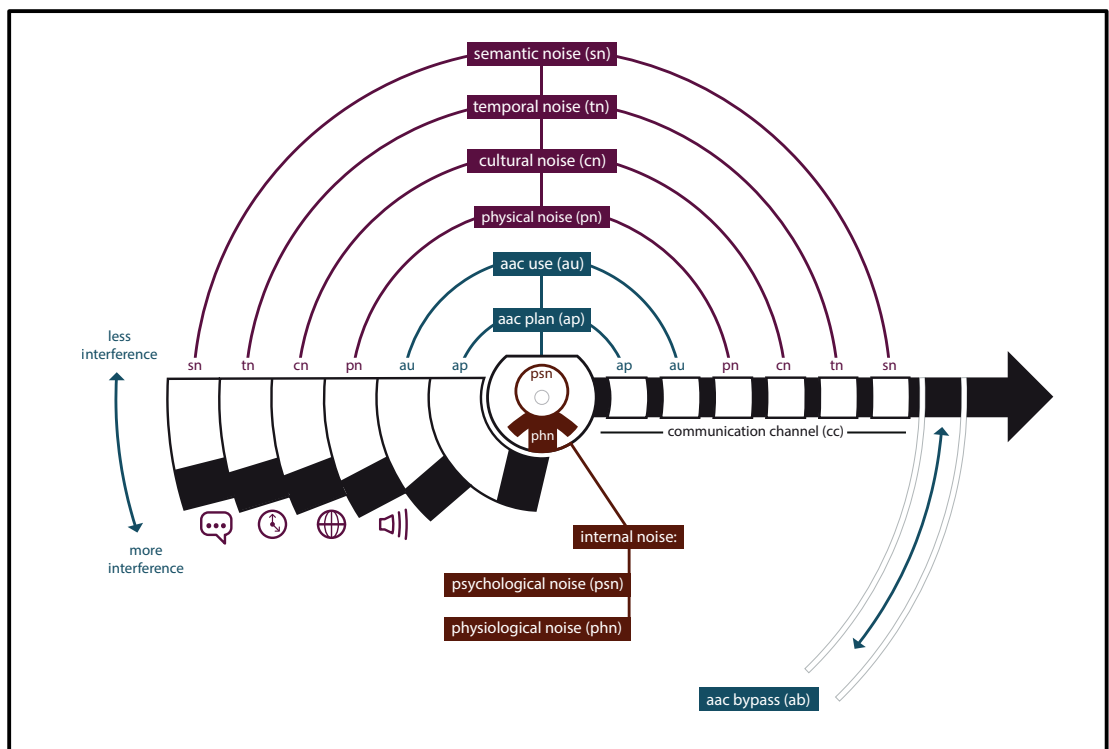


Figure 18: The Integrity of Message Model.

Following the criteria set up for the design brief, the physical model (shown in Appendix 5 as a series of photographs) is built from inexpensive, corrugated cardboard, with an acrylic front used to strengthen the model, and for the protection of an inserted, printed plastic sheet containing text and image details. Furthermore, the model has been constructed using inexpensive processes, laser-cut, or using laser-printed paper from a domestic printer, held together with glue and fasteners, available from suburban art-supply retail stores.

5.2.1 Component one

The first component (Figure 19) is the sender of the message, positioned in the centre of the circular model, represented by the first two layers. Together, both of these layers represent the internal noise that affects this individual, that is, psychological noise (psn), and, physiological noise (phn). As briefly discussed in chapter 4, psychological noise refers to a person's emotional state, such as sadness or happiness, and physiological noise to a person's cognitive and physical state, referring to the mental and physical impairments of a person.

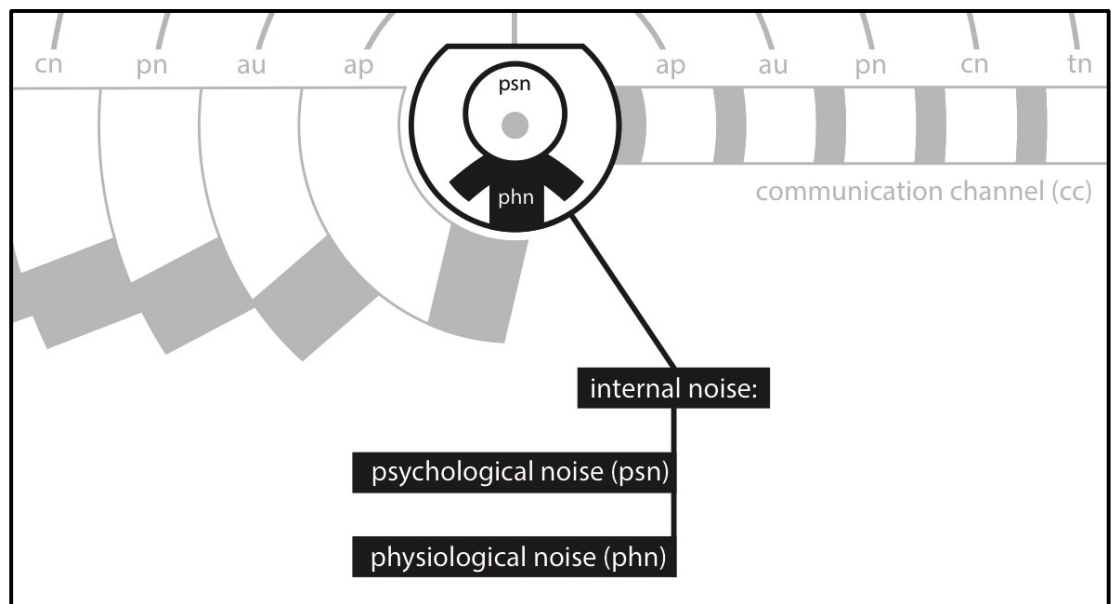


Figure 19: IMM component one.

The concept of the sender has been presented in all existing models outlined in this thesis in various ways, included as the originator of a message, named as, sender, source, or, communicator, in some cases with the model describing the communication processes of the sender as all or a large part of the model itself. In

the new IMM, the sender is presented simply, and graphically, embodying two aspects of noise adapted from earlier, existing models.

Layer one (psn) is designed to look like a person's head, symbolising the person's emotional, cognitive, and physical state in this area. Layer two (phn) is designed to look like the person's body, symbolising other aspects of their physical state, with the representation omitting the person's legs, suggesting that they can be standing or sitting in a wheelchair.

The parameters of these two centre layers cannot be altered by interaction with the model, and are intended to be a simplified representation of the internal challenges a person may experience at a given time. These first two layers are static because the emotional state of the sender is assumed to be appropriate for their intention to send a message, and their cognitive and physical state necessitate their adoption of various forms of AAC, displayed in the next, outer layers three and four.

These subsequent, interactive layers are intended to assist with the challenges brought about by the sender's biological state. The sender (component one) is a snapshot of the person sending the message, emphasising that their biological state is the reason for their reliance on AAC, displayed in the next component two.

5.2.2 Component two

The second component of the model (Figure 20) is made up of layers three and four, and show a simplified breakdown of the preparation for and use of AAC to send a message.

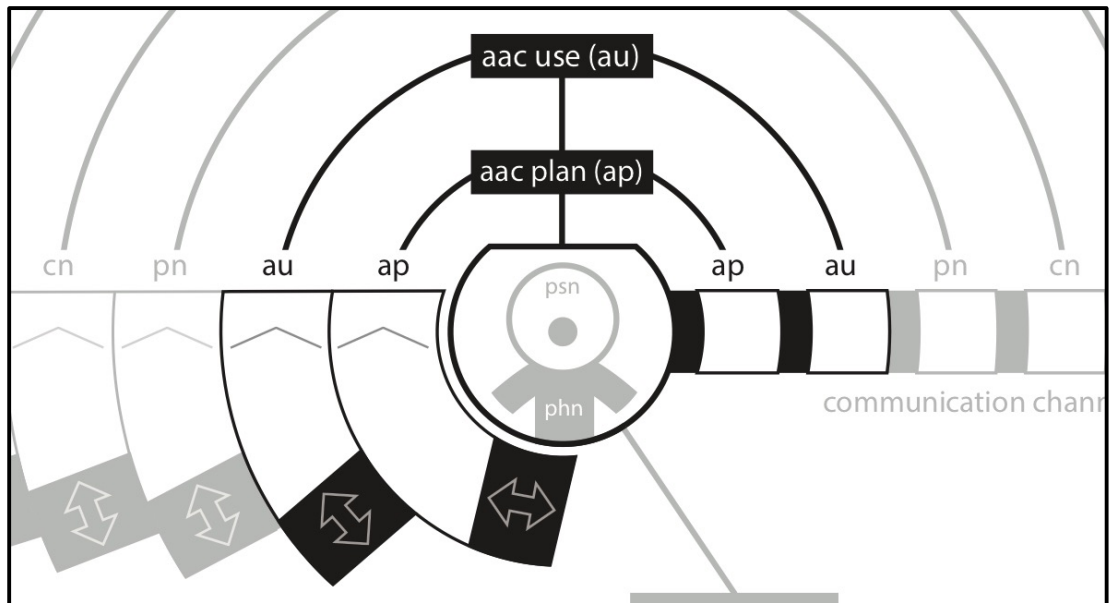


Figure 20: IMM component two.

Layer three describes, AAC plan (ap), and layer four, AAC use (au). The former includes the support of disability professionals in the assessment of that person's impairment, and their subsequent assessment of the functional skills of that person when using AAC. The latter is intended to show whether the appropriate AAC is available for use, and whether the aid has been appropriately matched to the user.

Layer three describes AAC support in the past for that person, and layer four describes whether that past support appropriately and currently enables the user to effectively employ AAC for the sending of that message. This split, in the preparation and use of AAC aids and methods, simplifies the complex nature of this form of communication, described in greater detail in chapter 2, but is intended to highlight the importance of both of these aspects of AAC exchange. As described in chapter 4, this form of face-to-face and mediated communication is unique.

In Figure 20, note the solid black/grey shapes in the bottom left of the image, (containing arrows), that represent handles used to turn each layer. To the top and bottom of each handle are additional graphic elements that suggest the handle can be pushed up or down, depending on the desired effect wanted in component four. More detail is shown in Appendix 5.

5.2.3 Component three

The third component of the model (Figure 21) includes interactive layers five to eight, which detail four types of external noise that may affect the integrity of a sent message. This integrity refers to the quality of the message itself, the degradation of which can potentially influence the correct interpretation of a message by a receiver.

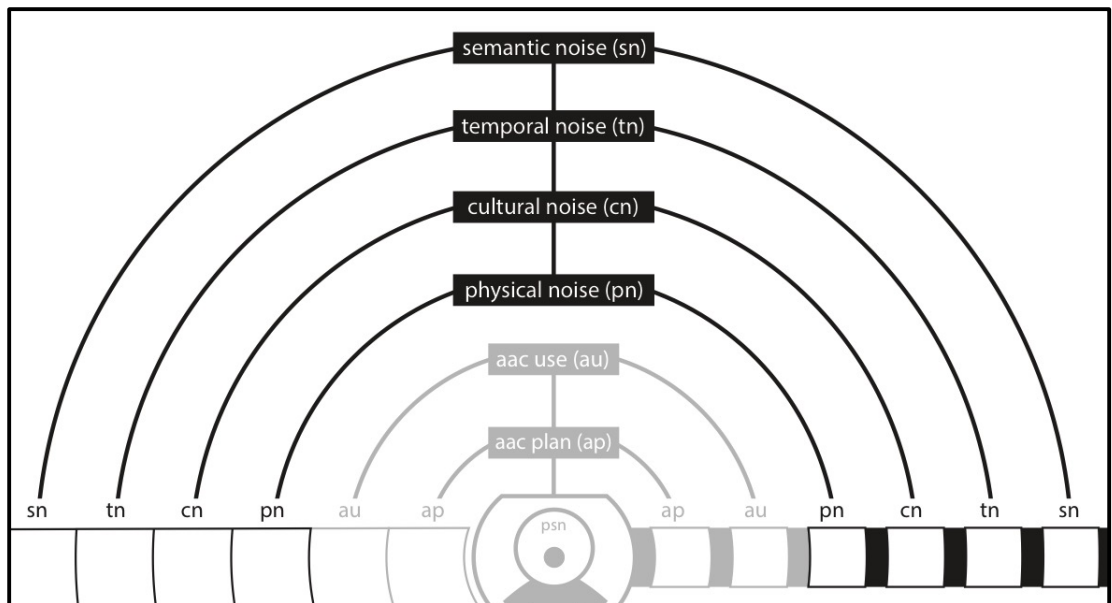


Figure 21: IMM component three.

The noise described in component three is any interference external to the sender, which can describe the physical environment, current situation, or the abilities and assumptions of a potential message-receiver. The receiver in this case can be an AAC user, or a neurotypical person. As described throughout chapter 4, noise is a concept included in every existing model. Another way that noise is described is with the concept of environmental, attitudinal, and institutional barriers, and in the negative/powerful use of language proposed by Foucault, both outlined in chapter 3.

Layer five is, physical noise (pn), which refers to external interference to the sender or receiver's senses, including audio, visual, and tactile noise. Examples of this include a sender unable to successfully use a speech generating device because of too much audio noise, or use Braille because a rough surface surrounds and interferes with the raised language-forms. Additionally, the receiver in this case may have difficulty interpreting the message because they cannot see, hear, or feel the communication, because of these sense-related environmental barriers.

Layer six is, cultural noise (cn), which refers to the differences in the cultural makeup of the sender and receiver, potentially affecting the interpretation of a message. For example, if communicators have very different attitudes about each other, such as a neurotypical receiver having negative beliefs about impaired people, or an AAC user having overtly racist beliefs about a receiver, factors that negatively influence and change the meaning of a message. The concept of culture has been discussed at length in this thesis, with Marx (1954) and Foucault (1982) discussing the objectifying nature of power between cultures, as described in chapter 3, and the DRM noting the attitudinal and institutional barriers inherent in the medical, charity, and economic models of disability. Furthermore, Standpoint, Muted Group, and Co-Cultural Theory, outlined in chapter 4, all describe the implications of social power imbalances in relation to disabled people.

Layer seven is, temporal noise (tn), which represents the time taken for a message to be prepared, sent and received. This concept is a new feature for a communication model, and represents the time needed for a sender to prepare and send a typically time-consuming AAC message, as well as the time needed for a receiver to wait for its completion and their own interpretation of such a message. Chapter 2 outlines the typically slow rate of AAC use.

Layer eight represents, semantic noise (sn), or differences in language. An example of this would be if the sender and receiver were using different spoken languages, or a receiver failed to understand a mediated message using AAC, because they were unfamiliar with the form it takes. For example, a receiver may be unfamiliar with the use of visual sentences, or with the manual sign language used by a sender. The difficulty of interpreting meaning from some types of AAC, including those using graphic symbols, has been discussed in chapter 2.

5.2.4 Component four

The fourth component of the new communication model (Figure 22) is the communication channel, showing the message generated and sent by the sender, which is represented by a thick, black graphic line moving from the sender in the centre to a potential receiver to the right of the model.

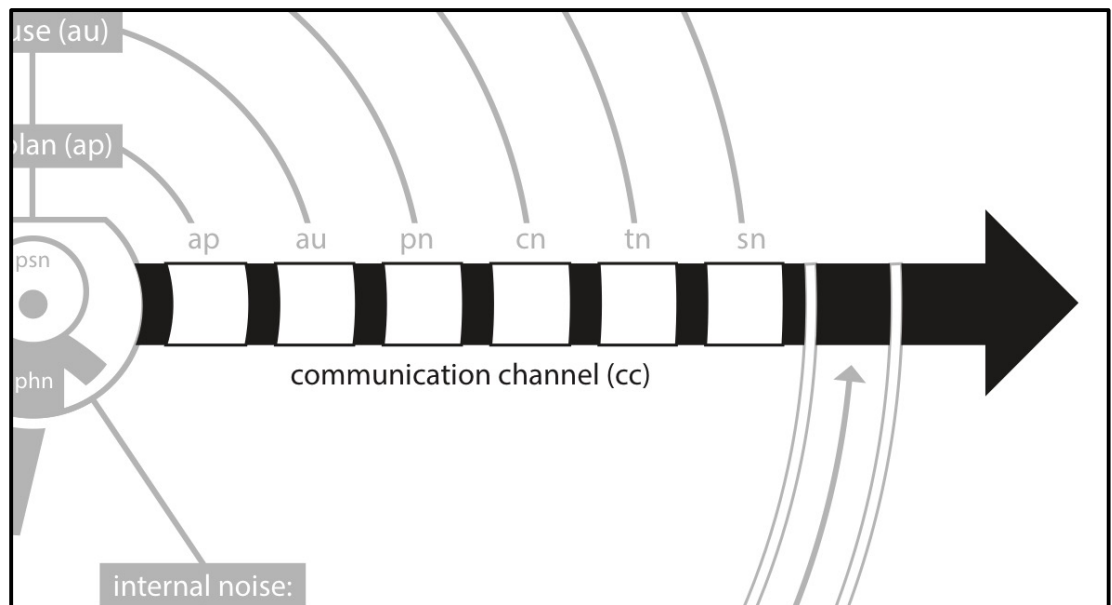


Figure 22: IMM component four.

The channel concept is adapted from existing communication models, notably the linear model. This is not because of any suggestion of power imbalances, but because a simple channel was required for ease of use and a clear understanding of message direction for the user. Sections of this line are cut out, and these removed sections line up with graphic areas displayed beneath the openings, shown on layers three to eight.

Using the handles, spinning each layer in components two and three create different effects within the communication channel, by completing the black line, thus showing an effective message, or introducing white areas within the line to indicate that the message has been compromised, or interrupted entirely. Graphic elements to the top and bottom of the handles suggest directions for this introduction of black or white. The presentation of the channel in various forms of visual completeness is the model's report of a given communication event, and the way in which the model is used as a diagnostic tool to show the integrity of the message being sent. Examples of some visual outcomes using the IMM are presented in Figure 23, at the end of each empirical-research section, and in the general discussion and conclusion chapter (chapter 8).

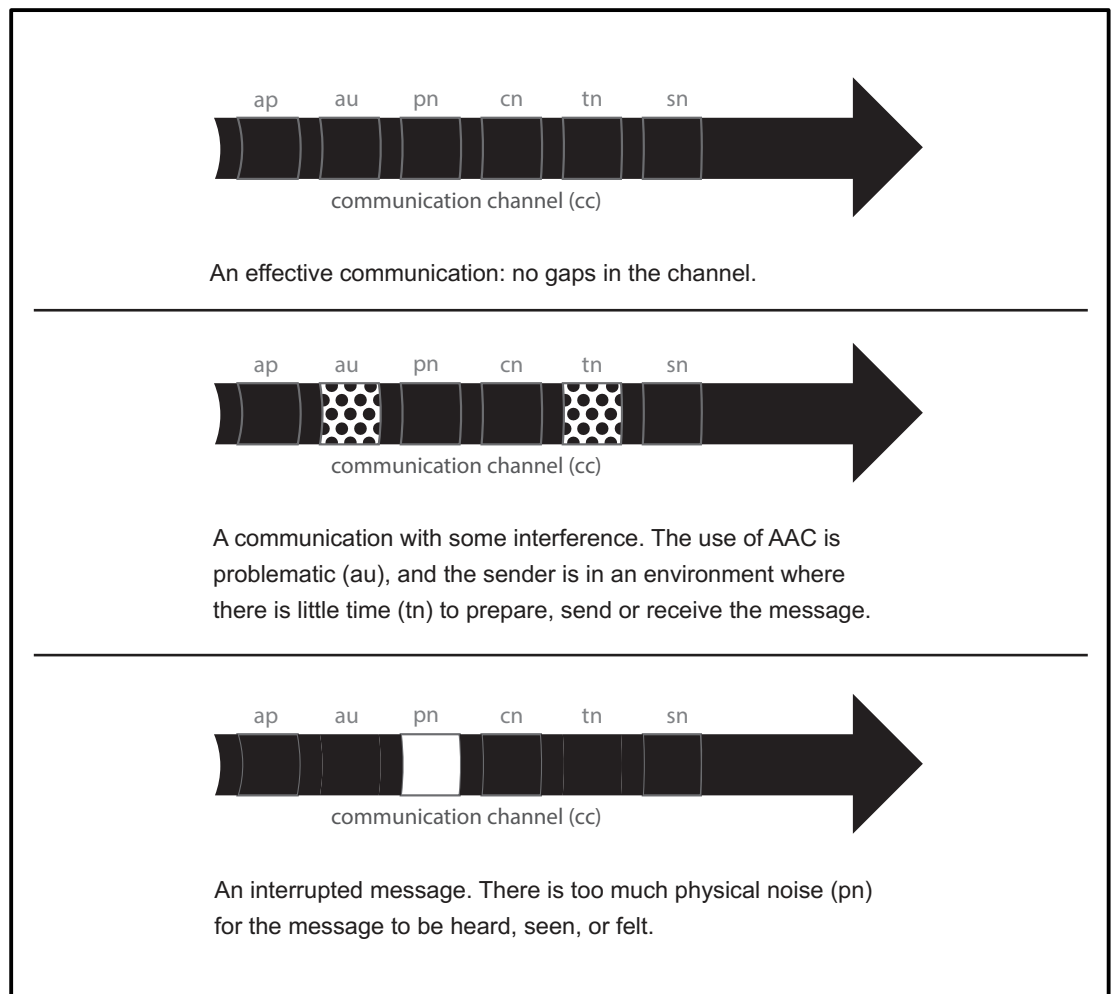


Figure 23: IMM component four: possible results.

In the first example in Figure 23, note that the black line remains unbroken, thus signifying that the message is able to move from sender to receiver with no interference. In the second example, some white areas appear in layers four (au) and seven (tn), indicating that there is some interference with the use of AAC by the sender, and an issue with the time needed to send or receive the message appropriately. In the third, the message has been interrupted entirely (in pn), with the white area indicating that there is too much physical noise in the external environment for the message to be transmitted correctly.

5.2.5 Component five

The fifth component is an AAC bypass, shown in both hidden mode (left-hand side) and engaged mode (right-hand side) in Figure 24. This is another interactive feature of the IMM, intended to represent the impact of shared experiences between the

sender and receiver of the message. This feature can be moved to cover component four (the channel), to show that familiarity with another person and their typical communication habits, can be used to give clues about the meaning in a message, overcoming some of the effects of noise, but denying the advantages of the use of AAC aids. Noise can potentially be lessened, because communication partners adapt their message exchange based on this knowledge of each other, with the use of non-verbal clues to help establish meaning in verbal exchange, patiently waiting for the slow sending of a CCN message, and being aware of, and compensating for cultural and semantic differences.

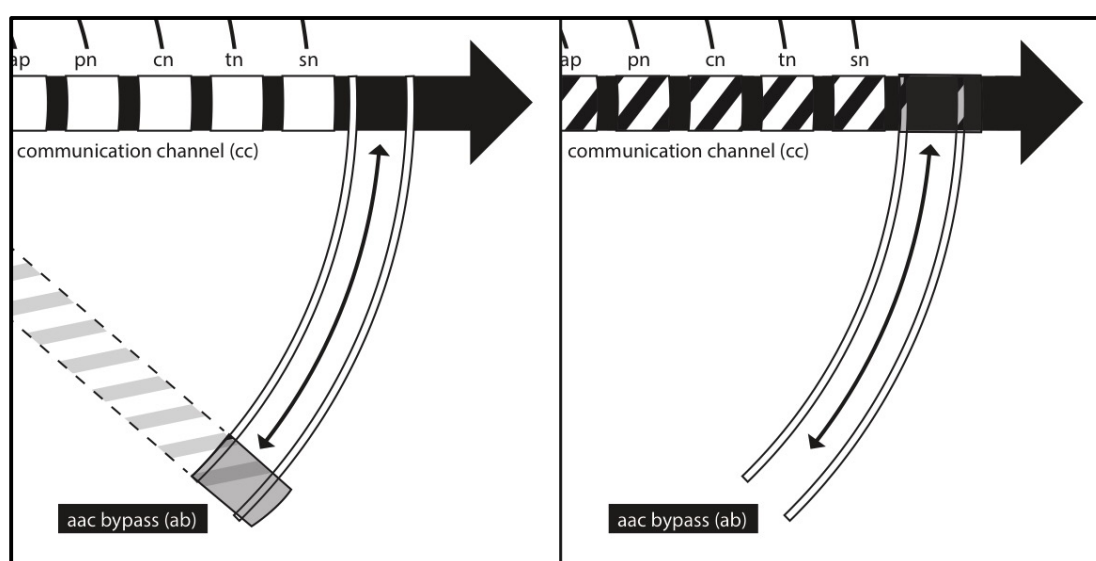


Figure 24: IMM component five: hidden and engaged AAC bypass.

This shared knowledge, about each communication partner (described as redundancy, in chapter 4.2.5), can be used in place of AAC, but this short-cut does increase the need for communication partners to be familiar with each other's experiences and abilities. This in turn limits the communication advantages the use of AAC aids could add to a person's vocabulary, and, again, could lessen the independence of the AAC user, when the user liaises with other, unfamiliar communication partners, without the use of aids.

5.3 Summary of chapter 5

This chapter has presented a new communication model, the Integrity of Message Model, developed as a means to identify and present visually the communication breakdowns among adults with CCN. In doing so, the model can be used to describe the type of message interference, and the effects of shared experiences on communication partners. As discussed, the model comprises several features enabling people who might struggle with the presentation of text-based, complex information to understand readily how it works.

Table 15 summarises the information embodied in the IMM, including a cross-reference to the related information from various sections of this thesis.

Table 15: Summary of features in the Integrity of Message Model (IMM).

Component or section of Model	Layer	Layer title	Chapter	Related barriers (chapter 3.3.5)	Description
Sender	1	Psychological noise	3.3.2	Attitudinal	Emotional state of person
	2	Physiological noise	3.3.2	Attitudinal	Impairment of person
AAC	3	Preparation for AAC	2.2.2	Institutional / attitudinal	AAC assessment & support
	4	Use of AAC	2.2.2	Institutional / attitudinal	AAC selection, supply & use
Noise (Foucault: Chapter 3.1.3)	5	Physical noise	4.2.1	Environmental	Audio, visual, tactile noise
	6	Cultural noise	3.2.1	Institutional / attitudinal	Different beliefs. Muting others
	7	Temporal noise	2.2.3	Environmental / Attitudinal	Time to send and receive
	8	Semantic noise	3.2.1	Institutional / attitudinal	Language differences
Channel		Communication channel	4.2.1		Message being sent
Bypass		AAC bypass	4.2.5		Redundancy

The following chapters present the empirical research of the thesis, with the first, archival research, developed in the initial study before the change was made to the research direction. An explanatory section after the archival research presentation outlines the reasons behind the change, then introduces the subsequent studies used in the new direction.

Chapter 6: Initial research direction

This chapter presents the archival study: the initial direction of this research. It was intended to:

- Provide contextual information about the existence of aided AAC at the disability day centre.
- Provide this information in order for me to redesign a set of improved aids for the centre clients with CCN.

These new aids were intended to be graphic-image based, because the use of this type of AAC is beneficial (See chapter 2). What is more, as discussed earlier, I am a designer and illustrator, with skills that could be used to develop aids such as new symbol-sets or other illustrations and creative outcomes.

The discovery during the archival study that AAC aids were most likely not used in the centre, suggesting that any additional, redesigned aids would most likely remain unused, was the justification for changing the research direction of the study. The archival research presented here is still relevant to the revised research direction as a description of the centre's communication environment and AAC aid storage.

A thorough understanding of the existence and use of current aids, as well as the users of such aids, was essential. Hence, the archival study was initially intended to use an Interactive Design process to inform the design of improved AAC aids. With the change of research direction, this approach was used instead to develop the IMM prototype. The description of the archival research is presented next.

6.1 Archival study of AAC aids

This archival research was a photographic and written record of the AAC tools that existed within the centre, conducted to understand the number and types of AAC tools that were at that time available for the study participants. As the design of revised graphic-image based aids was originally intended, the use of photography in this study was appropriate, in addition to the written description of existing aids. As described in chapter 2.2.1, this meant that the dual nature of these forms of AAC aids, where graphic imagery is typically displayed along with textual information, could be described and documented appropriately.

There are specific advantages to the archival study for the initial research. The use of the archive (Note, 2011; Picot, 2014) could, for example:

- Provide documented examples of the aided AAC aids, to determine the characteristics of the tools, including the potential suitability for adult adoption, perceived cost, participant access and ease of use.
- Be used to identify opportunities for improvement in the design and perceived use of these new aids.
- Be conducted during centre activities, as I could take photographs with minimal support from busy staff participants, and minimal or no contact with vulnerable client participants, as discussed in chapter 1.

The archival method and results are now presented, followed by a discussion of the study.

6.1.1 Method

All stored and displayed aided-AAC materials, available at the centre, were scrutinised. These included photographs of information display material, such as posters and signage, picture cards used to depict objects and activities, and schedules informing clients and staff about daily activities.

Photographs were taken of approximately 280 picture cards, as well as of 48 posters and signage. Photocopies of two different daily schedules were also collected. Care was taken to ensure that no individual or individual's image was photographed to preserve clients' right to privacy. Some information, such as one client's communication book (see chapter 2.2.1), containing photographs of a client and related scenes (for example, their bedroom at home), and used to help the client with daily communication, was seen but not documented.

Because of the busy schedule of the staff at the centre, planning for this documentation phase of the data gathering took four weeks of email and telephone communication, before a suitable time to meet the staff could be found and agreed upon. Once this was organised, the day centre manager assigned a staff member to allow access to rooms in the centre, to show relevant storage areas in three rooms, and to ensure the archival process could be conducted away from clients as the

clients rotated through various activities in different rooms. The staff member was on duty, so they needed to balance time to help the study and for their regular duties.

Documentation of the AAC aids in the centre took five hours, during one weekday, with the assigned staff member giving approximately 30 minutes of their time to help the research. By way of comparison, it is to be noted that the entire dataset, for all of the data collection in this research, before and after the change of direction, was completed over a total period of approximately 36 weeks.

Results

Documentation of aided AAC material showed that the centre displayed or stored three main types of aided AAC: posters and signage depicting safety, room information or object location, picture cards used to assist clients with communication, and daily printed activity schedules, available for staff and clients. These are outlined in Table 16 below. In the Table, the first column to the left shows the broad types of AAC found in the day centre. These types were then divided into categories according to signage subject-matter in the second column. The next three columns show a breakdown of how the AAC was constructed, with text and/or pictures. The final column to the right contains notes about each category, including more specific information including subject matter.

Table 16: Types and number of AAC identified at the centre.

AAC types	category	Uses text	Uses illustrations & text	Uses photography & text	Notes
48 Posters/signs	13 general room identification signs	11	2	-	'Kitchen', 'craft room', etc.
	8 toilet signs	2	5	1	'Male', 'female', 'staff', etc.
	11 Safety signs	3	8	-	'Hot', 'first-aid', etc.
	15 object location signs	1	14	-	
280 Picture Cards	187 commercial object-picture cards	-	187	-	PCS cards
	12 commercial object-picture cards	-	-	12	Photos of food
	63 centre-made object-picture cards	-	-	63	Photocopies of product/food
	18 centre-made activity-picture cards	-	-	18	Photos of objects used in activities
2 timetables	2 daily photocopied timetables	1	1	-	Shows activities, plus staff & clients involved
Totals	330	19	217	94	

Posters and signage

Of the eight toilet signs in the centre, four used the ISO 7001 (International Organization for Standardization, 2013) standard graphic icons, indicating male and female toilets, as well as accompanying text to denote gender and staff use. These are illustrated in the two leftmost images in Figure 25 below. Another pair of toilet signs used text, a photograph and an ISO 7001 icon to describe these rooms, as shown in the rightmost image in Figure 25. Other toilet signs used text only to designate them as staff toilets. Evidently, there was a lack of consistency in the use of graphics in this signage.



Figure 25: Toilet signage at the centre.
(International Organization for Standardization, 2013).

There were 11 safety signs across the centre. This included two detailed colour posters with text and illustrations, depicting first aid procedures and injury hotspots, and these were displayed in the staff room. Colour safety signage, including one sign for a security camera, and one each for a fire blanket, and a fire extinguisher (shown in the centre image in Figure 26), used text and pictures. Two other safety posters included predominantly text-based posters for the locations of toxic chemicals (as in the rightmost image in Figure 26), and a hot kitchen appliance (as in the leftmost image in Figure 26). Other safety posters included an emergency evacuation map, posters describing food health and a turning-off-lights procedure.



Figure 26: Public-safety signage at the centre.
(International Organization for Standardization, 2015b).

Of the 13 rooms other than toilets, only two used imagery to encourage the comprehensibility of these predominantly text-based room signs. The remaining rooms used text-only signage to denote the purpose of the room. In a corridor near reception, there was one picture and a text-based poster with removable sections that showed the weather conditions of the day. Figure 27 shows the complete, assembled poster on the left, and individual, removable sections in the centre and right images.



Figure 27: Centre-made signage showing the weather each day.

In the kitchen, there were 15 small picture- and text-based signs denoting cutlery, plate, cup and refrigerator locations, and preparation and washing up areas. Various examples of the position of these are shown in figure 28.



Figure 28: Centre-made picture-based signage, used in the kitchen.

Picture cards

Sets of Boardmaker PCS picture cards (Spectronics, 2017), were stored in a box in the centre's staff room. These consisted of 187 picture cards in plastic folders, containing simple full-colour illustrations of food, clothing, actions and objects. The rightmost image in Figure 29 shows a picture card of an activity, in this case a person getting dressed. The leftmost image shows various object illustrations.



Figure 29: Commercial, illustrated PCS picture cards stored at the centre. (Spectronics, 2017).

A set of 93 commercially-produced cards, showing colour photographs of various foods and objects, were also stored in the same location (Figure 30).



Figure 30: Commercial, photographic, food picture cards stored at centre.
(Spectronics, 2017).

In the sensory room, where clients interacted with objects and listened to music, 18 photographic, centre-made cards (Figure 31), depicting a broad range of centre activities, were stored in a folder under a bench. These included cards showing objects such as balls and chairs, and activities such as using a walking frame or getting ready for lunch.



Figure 31: Centre-made, photographic, activity picture cards stored at centre.

Activity schedule

On a table in the centre's staff room, a pile of photocopied activity schedules was found. These were copies of an A4, landscape, text-based page, divided into grids and populated with information about daily activities, rooms in which they took place, and the names of staff members and client-groups that took part in the various detailed activities. A section of the blank schedule template can be seen in Figure 32.

The staff member helping with this study provided three versions of this schedule with different, daily details added to the grid, explaining that these were made available to staff and clients daily. The staff member also provided another schedule (Figure 33), which included pictorial icons throughout the grid, but mentioned that this latter version was not used at that time in the centre.

MONDAY TIMETABLE					
DATE : / /					
LAWN BOWLS / GYM	LIVING SKILLS	WALKING & PARKS	WATER SPORTS	CATERING	DANCE
All Day	All Day	All Day	All Day	All Day	All Day
1AS	Walking	9YH	WNT	358	9YF

Figure 32: Example of a section of text-based daily timetable.

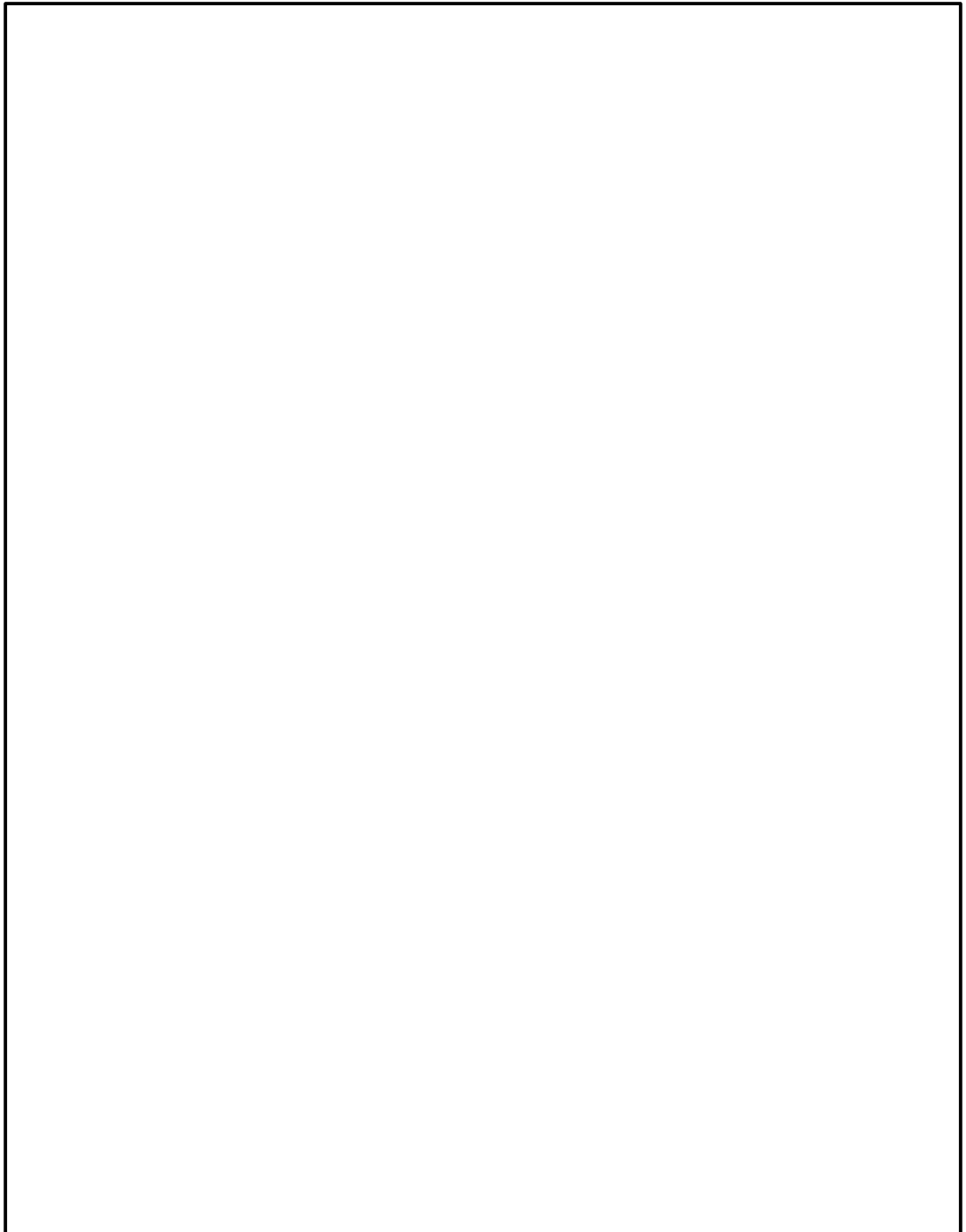


Figure 33: (IMAGE OMITTED) Example of a text and image-based daily timetable.

As discussed in chapter 2, there is research suggesting the popularity of picture-based aided AAC use, as well as evidence outlining challenges associated with the development and support of this and other forms of AAC. Still, it was surprising that few public or individual AAC aids were displayed or seemed to be in use at the centre. Picture cards were dusty, and packed away in cupboards, and few signs and

timetables were designed for effective use by individuals with an impairment. Chapter 6.2 discusses this in greater detail, with possible explanations for the lack of AAC use within the centre, as well as more details about the subsequent change of research direction.

Before the next section, however, an example of an IMM result is displayed in Figure 34, showing how the use of the model represents particular breakdowns in communication, as described in data gathered from the archival study. In this case, the white breakdown in the section (au: AAC use), is shown as an interruption to the solid black line that would represent effective communication if complete. As with other contextual examples of IMM results shown in this thesis, note that this is one possible summary of the data, and that each result is intended to identify breakdowns in order for this information to be used to address those challenges.

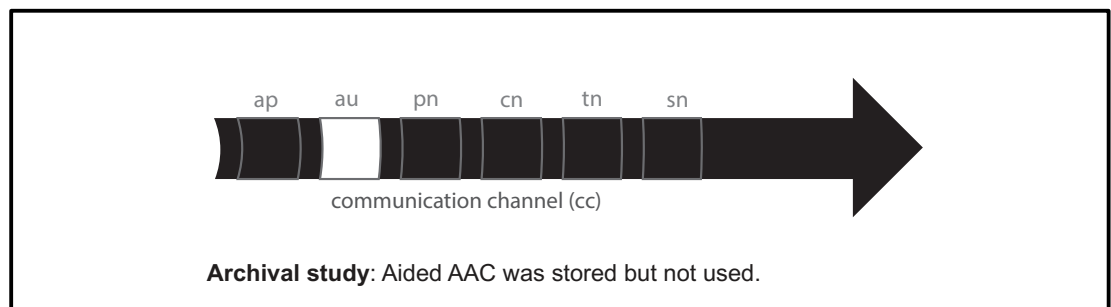


Figure 34: Example of an IMM result for archival study data.

6.2 Reflections on change of direction

Before describing the next phase of research, I will reflect on and justify the change in research direction. Based on the results of the archival study, I chose to move the focus of this research from the design of revised AAC for clients, to an investigation of the communication breakdowns and AAC use at the day centre. (See appendix 4 for the change of thesis title, as an indication that ethics was approved for this research based on an earlier thesis description). This change ultimately informed the development of the IMM, described in detail in chapter 5. It embodies the information obtained from the centre and participants, as well as the background literature review presented in the thesis.

The results of the archival study pointed to AAC existing at the centre, but these tools were seldom designed for, or potentially used by, the study participants. Of the poster and sign display material, only the weather poster and 15 smaller signs denoting food, utensils and food-areas looked to be specifically designed for general clients' needs. Other signage presented standard, neurotypical examples generally shown in public places (International Organization for Standardization, 2013). Furthermore, despite the large number of picture cards identified in the centre (n=280), none of these seemed to be used regularly by clients or staff, as they were dusty, and were hidden away, stored in various boxes in cupboards and filing cabinets.

The only regularly updated communication aid seemingly in use at the centre was the black and white photocopied daily schedule made available to clients and staff. As clients with Autism and other conditions have difficulty coping with change (Baron-Cohen, 2008a, p. 40), they are known to benefit from clearly structured aids such as these in their daily lives (Beukelman & Mirenda, 2005), so the availability of this aid was typically of benefit to participants. As the schedules were text- and not picture/text-based, though, clients who struggled with written words may not have benefitted from that text-based form.

The archival study provided no evidence to suggest that more than one individualised AAC aid was in use at the centre. One individual communication book, described in chapter 2.2.1, was seen but not used during the course of this study, as the book was packed away in the client's bag, and shown to me by a staff member. The book contained photographs of the client in their home and other environments. The book also had photographs of the client's family and relatives, as

well as personal items. This material is not recorded in this thesis to preserve that client's privacy.

It is important to note here that no evidence of any type of personal AAC aid use was seen during the course of any of the studies outlined in this thesis, including the use of devices that helped clients with speech, touch or vision (Robitaille, 2010). This further justifies the change in research direction. Several possible explanations for the limited use of AAC in the centre can be posited. Four of these are now discussed.

First, staff may be too busy to develop further or use AAC in their daily interactions with clients. The use of picture-based aided AAC for communication between clients and communication partners is slow compared with the rate of spoken communication, as discussed in chapter 2.2.3. As staff members are typically responsible for more than one key client in any given activity group, working individually and slowly with a single client, using a form of aided AAC, may not be feasible, as the needs of another client in their duty of care might be ignored during such an interaction.

Second, staff may not have access to adequate training in the use of the AAC currently in the centre. Ongoing training courses for disability workers are described in chapter 1, but these may not be made available to staff at the centre for financial and other reasons.

Third, staff may feel that they know their clients well enough to communicate with them without the use of aided AAC. This has been described as the process of, redundancy, included as a major component of the IMM, and further described in chapter 5.2.5.

Finally, it is possible that the available AAC is inadequate to meet staff and client needs, or that clients and staff do not have the necessary financial resources to purchase appropriate commercial AAC aids. AAC communication is a complex, challenging process for users and communication partners, as discussed in chapter 2.2.

The next chapter outlines the range of studies undertaken for the new direction in the research. The revised aim was to gather and analyse data about communication

breakdowns among participants at the centre. A justification for the use of, and explanation of each method, is presented at the beginning of each study description.

The research methods employed in the empirical research were selected taking into account factors discussed in the next chapter, as well as centre-management recommended criteria as outlined in chapter 1. These latter criteria were considered to ensure that the studies would:

- Be minimally disruptive to lessen the impact of the research on any vulnerable adult participants with impairments.
- Conform to specific ethics guidelines, designed to protect this vulnerable participant group (Ethics approvals are in Appendix 1).
- Conform to ethics guidelines for my protection, by ensuring that I was always with a trained centre-staff member when taking part in any of the data-gathering activities undertaken in these studies near clients.
- Be efficient, to gather information from any busy professional staff and family caregiver participants, who care for the disabled adults in the course of their employment or relationships.
- Include as many stakeholders as possible in the research, as communication at the centre involved people with CCN and neurotypical communication partners.
- Provide useful information to inform an Interactive Design process in the development of the physical IMM prototype.

The empirical studies are now presented, starting with a discussion of the focus group sessions in Chapter 7.1. Observations of staff-client interactions follow in 7.2, with parent interviews described in 7.3, and staff interviews in 7.4.

Chapter 7: Empirical studies

7.1 Focus Groups

This first empirical study, conducted after the change in direction of the research, was designed to:

- Gather information from staff and parent participants about the challenges to their daily routine, specifically in their communication with clients or their impaired children.
- Take advantage of opinion-based methods, in which participants' opinions are collected and analysed, to learn more about their perceptions of daily communication challenges.

I had initially considered conducting interviews (Boyce & Neale, 2006; Denscombe, 2014) with these participants. However, each type of interview technique was unsuitable here. Unstructured interviews, in which the researcher relies on open-ended questions to very broadly explore a topic, were not used because I needed more information from the participants than this method could provide. Alternatively, fully structured interviews, where participants select answers from a short list of possible responses, to ensure controlled data collection and a minimum of response formats, were also not appropriate. I had not collected enough information to that point to be able to design and run those very structured sessions.

Individual semi-structured interviews, a mixture of closed- and open-ended questions, designed to give direction but also allow for flexibility to expand upon discussion, were more promising. However, despite this technique allowing for the desired descriptive but focused data, the time limitations of participants meant that other methods were more suited, particularly those that more efficiently targeted a group of participants rather than individuals.

While a group interview may have been more efficient, because participants fill out a questionnaire together in the company of the researcher, the same lack of information would still have been a problem. Group-based methods include workshops and focus groups. As the intention of this study was to collect information from participants, workshops were deemed unsuitable, because they are used for attendees to work on tasks for “problem solving and/or skill acquisition” (Steinert, 1992, p. 4).

Focus groups then were deemed appropriate for this stage of research, designed to gather information from participants quickly, in a group environment that encourages discussion within a group, about some introductory topics presented by the researcher. Additionally, the nature of the focus group allowed concepts to be categorised and sorted interactively throughout the sessions, a technique that allowed the group to discuss and cross-reference many topics, and for me to guide the conversations as desired, and away from any dominant speakers that emerged, for a more balanced, group contribution.

Two focus groups run in the disability day centre are reported next. A follow-up poster, depicting results from the focus groups, was also displayed at the centre, to gather written information about what participants thought of the data to that point, and for them to offer additional written information on the posters if necessary. The poster is also presented here.

7.1.1 Method

Participants

To facilitate participation in the focus group discussions, I consulted with centre management, over a period of three weeks, who in that time recruited a total of 15 centre staff members for the studies. Twelve participants (n=12) took part in the first group (ten female, two male), and three (n=3) in the second group (two female, one male). A more equal distribution of participants in the two groups had been anticipated, but staff time and availability were too constrained to allow that. At the same time, focus groups with the parents and other guardians of centre clients was unable to take place due to the lack of availability of, and responses from these participants.

Both staff sessions were conducted in the centre's craft room, immediately after staff had finished work for the day, at approximately three o'clock PM, on two different afternoons a week apart. Each focus group took one hour, and all participants volunteered their time. The centre provided snacks and drinks for each session, but participants were not paid.

One participant, who took part in the first focus group, supplied additional written information on one of the follow up posters. The posters were put up for display

three weeks after the completion of the focus groups, then taken down two weeks after that.

Materials

Informed-consent forms, together with information sheets, were prepared to facilitate and guide focus group discussions (see Appendix 2). The information sheets outlined the objectives of the overall research, introduced researchers and the university involved, and provided participants with information about the procedure. In line with University ethics requirements, a request to audio record the sessions was included in the informed-consent forms. A standing whiteboard was situated at one end of the room, which I used to note ongoing comments from participants during the focus groups and to encourage focused discussion. Two audio-recording devices were prepared, with one placed at each end of the room, close enough to participants to capture all sounds.

Follow-up posters were printed on A3 paper, and put up on a cork board in the centre staff room with pins. A collection of pens was made available, next to the posters, to enable staff members to write comments on the posters.

Procedure

Focus groups

Once participants were seated around a communal, three metre square table, I introduced myself and outlined the purpose of the focus group. Participants were then asked to read and sign the informed consent form, before being given the written introduction in the information sheets, containing the following prompt to facilitate the discussion:

It would be most helpful if you could give some thought to the kinds of difficulties you have experienced understanding clients when they attempt to communicate something to you. I would also like you to talk about the kinds of difficulties you believe your clients have experienced when you have attempted to communicate something to them.

In each of the two focus groups, I collected the signed consent forms, ensured that the audio recorders were working, then read out the above statement to facilitate the

group discussion, and to ensure the statement was acknowledged by the participants. Participants then began by responding to the statement in turn, with other participants adding to or remarking on group comments. I continually prompted the participants throughout the discussion, by repeating the opening statement as needed, by noting comments on the whiteboard as dot points, and by ensuring approximately half of the time in the focus groups was spent discussing each of the two parts of the introductory statement. The whiteboard notes were used to show the participants what they had previously discussed, and to start to organise the information into similarly themed topics, which were further sorted in subsequent data analysis. At the end of the discussion, participants were thanked and excused.

Follow-up posters

After the focus groups were completed, data from the sessions were analysed, and the A3 poster designed with the results shown on the page. Two copies of the posters were then displayed in the centre staff room.

As well as the data from the focus groups, the posters displayed an introduction section, outlining the purpose of the poster and the follow up:

Thank you for being part of the focus groups conducted at the centre here this year! We discussed topics and issues that staff found challenging in communication to and from clients. Below is some information collected from those sessions. These contain the top, most discussed topics from both focus groups.

Please add your comments below somewhere, whether you agree, disagree, or you'd like to add any more information that may be useful for the project.

This extra information will be used to make sure we're on the right track!

Results and discussion

Focus Groups

Audio recordings were transcribed verbatim, separately for each session. These were then analysed, to categorise and arrange the data from both groups into semantically similar categories, and eventually into category-hierarchies, as used in the affinity diagramming method (Beyer & Holtzblatt, 1997). An affinity diagram

“organizes the individual notes captured during interpretation sessions into a hierarchy revealing common issues and themes” (p. 154).

Emerging themes that were common to both focus groups were identified, in both the *communication to clients* and *communication from clients* categories, and documentation of the sorted outcomes is presented in Figures 35 and 36 below.



Figure 35: Data from the communication *TO* clients category.



Figure 36: Data from the communication *FROM* clients category.

Staff members suggested the addition of two more themes, briefly noting that there were some challenges during *staff to staff*, and during *client to client* communications (Figure 37). A thorough affinity diagram was not necessary for these two new themes, because they were only briefly mentioned in the focus groups, and there was only one main topic under each theme. Nonetheless, information from all four themes was presented in the follow up poster.

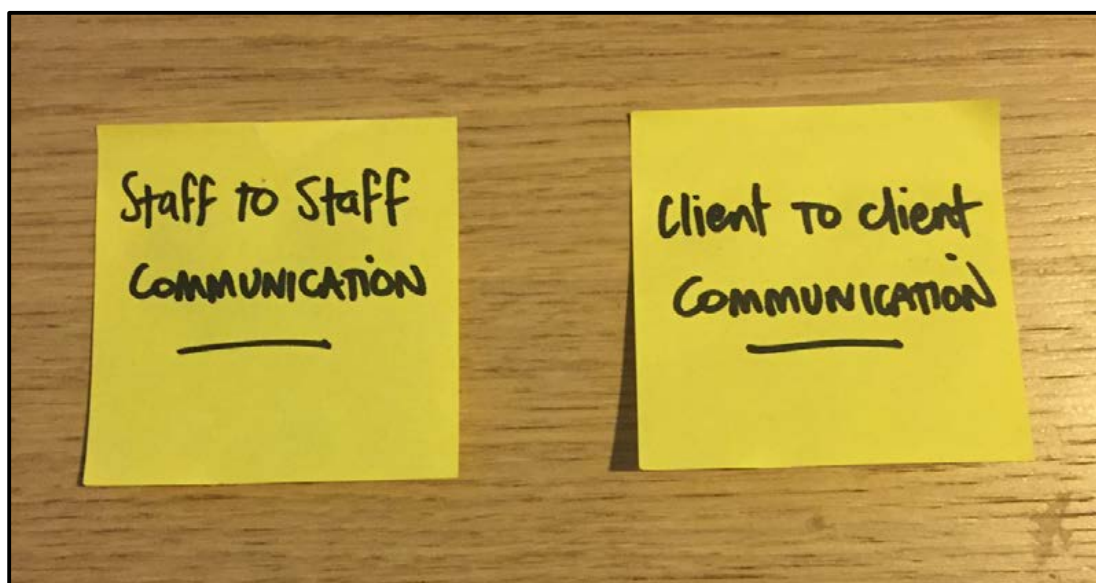


Figure 37: Categories added for communication among staff and clients.

Follow-up posters

A copy of the follow up poster is presented in Figure 38. This also serves as an example of the information detailed under each analysed theme. The poster explicitly asked for more information after the focus groups were completed. This yielded a small amount of additional data from one staff member. This new data reiterated the importance of staff successfully transferring information to each other about clients' needs and wants. This was previously identified as one of the reoccurring themes in the focus group data analysis.

Swinburne communication research

Thanks for being part of the **focus groups** conducted at the centre here this year!

We discussed topics and issues that staff found challenging in communication to and from clients.

Below is some information collected from those sessions.

These contain the top, most discussed topics from both focus groups.

Please add comments and any extra information you may have, to any of the spaces below. This extra information will be used to make sure we're on the right track!

Most discussed topics

..about communication TO a client

Client's personal state:

Difficulty communicating **to** clients about:

their **personal hygiene**.
i.e. toilet incidents & cleanliness 1

their **emotions**.
i.e. Are they happy, sad, lonely? 2

their **well-being**.
i.e. gauging their state / picking cues before behaviours of concern develop 3

Boundaries:

Difficulty communicating **to** clients about:

what **appropriate behaviour** is expected at the centre. i.e. appropriate touching, personal space and dress 4

what **client boundaries** are. i.e. what is expected of them at the centre. They have jobs to do / responsibilities 5

what **staff boundaries** are. i.e. the limits of what staff can do/saying no to clients/not able to fix everything for them 6

clients' & others' **safety**. i.e. don't "help" lift or push other clients / don't hit or touch strangers/ Fire drills not social 7

Information sharing:

Difficulty communicating **to** clients about:

their **recent history**. i.e. what is happening in their lives lately at home/ information sharing from other staff. 8

..about communication FROM a client

Client's personal state:

Difficulty clients seem to have communicating about:

their **personal hygiene**.
i.e. toilet accidents 9

their **emotions**.
i.e. Are they happy, sad, lonely? 10

their **likes/dislikes/wants/needs/fears**.
i.e. what sort of drink they want/why they don't want to do something 11

their **well-being**.
i.e. gauging their state / picking cues before behaviours of concern develop 12

Information sharing:

Difficulty clients seem to have communicating about:

their **recent history**. i.e. what is happening in their lives lately at home/ information sharing from other staff 13

Two additional themes suggested...

Staff to staff communication

14 staff members not sharing client information with each other

Client to client communication

15 behavioural issues between clients. communication as physical abuse

Figure 38: Follow up poster, presented to participants.

Examples of communication exchanges at the centre

A further breakdown of the focus group data is presented next, as examples of comments made by participants during the two group sessions. Transcriptions of the results revealed many challenges that staff members felt impacted their ability to communicate freely with the clients at the centre.

As discussed, the transcribed exchanges from focus group discussions fell into four main types, namely the two types suggested in the introductory statement, and the two the participants suggested in the focus groups. These were staff member to client communications, client to staff member communication, communication among clients, and communication among staff members. The following transcribed quotes are arranged within each of the four types to provide contextual and illustrative examples for each, as well as to preserve the original participant statements.

Staff to client communication

Discussions revealed that staff found it challenging to communicate personal hygiene issues to clients, as these required a very delicate balance between maintaining respect for the client, and highlighting a health issue. As individuals with intellectual conditions sometimes struggle with self-esteem (Barnhill, 2001), the delivery and phrasing of sensitive topics such as these were of concern to disability workers and their clients, as the following quotes illustrate:

Personal hygiene, and still trying to maintain that respect. You can't turn around and say, 'Dude, you really stink.' You can't do that so it's really difficult.

This delicate approach extended to trying to pre-empt a toilet visit as well:

Personal care. Some of them can't say, 'I need to go to the toilet'. It's prompting too. For them to go.

Staff to client communication about issues that limited or controlled behaviour and actions, were also raised. This included discussions about the appropriate way in which clients were expected to behave, staff responsibilities and safety issues:

For some of us, it's difficult to communicate that the clients have responsibilities here. They really have to abide by some of the regulations of the place. Take a cup out and wash it. They don't understand why in the morning they have to come to home group. We sit them down and say (it's for) safety reasons. Fire drill. And they still don't understand. For them it's more a social thing, to come in the mornings to a room. For them it's social.

How to explain what our role as staff members is. Where the limitations are. What they think they are: 'I'm not your housekeeping tea lady'. A good example of that is, when we caught up with that client before and he said, 'I'm having problems with my relationship. Can you fix it'?

How to communicate to a client not to hit strangers or the public. How not to approach. Not to touch.

Client to staff communication

The topic of personal hygiene was also mentioned in the client communication to staff as a delicate challenge:

Personal stuff. A client took me to one side the other day and said, 'Can I please have a spare pair of underwear?' Everything was confidential, but I could tell that it was really personal and she really understood. I think she showed a bit of trust. You've got to deal with that delicately.

In addition, client communication about their well-being and current emotional state to staff was described as challenging to gauge. Here are some illustrative comments:

Expressing that emotion or they personally don't understand that emotion. Trying to get them to understand that emotion, or identifying it. For instance, the emotion of rejection. He doesn't understand really that you're trying to help him without rejection. How to go through it, knowing that his acting out has originated in his sense of rejection.

Are they lonely? Are they happy?

When he gets upset. He just shuts down. He doesn't talk. He just sits there. So he's getting to that part where he doesn't express what he's feeling. He

has something blocking him, from telling us what he feels and what he thinks. Unless you prompt him.

Their feelings. Their emotions. Their well-being. It often gets to a physical point until we notice.

Client to client communication

Clear communication and positive interaction between clients was important for matters of safety and for maintaining a professional working relationship with all individuals at the centre. The focus groups raised a challenge there too:

There's one of the clients here that likes to help a lot. He drags around other clients and they get really annoyed and angry. So if you tell him no, thank you for your help and you can do something else he still doesn't listen and still drags them around.

Staff to staff communication

Communication between staff was discussed. Of particular interest here was the importance of the sharing of information:

Staff to staff communication. If they've picked up something and they do something a certain way with one client but hasn't let another staff member know.

This is one of the barriers. (Clients) have information that only comes out in situations and discussions. So I might harbour information about someone for 20 years and not say anything because I haven't been prompted to say anything about that.

He has epilepsy. No one knew and it's not in his file. That should be on the front page.

With the results of the focus groups analysed and presented, the next section concludes the focus group segment of this chapter, with a discussion about the implications of the data on AAC use, along with a result from the IMM representing aspects of that information. An overall summary of focus group data will not be presented here, as this has been previously outlined on the poster in Figure 38.

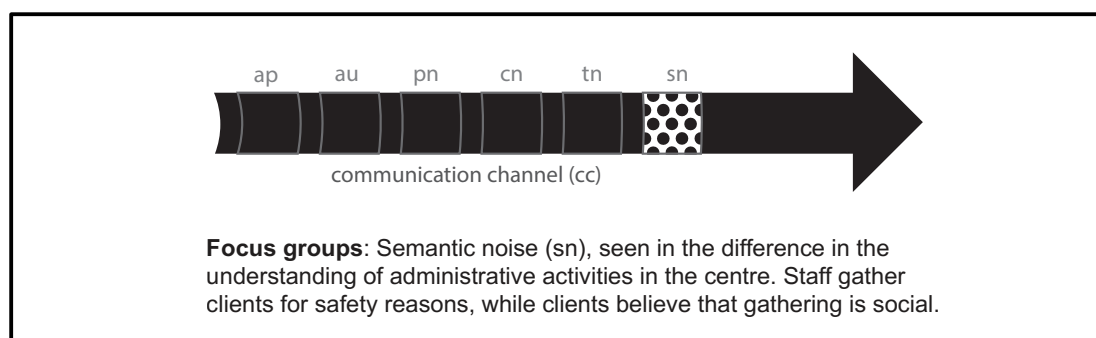


Figure 39: Example of an IMM result for focus groups data.

The IMM result example shown in Figure 39, where interference is present in the right area of the graphic, represents the semantic noise (sn) affecting communication between staff and clients where safety is concerned. Staff gather clients together for safety drills and attendance records, while clients typically believe that gathering is social. The IMM could be used to clearly visualise any of the challenges outlined by staff in these focus groups, showing the implications of these issues on message exchange with a simplified degree of interference shown graphically.

As is evident from the myriad of communication challenges staff discussed in the focus groups, analysis and collation of the data was needed to refine the challenges into a coherent list presented by participants. If staff had access to the IMM in order to work through these issues on that device, this process may have been simpler and more effective.

7.1.2 Implications for AAC

While focus groups were designed specifically to gather information about participant's attitudes to communication exchanges, and subsequent studies enquired about AAC use, the focus group data does offer some insights to AAC at the centre.

Taken together, the data from these focus groups points to discussions about safety and boundaries in each of the four types of exchanges. The earlier archival study had revealed that there were just two standard safety posters in the centre. Safety

would therefore seem to be one example of a category worth exploring further with respect to designing refinements to publicly-shown AAC in the centre.

Discussions about hygiene and determining the current, personal state of clients were highlighted across communication categories, so exploring discrete methods of AAC that could be used to communicate a client's well-being or situation would be beneficial also, as it could save embarrassment for clients and staff alike.

The successful sharing of information between staff members, about clients' conditions, and recent history, was of concern to focus group participants. This would suggest the better use of sharing-information software, or more effective, interpersonal staff communication was necessary.

The focus groups yielded valuable information about communication challenges in the centre, as well as future possibilities for the design and development of alternative AAC. However, as the data represented only staff perceptions and opinions, it was worthwhile also to capture data about clients. Observations of staff and client interactions are presented in the next section.

7.2 Observations

With data concerning the number and type of AAC tools obtained from the centre, and information about communication challenges gathered from staff participants, the next study was designed to:

- Gather first-hand, performance-based information about these challenges from additional participants in a natural environment.
- Specifically collect information about the staff-client communicative interactions, with little to no interaction with the researcher.

As with the previous study, it was still premature to conduct interviews here, and surveys (Rea, 2014, Chapter 1) would have yielded more opinions, rather than allowing me to witness staff-client interactions first-hand. Thus, to obtain performance-based data gathered from real-life contexts, I decided to observe interactions. As discussed in chapter 1, interviews and similar methods were likely to be disruptive for typically vulnerable clients, because of my lack of training in disability services, and because clients may have been unable to understand or appropriately answer direct questions, depending on their impairment. Assistance with direct methods for client liaison would have also meant disruptions for busy staff participants.

Two types of observation study were deemed appropriate for this phase of the research. The first was an ethological method, and the second an ethnographic approach.

Ethological studies are conducted in participants' natural environments while they go about their daily routine. The researcher's role is to decide on target activities a priori, as it is impossible to take in and record everything that is happening at any time. Once the target behaviours have been identified, the researcher counts the number of times each of these is observed in a given time. Thus, the researcher:

...rather than simply writing down a description of what he or she sees, will score incidents of specific behaviors defined according to certain generally accepted criteria. This produces a numerical, rather than a purely written, description of the behavior or behaviors being observed (Anderson & Perona, 2014, p. 18).

Using this method, I could identify target behaviours I planned to observe ahead of time, allowing me to focus on those specific areas, and to be as unobtrusive as possible (Lehner, 1998, p. 106) during sessions. The intention to use ethology as a means to observe participants without contact, would work well if participants were in an indoor area, and I could observe from a static location. However, if clients moved off-site for other activities, where I was less likely to distance myself from any situations occurring, a more ethnographic approach would be necessary.

In contrast to ethological studies, in which target behaviours are predetermined and remain the focus of the observations, ethnography (*italics added*) is:

...the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher *participating directly in the setting, if not also the activities*, in order to collect data in a systematic manner but without meaning being imposed on them externally (Brewer, 2000, p. 10).

The emphasis on this technique calling for a researcher to "immerse themselves in a society" (Bryman, 2001, p. 3), is problematic, given the nature of the participants in this study, but is useful if the technique is used sparingly, and supervised by staff participants, as discussed in this chapter.

Note that I used written notes as documentation during observations. This was suitable to collect the data according to various communication categories. Audio and video recording was not necessary, nor was it desired by the centre director, who gave only a basic consent by proxy for the clients in the centre.

7.2.1 Method

Participants

The observations included a total of six staff members and 27 clients. Two additional staff members helped during preparation, with the centre director signing off the consent form on behalf of the clients, and a centre manager helping to recruit the staff participants, provide a breakdown of client participant diagnoses, identify the sessions to be observed, and decide on suitable observation times.

Table 17 shows a breakdown of each of the six main staff members' approximate age and years of experience as a disability care worker. As shown in the table, their ages ranged from 35 to approximately 60 years of age, with three falling into each of two age groups (35 to 45 years, and 50 to 60 years). Also shown is their relevant experience, ranging from five to 25 years, with an average of 12.17, and a median of 9.0 years of experience.

Table 17: General breakdown of staff ages and experience.

Staff member	Age-range in years	Approximate experience in years
aa	35–45	5
ab	35–45	5
ac	35–45	8
ad	50–60	25
ae	50–60	10
af	50–60	20

Table 18 shows a breakdown of the diagnoses of the 27 clients observed. The information shows a total of 51 impairments among these clients, highlighting that nearly all of them have been diagnosed with co-morbidities, as discussed in chapter 2.1. Of these 27 clients, nine male and nine female clients could use simple spoken words, one male and three females had very limited verbal skills (noises as communication), four females and one male had no verbal but sign language skills, and one male had no verbal or signing skills. This means that over 70% of the client participants had some level of verbal communication skill. As discussed previously (in chapter 2.1), verbal, refers to the ability of an individual to use vocal noises in a communicative way, and, non-verbal, refers to the absence of any vocal ability. Note that AAC is an augmentative, as well as alternative process, and useful for those with some verbal skill.

Table 18: Diagnoses for the 27 clients observed.

Client diagnoses	ID	Epilepsy	Cerebral Palsy	Autism	Blindness	Down Syndrome	Diabetes
No. of male clients with:	8	6	4	3	2	2	0
No. of female clients with:	10	2	0	1	2	1	2

Client diagnoses	Spasticity	Pharyngeal Dysphasia	Fragile X	Gastric issues	Pixie syndrome	Multiple Sclerosis	Prader Willi
No. of male clients with:	0	1	2	0	0	0	0
No. of female clients with:	1	0	0	1	1	1	1

Materials

Four A4 portrait documents were designed in preparation for the observation sessions, namely (1) outlining this study phase and providing ethics information, (2) informed consent forms for participating staff, (3) informed consent forms for the centre director to sign on behalf of the participating clients, and (4) an observation protocol. The observation protocol outlined the range of behaviours I expected to witness prior to launching into the formal observations. A pen was used to note behaviours during the observations, and a new protocol sheet was used for each observation session. The timer on a mobile phone was used to measure the duration of each session, and to check the start and end times. Consent and information materials are presented in Appendix 2.

The observation protocol was designed to allow for ease of use when observing staff and clients on- and off-site. Small, distinct fields were positioned enabling me to enter frequency marks accurately to be tallied up during data analysis. Other, larger fields, were positioned where qualitative, contextual notes could be quickly written to support these quantitative results. The protocol was divided into three main themed sections top to bottom, with up to four columns dividing the top two sections. The top

section was designed to accommodate participant and general session data. The middle section was designed to contain quantitative data about observations within each category. The bottom section was an area where the contextual quotes from participants and other qualitative information could be noted in greater depth. The first version of the observation protocol is presented in Figure 40:

Staff member ID:		Clients ID:
Date of Observation:		
Time	from:	to:
Observation number:		

Behaviour	Staff Initiated	Client Initiated
Ask Question verbally?		
Ask Question non- verbally?		
Answer question verbally?		
Answer question non-verbally?		
Give order		
Reprimand		
Make request		
Total n occurrences observed		

Notes

Figure 40: First iteration of observation protocol sheet.

As Figure 40 shows, to the left of the top section, the protocol contained four titles. The first title was, staff member ID, where a staff participant's coded name could be entered in the field to the right of the title, to preserve anonymity. The second title was, date of observation, and the third was the start and end time of each observation. The final of the four titles to the left of the top section was the observation number, to indicate where a number was entered to designate which session was observed, noted as session one to thirteen (for on-site sessions) or one to six (for off-site sessions). To the right of the staff member ID title was the client's ID title, indicating an area for the coded client identities participating in each session. As with the staff identities, clients were also given a code to preserve their anonymity.

The middle section contained a series of incident category titles down the left hand side, with two columns to the right of these categories, indicating whether the exchanges noted (as number of exchanges) were staff initiated (in the first column) or client initiated (in the second).

Design

It was expected that the following behaviours would be observed:

- Ask question verbally, that indicated questions asked using spoken words.
- Ask question non-verbally, that indicated questions posed using non-verbal communication, as sign language or with an aided AAC aid.
- Answer question verbally, that indicated answers given using spoken words.
- Answer question non-verbally, that indicated answers given using non-verbal communication, as sign language or with an aided AAC aid.
- Give order, that indicated instructions given that insisted on an action of another individual.
- Reprimand, that described communication attempting to control/alter an individual's actions.
- Make request, that indicated communication requesting something from another participant.

The total number of staff-initiated or client-initiated communication exchanges were counted, and qualitative information such as participant utterances or nonverbal gestures, telling facial expressions, and the like, could be added about each session.

Each complete communication incident observed (such as one verbal question) was noted on the protocol as one incident in the relevant category field. A new protocol sheet was used for each observation session to keep all data from a given session together in one place.

Centre management was presented with information sheets and consent forms one month before the observations took place. This was to ensure that management and staff were familiar with this phase of the study ahead of time, so they could suggest and consult with suitable and interested staff for participation, and arrange for my access to sessions required for observation. The observation protocol sheets were not presented ahead of time because of the possible effect this knowledge may have had on participants' behaviour.

All staff were asked to sign consent forms before their respective sessions, with six staff involved in the observation sessions. Staff were also not told when observations would take place, in order to try to keep sessions to typical activities and behaviour. It was planned that one-hour breaks would be taken between observation sessions involving the same staff member in on-site sessions at the centre, and 30 minutes between observations in off-site sessions away from the centre.

Group client sessions in and out of the centre were expected typically to involve two staff members and between five and eight clients of varying abilities and conditions. Each observation would target the communication exchanges of one staff member at a time, and observe all of their exchanges with all of the clients present at the time. Data from each session would be recorded using written notes, and sessions were not audio or video recorded. It was expected that one on-site pilot session be conducted to test the observation protocol before conducting subsequent sessions, giving an opportunity to update the protocol if necessary.

Procedure

On-site sessions

On the morning of the first day of observation, a single pilot session and subsequent observation sessions were conducted on-site within the centre. The centre director signed a consent form on behalf of the clients (National Health Medical Research Council, 2007), and all staff participants signed consent forms ahead of their respective sessions (See Appendix 2).

Once the signed informed-consent forms had been collected, I moved to the first, 30-minute pilot session (in the sensory room, as seen on the map in chapter 1). In an attempt to observe natural communication exchanges, I sat in a corner of the room, approximately three metres away from staff and clients, close enough to hear the conversations and see their facial expressions, but far enough away to ensure that participants did not see me seated within the group of people conversing. I then wrote down the current time on the protocol sheet, after referring to a mobile phone, set a timer on the same device, then observed the session, noting the occurrence of each behaviour and communication exchanges on the protocol with a pen. At the end of the session, I checked the time, stopped the timer, then asked the staff member if they had any comments about the session, including whether the session was typical, and recorded those answers on the protocol. I then thanked participants, and left the room. This was typical of each on-site session. After the first pilot session, I proceeded to the centre staff room, where I made changes to the protocol for subsequent observations.

Off-site sessions

The six off-site sessions were all conducted on one day. At the start of that day, I presented and collected any outstanding informed-consent forms from staff, then waited for staff to help clients board the centre's van parked approximately ten metres away from the front door of the centre. Once the clients were in the van, I entered the van and rode with the staff and clients for ten minutes to the shopping centre, where the bowling alley and food court were situated. A major difference between the on-site sessions and the off-site sessions was that I, with supervision from staff, had direct contact with clients outside of the observation sessions. This included holding objects for clients and guiding them as they walked around the

shopping centre between observations. In these instances, the observation method shared similarities with the participant-observer ethnographic approach, as I was more involved in the sessions off-site due to this contact. As with the on-site sessions, I was also sitting approximately three metres away from the participants during the off-site observation sessions, noting both the frequency of communication exchange and contextual information on each protocol sheet.

Data analysis

The nineteen total observation session results were divided into (n=13) on-site sessions at the centre and (n=6) off-site sessions. Quantitative and qualitative data were analysed by staff-initiated (SI) and client-initiated (CI) occurrences. The frequency, mean, median and standard deviation of exchange occurrences were calculated for each observation session, and contextual written information was analysed to illustrate and support these quantitative data.

7.2.2 Results and discussion

Results are presented and discussed in the next five subsections, namely:

- changes to the observation protocol
- notes across all 19 sessions
- on-site sessions
- off-site sessions
- comparison of on- and off-site sessions

Changes to the observation protocol

During the pilot study, it became obvious that changes needed to be made to the original observation protocol sheet. Note that while two staff members and six clients were observed during the pilot session, the observational data gathered from the pilot session was discarded from analysis. This second, final protocol, used in the remaining formal observation sessions, is presented in Figure 41.

Staff member ID:		Clients ID:	
Date of Observation:			
Time: from		to	
Observation number:			
Behaviour	Staff Initiated	Client Initiated	Topics discussed
Ask Question verbally?			
Ask Question non- verbally?			
Answer question verbally?			
Answer question non-verbally?			
Give instruction			
Demonstration			Type of non verbal communication Sign, gestures, nodding, Aided AAC. S Key word signing G Gestures N Nodding AP Aided AAC - pictures AW Aided AAC - writing AO Aided AAC - other devices
Prompting			
Reprimand			
Compliment			
Staff Information exchange			Actions-Helping clients: toilet/eating
			Was this interaction typical?
Total n occurrences observed			
Notes			

Figure 41: Second iteration of observation protocol sheet.

Accordingly, the following changes were made to this second protocol sheet prior to the first formal observation session:

- Changing, give order, to, give instruction, to better describe staff members' supportive transfer of information this way to clients.
- Taking out, make request, as, questions, already covered this category.
- Replacing, prompting, with, give instruction, to allow for a better description and division of occurrences according to intent (the other being reprimand).
- The addition of, staff information exchange, to allow for frequency data on this previously overlooked category.

A fourth column, to the right of the middle section, was added to support the entry of basic, contextual written information for each session beyond participant quotes. The purpose of this was to refine further the process of observation, by allowing efficient, categorised qualitative, as well as the quantitative data to be entered during observation. This allowed the notes section to be used solely for contextual quotes by participants.

This fourth column contained four areas:

- An area to note the general, topics discussed, in each observation.
- A key to the possible type of non-verbal communication observed
- An area to enter, actions observed.
- An area where information was added about whether observed communication interactions were typical.

This final area was used to enter additional information at the end of each observation, when I thanked the participants, and invited any comments from them about session typicality and exchanges of note within the observed session. With respect to the overall observation procedure, no changes were made after the initial changes.

Notes across all 19 sessions

Comparison of total staff and client-initiated exchanges (n=999), across all nineteen sessions, showed that more than 70% (n=731) were staff-initiated and less than

30% (n=268) client-initiated. There were some differences in the number (and verbal abilities) of client participants in the individual sessions, as well as different staff participants and activities.

Figure 42 shows the percentage of total staff-initiated communication exchanges by category. The majority of staff-initiated exchanges were verbal questions to clients (n=233), followed by staff-to-staff information exchanges (n=137), and then instructions given verbally to clients (n=111). Note that only 15% of the 731 staff-initiated communication exchanges (Verbal Answers and Compliments) were communications intended to directly answer or respond to client-initiated questions or actions.

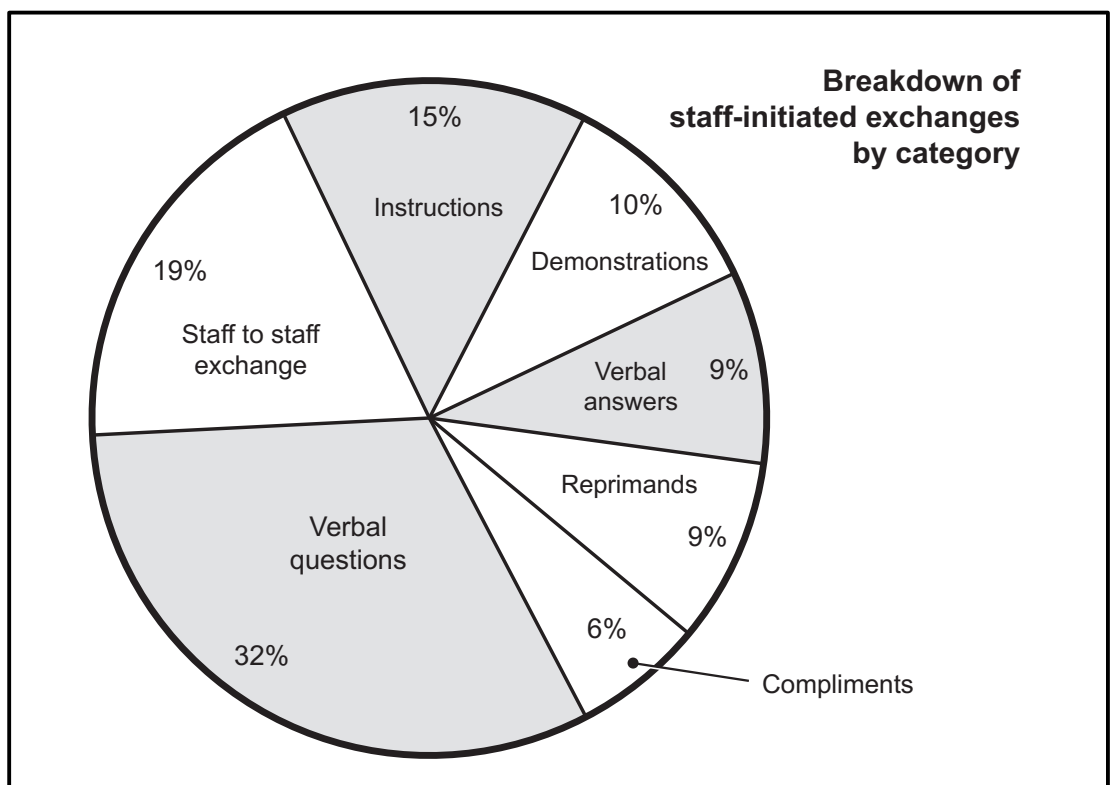


Figure 42: Percentage breakdown of staff-initiated exchanges by category.

The large percentage of staff-to-staff exchange was typically staff exchanging information in a session, for example, about an activity, such as, “the ribbon’s over there”, or about a client, such as, “we had an awesome day with him yesterday!” This was the only category denoting staff-to-staff communication. All other categories were communication exchanges with clients.

Figure 43 shows the percentage of total client-initiated communication exchanges by category. The majority of client-initiated communications were verbal answers to staff (n=113), followed by non-verbal answers or reactions (n=77), and then verbal questions to staff (n=69). Note that 69% of the 268 client-initiated communication exchanges were verbal or non-verbal answers in response to staff-initiated questions.

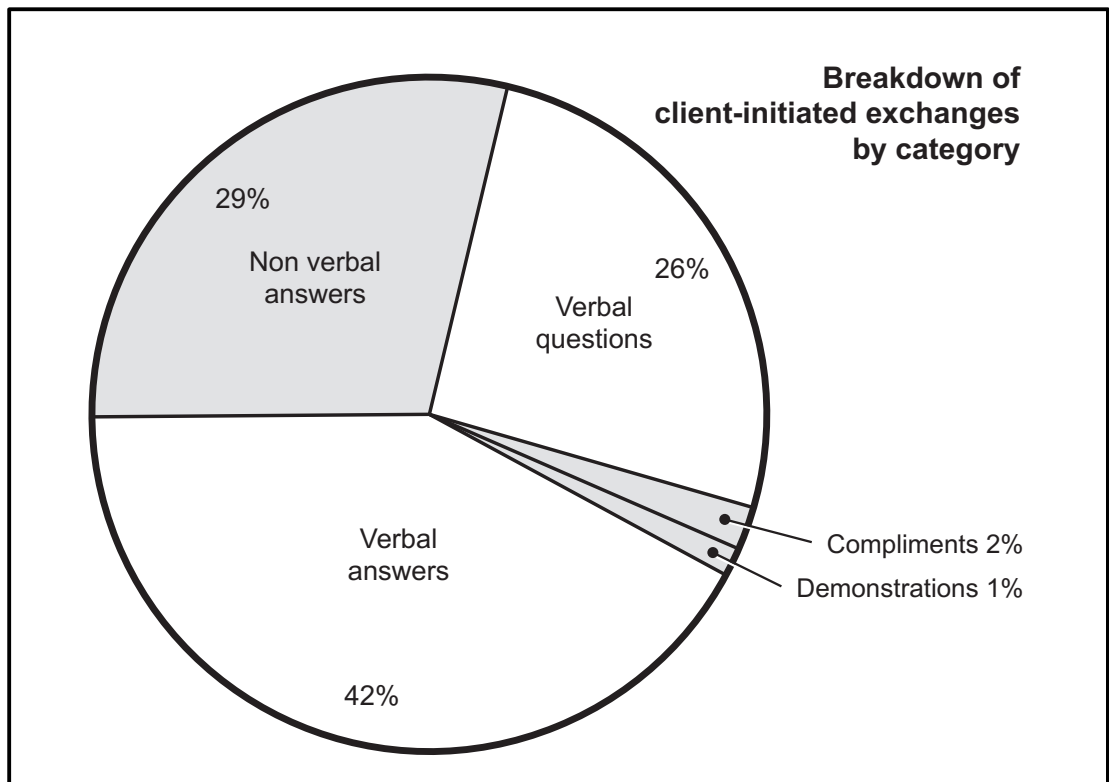


Figure 43: Percentage breakdown of client-initiated exchanges by category.

The very small percentages of client-initiated compliments and demonstrations represent the only times that clients communicated with each other in the observed sessions. There were five compliments by clients in a single off-site ten-pin bowling session, including comments such as, "Good shot!", and four demonstrations by clients in a single on-site craft session, including someone saying, "Put the glue on the cork".

Figures 42 and 43 also highlight some of the limitations of the observation sessions. Even though no changes were made to the observation protocol (after the amended copy was used after the pilot session), there were still challenges in trying to note the communication frequencies of two categories in particular. It proved too difficult

to note non-verbal questions, and non-verbal answers were noted only in the client-initiated examples. The nature of non-verbal communication was typically subtle (nods and various other small gestures were observed, for example), and trying to distinguish between a non-verbal question and answer proved extremely difficult. As many of the clients struggled with communication, I decided in the very first observed session to concentrate on any type of communication the clients exchanged, but only to focus on the verbal responses from staff participants. This enabled me to use some of the time to write contextual quotes from participants and to observe by listening to exchanges as well as sighting them.

In order to capture all non-verbal communication accurately, it would be necessary to video record each complete session. However, given that the primary purpose of this research was to identify communication challenges and AAC use of those with an impairment, detailed analysis of subtle non-verbal interactions from staff participants was of less importance at this point, and beyond the scope of this study. These will therefore not be commented on again.

On-site session results

Observations on-site at the centre included the thirteen group sessions conducted in two indoor areas: in the sensory room (n=4) and in the craft room (n=9). For room reference, see the map in chapter 1. Observed on-site activities included staff and clients taking part in craft activities, playing board- and other games, and listening to music, with staff taking clients to the toilet, and otherwise attending to clients' dietary and hygiene needs during these various activities. These sessions were conducted over a period of two weeks.

Figure 44 shows the total on-site exchanges (n=694) observed in each of the thirteen sessions. This represented 69% of the total number of exchanges (n=999) observed. The mean, median and standard deviation of exchanges were calculated across all sessions ($M=53.38$, $Mdn=55$, $SD=10.26$), with exchanges ranging from 74 (Session 1) to 32 (Session 6) in a session.

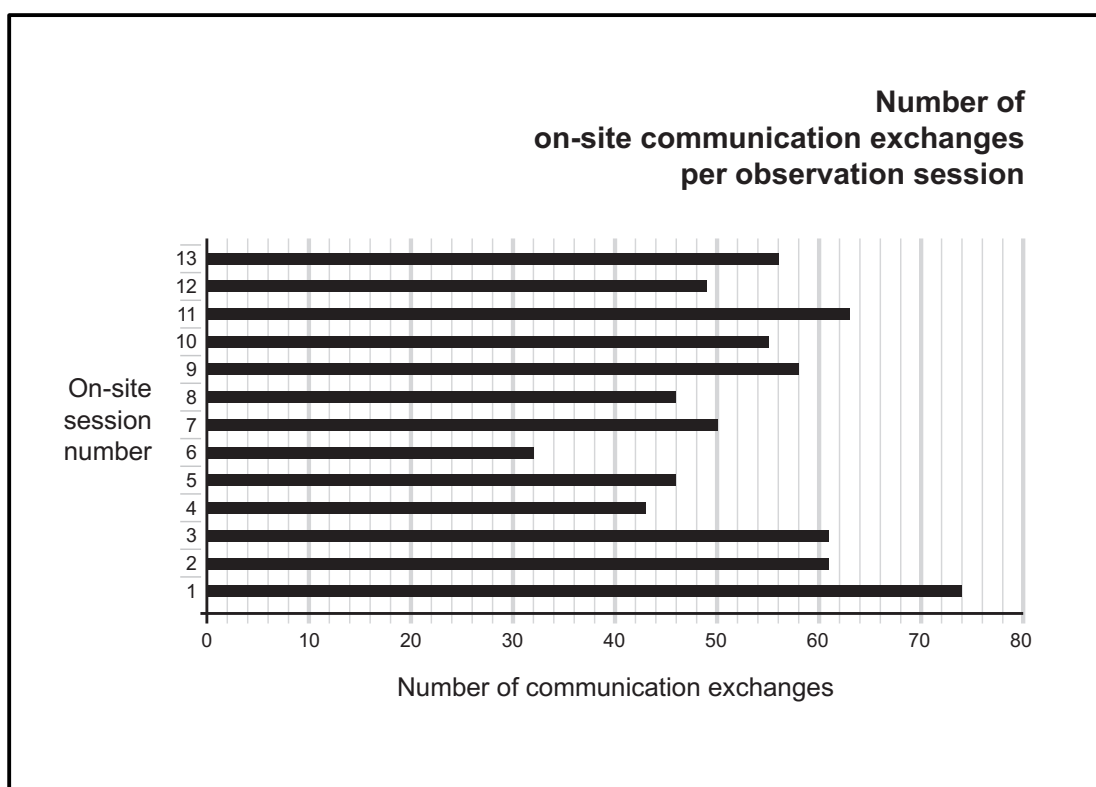


Figure 44: Total number of on-site communication exchanges per session.

The largest difference in the frequency of total exchanges between sessions one and six, (even though both sessions were in the same sensory room) can be explained in the following three ways:

Firstly, by looking at a breakdown of verbal and non-verbal client participants in each session. Session 1 had four verbal and two non-verbal clients yielding more than double the number of exchanges ($n = 74$) than session 6 ($n = 32$), in which two verbal and five non-verbal clients were present. Verbal clients contributed to the number of spoken exchanges in a session, whereas non-verbal clients typically required care from a staff participant, rather than engaging in communication, as the non-verbal client participants would often have ambulatory and other health issues.

Secondly, by looking at a breakdown of staff participants in each session. The staff participant in Session 1 was the only younger staff member observed on-site (staff member, ac, in Table 17), and was observed over the first four sessions. However, the data do not show a discernible pattern with regards to staff members' ages (in overall on-site sessions) affecting communication frequency. Attempts were made to minimise the likelihood of staff members knowing when they would be observed, but

the results of this first on-site observation session were affected by the staff member getting used to my presence.

Finally, by looking at the types of activities in each session. Session 1 involved staff instruction (n=17) and client involvement in that activity, while Session 6, in which far fewer instructions (n=4) were noted, instead involved a staff participant exercising with a client, supervising morning tea, and taking other clients to the toilet.

Session 1 included instruction about dough making in the sensory room, yielding staff-initiated exchanges such as, “Grab a chair. Get a bowl”, and, “Add this and mix it”. One client’s responses to this were simple words, including, “OK”, and, “Yeah”. As was typical in many sessions, there was also some behaviour and health management with selected clients. The staff member asked one client about whether they had “any funnies at the moment?”, where, funnies, are an agreed-upon term for warning signs shown before violent behaviour. The staff member also helped another client into a new position, from a wheelchair to the floor, and this was done with comments such as, “I’m just helping you to the floor” to the client, and a discussion of how to do this safely with another staff member.

Session 6 included the staff participant chasing a client with a ball, in and out of the sensory room for much of the session time, which was a method this staff member described as tricking the client into getting exercise. “I’m coming to get you”, and, “You tell them I made you run again”, were typical staff comments in that session. Similar activities were conducted in sessions five and seven.

Moving into comparisons across participant groups, Figure 45 shows the comparison between staff and client-initiated communication exchanges across all of the on-site sessions.

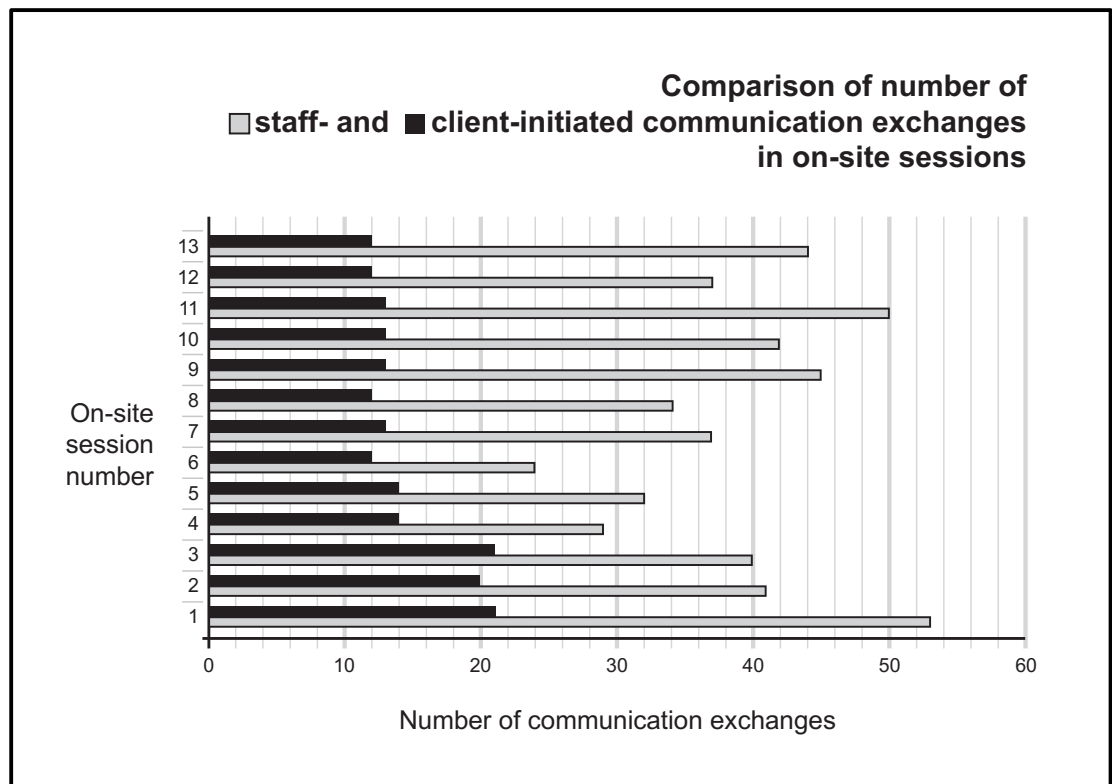


Figure 45: Comparison of on-site staff/client-initiated communication.

Note that the number of staff-initiated exchanges always exceeded the number of client-initiated exchanges in each of the thirteen sessions. The smallest difference ($n=8$) in staff- and client-initiated exchanges occurred in Session 6, and the largest ($n=37$) in Session 11. In total, there were 504 ($M = 38.77$; 72.62%) staff-initiated exchanges, and 190 ($M = 14.62$; 27.38%) client-initiated exchanges across all 13 on-site sessions.

Similarities between these and other data can now be seen. Comparison of on-site staff- to client-initiated communication frequencies (approximately 70:30%) were similar to the comparison of total staff to client-initiated exchanges. So, despite different activities and make-up of participants in each area, this ratio remained steady across the 19 sessions on- and off-site.

With respect to the frequency of client-initiated exchanges, these were similar in the on-site and off-site contexts, where there was less variance between sessions (Figures 45 and 47), compared with staff-initiated exchanges, which fluctuated considerably more. The communication limitations of a few clients were relatively

constant between sessions, but staff participants used their much greater verbal communication skill in whatever way was most effective for each activity.

In particular, (see Figure 45), sessions 1–4 were supervised by the same staff participant, with the same number of verbal client participants in each session. Client-initiated total communications are similar for three of the four initial sessions, with the fourth session showing less client-initiated communication because of the nature of the activity in this fourth session: lunch preparation and eating food.

Sessions 2–4 were in the craft room, and involved clients making small Christmas trees. Staff communications included typical exchanges to clients about tasks, such as, “Hold the cork”, and, “Put the sprinkles on”, with exchanges about well-being such as, “You OK?” and, “Help her out please”. There were some behaviour and health-related exchanges as well, with one client who had shown aggression some time that morning. The client stated that they wanted coffee and the staff member replied with, “You’ll get coffee when you can show your behaviour has improved”. Staff ensured that clients had activities to do, but also that certain clients, whose behaviours were potentially dangerous, were monitored and safe.

Sessions 5–13 showed a very steady total for each of the client-initiated communications, with a very different make-up of client participants in each session. This constancy can be explained by the presence of a particular verbal client who asked and answered a similar number of questions in each session, regardless of room type or activity. There were three staff participants over these nine sessions, supervising three sessions each.

Sessions 5–7 were in the sensory room, with the remaining six sessions taking place in the craft room. The activity in the craft room involved clients making decorative owls, and included staff exchanges such as, “Now they all want to have a go at sewing it. Is that a good idea?”, and, “No. No. Smaller than that”, about tasks, and, “Do you want to take off your jumper?” and, “Aren’t you hot?”, about client well-being. Conversation about organisation included, “There’s a taxi here for her”, and, “On Friday, we’re cleaning this out”. Client-initiated questions were about wants and needs, such as, “What about me?”, and, “Drink?”, and client answers were typically mono-syllabic, such as, “Yes”, “No”, and, “OK”. Non-verbal answers included gestures such as nodding of the head or sign language.

When comparing the categories of on-site staff- and client-initiated exchanges, it is interesting to note that staff asked almost exactly three times as many questions ($M=12.23$, $SD=3.12$) as clients ($M=4.08$, $SD=1.98$). This mean number of exchanges was close to the median (staff: $Mdn=12$; clients: $Mdn=4$), suggesting a very stable trend. In total, staff initiated communication exchanges much more often than clients did, at nearly three times the frequency (staff: $M=38.77$; clients: $M=14.62$). Because of the busy nature of each group activity (where one staff member was responsible for up to six clients) staff were typically more involved with verbal clients (who asked for attention), than non-verbal clients, although this was also determined by the type of activity in each session.

While client-initiated data shared similar mean frequencies between the two on-site areas (craft and sensory rooms), comparison of staff-initiated data across these two rooms showed some differences. In total, there was a mean of approximately five more staff-initiated communications in each craft room session than in each sensory room session. Most of the communication categories showed similar results between rooms, with one exception: the mean frequency of demonstrations by staff in the craft room (SI: $M=4.78$, $SD=2.53$), were more than double of those in the sensory room (SI: $M=2$, $SD=2$). This reflected the nature of the demonstrated craft activities in the craft room.

On-site observation showed that staff had tasks to complete throughout each session, and needed to be aware of their surroundings and their clients at all times. As well as communicating with and listening to clients, they also had to monitor them for any health/hygiene issues (to see if they needed to go to the toilet, for instance), behavioural issues (where early warning signs could signal behaviours of concern), prepare and execute activities to stimulate or calm clients (depending on the condition or individual), and sometimes perform tasks based on the client's unique needs (such as feeding someone through their side or moving a client in a safe way).

This splitting of tasks ensured that clients were safe and as engaged as they could be, but it also meant that staff had to spread their attention over a group of client participants at once. This was why ambulatory, verbal clients received more communication and attention from staff than other non-verbal and/or non-ambulatory clients, even though staff would typically supervise group activities in pairs.

In summary, for observed on-site sessions:

- Observation of on-site sessions occurred in two rooms: sensory and craft rooms.
- On-site sessions represented 69% of the total observed communication exchanges.
- Staff-initiated exchange frequency varied widely across sessions, as compared to client-initiated.
- The number and abilities of participants, as well as the type of activity in each session, affected communication exchange frequencies.
- Notable results included on-site staff-initiated total exchanges and verbal questions occurring three times as much as client-initiated exchanges, and mean demonstrations by staff occurring twice as much in the craft room as in the sensory room.

Off-site session results

Observations off-site, away from the centre, included six sessions conducted in two areas over one day: three at a bowling alley (Sessions 1–3) and three at a shopping centre food-court (Sessions 4–6). These visits were regular outings for the clients. Observed activities included clients taking part in ten-pin bowling, food preparation and eating, and staff attending to client's dietary and hygiene needs. The observations were conducted in much the same way as in sessions on-site, when clients were gathered. The noise level was similar to the sound in the on-site sessions, and I was situated at a similar distance from the observed participants. Three of the clients were verbal and three were non-verbal. One of the non-verbal clients was in a wheelchair and one had ambulatory difficulties but could walk with staff assistance. Two staff supervised this group of clients, and were each observed in alternating sessions.

Figure 46 shows the 305 exchanges observed in the off-site sessions, which represented 31% of total exchanges (n=999) observed across all nineteen observed sessions. The mean, median and standard deviation for the 305 exchanges over

these sessions were calculated ($M=50.83$, $Mdn=53.5$, $SD=16.77$), with occurrences ranging from 76 (Session 1) to 21 (Session 6) in a session.

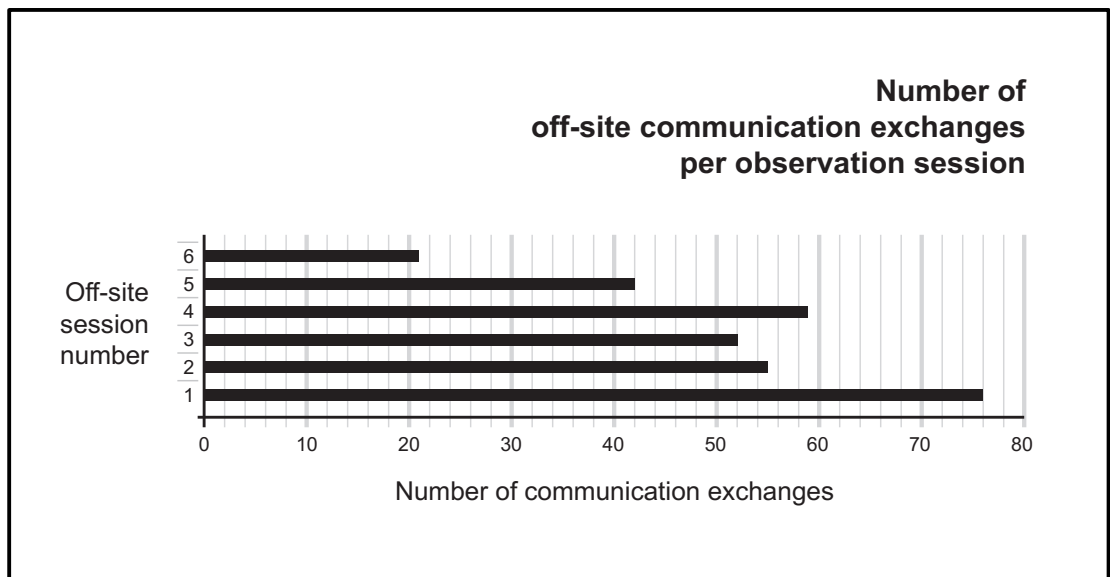


Figure 46: Total number of off-site communication exchanges per session.

Session one included staff and clients seated at the bowling alley café, with staff preparing or buying food for clients, and talking with each other and the clients about the upcoming bowling (in sessions 2 and 3). Staff helped unwrap sandwiches and buy food for the non-verbal clients, with comments such as, “Do you want the bread?” and, “Here I’ll unwrap that for you”, and discussed bowling, with exchanges such as, “That’s our lane there”, and, “We’ll move there soon”.

The three verbal clients wandered through the bowling alley, playing video games or talking with bowling centre staff, and this meant that staff also had to monitor their behaviour and movement. Reprimands such as, “You need to stay in the group, not play video games”, and, “Leave the lady alone. She’s trying to work”, were typical. Client responses included, “I wasn’t”, “But he’s over there”, and, “OK”. These three clients were not violent or confrontational, but did need some guidance as to what was acceptable public behaviour, and why staff needed them to be in a group for their own safety.

Session 6 was at the end of the day, and was at a food court, with clients finishing off their food, cleaning or packing up their belongings and preparing to leave the food court. There was very little communication in this session, apart from staff communications such as, “Ready to leave guys”, and, “I’ll take him to put his rubbish

away”. One client was reprimanded for deliberately knocking a hat off a stranger, something that the client did continually to gain the attention of those around them. This annoyed the other clients and caused some tension between them and other participants throughout the day.

As each of the six off-site sessions included the same three verbal and three non-verbal clients, and the same two staff members, the differences in communication frequency are attributable to other factors, such as activity and environment. Figure 46 shows that there were more communications in Session 1, with a gradual drop-off, then a jump in frequency to session 4, and a decline again. This mirrors the start of each new activity, namely bowling alley activity for sessions 1–3, and food court activity in sessions 4–6. Indeed, session 1 included approximately double the number of staff to staff communications than the other two bowling sessions (session 1 (n=10), session 2 (n=5), session 3 (n=6)), and double the number of reprimands (session 1 (n=12), session 2 (n=5), session 3 (n=6)), as staff needed to settle/manage client behaviour and belongings (food, bags, and so on) in the setup of an activity lasting three observed sessions.

The data also reflect the fact that once clients were engaged in the particular activity, the number of communication exchanges decreased. Even with an increase in questions from staff over the three sessions, client-initiated answers and questions dropped. Specific communication categories also dropped off in frequency from sessions 4–6, with staff-to-staff communications and reprimands dropping by half over the three sessions, and client categories. Verbal answers, for example, dropped from nine in Session 4 to one in Session 6. The pattern mirrored the activities in these sessions, with session 4 being the set-up of the clients in the food court (with management of client seating, and preparation or purchase of food), and the subsequent two sessions eating the food.

Given that the six off-site sessions occurred over the course of one day, the drop-off in frequency over time could also be partly attributed to the declining energy levels of participants over both three-session-blocks, which were observed at the end of the day’s sessions; instances of some clients finishing a task early and looking bored and displaying challenging behaviour were observed towards the end of the outing.

Figure 47 shows the comparison between staff and client-initiated communication exchanges across all of the six off-site sessions. Note that the number of staff-initiated exchanges again exceeds client-initiated exchanges in all six sessions, with a minimum difference of (n=15) exchanges in session 6 and a maximum of (n=31) exchanges in session 4. In total, there were 227 (74.43%) staff-initiated exchanges, and 78 (25.57%) client-initiated exchanges across off-site sessions.

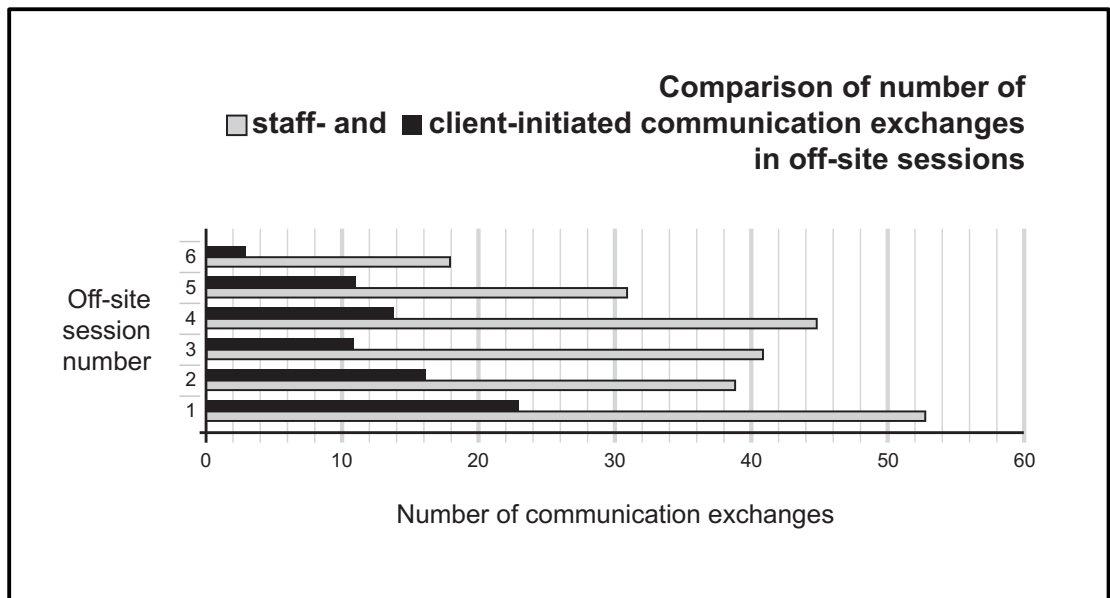


Figure 47: Comparison of off-site staff/client-initiated communication.

Figure 47 reveals the same pattern of the two drop-offs in frequency as in Figure 46, with a small increase in Session 3 as a modest increase in staff-initiated exchanges. This included a spike in staff instructions and verbal questions (Instructions: Session 1 (n=5), Session 2 (n=6), Session 3 (n=7), and verbal questions: Session 1 (n=15), Session 2 (n=13), Session 3 (n=20). These were mainly encouragement and guidance for clients, with comments such as, “Who’s next?” and, “Hold it like this”, and planning for the move to the food court next session, with comments such as, “Pack up soon everyone”. Client communication during the activity included, “My turn”, and, “That ball”.

Comparison of staff and client observations across the two off-site areas (bowling alley and food court) showed different results to the same comparison across the two on-site rooms (sensory and craft rooms). Where the two on-site rooms showed only slight differences between rooms, there is a distinct drop in both staff- and client-initiated off-site exchanges, from bowling alley through to food court activities.

Staff-initiated instructions, compliments and staff to staff exchanges, and client-initiated verbal questions and non-verbal answers all dropped by half the number between areas. As discussed previously, this reflected the nature of the activity in these sessions, and the observed declining energy levels of participants off-site.

Off-site observation showed that staff typically had more challenges there than in on-site sessions. As well as the multi-task nature of preparing and executing group activities while caring for clients, staff also had to monitor the surrounding, dynamic environment, limit the movements of clients around those areas, and ensure that all participants, and individuals were safe. Staff showed extreme patience, with certain clients repeating challenging behaviour constantly. Staff did not have the benefit of different on-site rooms available that they could separate troubled clients into, for instance. Staff needed to work well together, to swap information about clients or activities, and to coordinate client toilet visits with other supervisory tasks.

In summary, for observed off-site sessions:

- Observation of off-site sessions occurred in two areas: bowling alley and food court.
- Off-site sessions represented 31% of the total observed communication exchanges.
- Off-site session frequencies peaked at the first session of each area, and then dropped off over the duration of the three sessions from the same area. The exception was in session 3, where staff-initiated exchanges rose to reflect the staff management of the client bowling activity, and the set-up of the next activity.
- The number of participants was the same in every off-site session, but the type of activity in each session, the energy level of participants, and the environment affected communication frequency.
- Many staff- and client-initiated exchanges halved in frequency from the Bowling Alley to the Food court.

Comparison between on- and off-site session results

Figure 48 shows a breakdown of particular staff-initiated communications in categories across on- and off-site sessions. While the mean number of verbal

questions and answers, demonstrations and compliments are similar across sites, three categories showed notable differences.

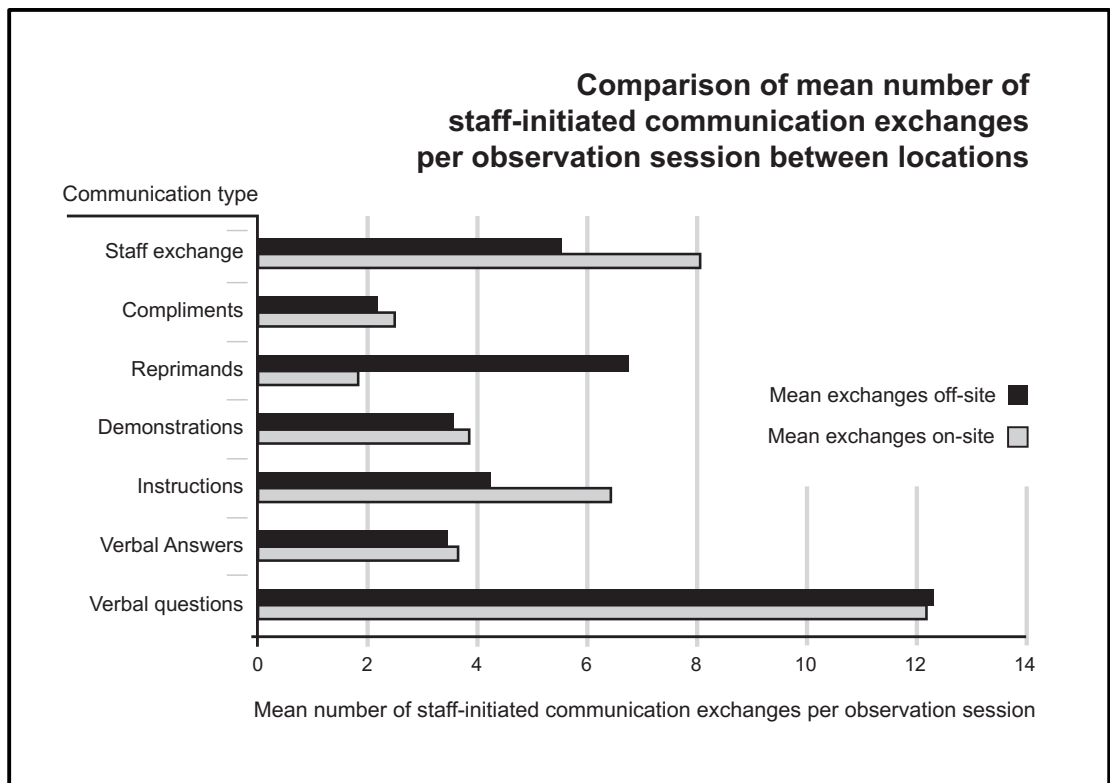


Figure 48: Comparison: number of staff-initiated exchanges between locations.

The number of Instructions (On-site (M=6.54), Off-site (M=4.33)), and staff-to-staff exchanges (On-site (M=8.08), Off-site (M=5.33)), were higher in the on-site settings, whereas there were more reprimands in the off-site sessions (On-site (M=1.85), Off-site (M=6.83)). Again, these differences reflected the various activities and the environment in which the observations took place.

Instructions during activities in on-site sessions included exchanges such as, “Thread this through here”, and, “You’re doing it right. Pull it out a little bit”, and on-site staff to staff exchanges included, “Did AA cut any more strips for your guys?”, and, “AA and I are cleaning that out”. Even though there were on-site examples of staff reprimanding clients, with comments like, “Give her time to answer please”, and “We don’t start lunch until we pack up”, off-site examples of exchanges were typically stronger-worded reprimands, and these sessions often showed a change in priorities (and the exchanges) for staff. The management of client movement and behaviour in a different, much more open and distracting public environment, meant

that staff exchanges were typically about the safety of participants and members of the public, with comments such as, “You need to sit down. It’s about safety”, “Up you get. It’s not Program now”, and, “You need to stay with the group”. The three verbal clients in off-site sessions were assertive, and would answer with, “I wasn’t”, and, “But I wanted to see”.

While the three assertive verbal, ambulatory clients were challenging for staff, two of the other clients also showed behavioural idiosyncrasies. As discussed earlier, the client who walked with assistance would knock people’s hats off to get attention, and this annoyed the other clients as well as challenging staff. Clients would typically react to these actions, sometimes by even threatening to, “Hit ‘im if he does that again”. Staff of course had to defuse the situation and try to explain to the public and other clients why the client was doing this. This communication was challenging because of the other clients’ limited comprehension skills.

Another client, the only female in the group, had one very unorthodox method of greeting new male individuals. Very discreetly, and very quickly, she would grab a person’s genitals. This happened once, when I met the group, and her actions were an immediate look at the often-controversial topic of impairment and sexuality (Bryen, 2008), and the vulnerability of individuals with CCN

There was a decrease in the mean client-initiated verbal questions and answers from on-site to off-site communication exchanges, with an increase in non-verbal responses. Thus, even when clients were engaged in eating or bowling, they still answered some questions non-verbally. Note that there were many instances, on- and off-site, of staff asking questions that did not necessitate an answer, and were designed to guide a client or attempt to control behaviour, such as, “Can you please help her pack up the craft stuff?”, and, “Can I have that, darl?”.

Overall observations revealed a busy, often chaotic environment with vulnerable clients who had communication difficulties. Staff had to operate as professional, assertive individuals with these sometimes overly sensitive clients, and attempted to keep them safely engaged. Higher functioning, verbal clients would typically get more attention from staff participants, but staff always made sure that other, non-ambulatory, non-verbal clients were safe and monitored.

In summary, a comparison of communication exchanges between on- and off-site sessions showed that:

- Staff initiated communication exchanges more often than clients in every observed session.
- In only two categories, clients communicated more than staff, as verbal and non-verbal answers.
- There were differences in communication exchange frequencies between sessions, attributed to the make-up of participants and the types of activities in each session.
- Noteworthy comparison data includes instructions and demonstrations being higher on-site, and reprimands being higher off-site, reflecting the nature of each group activity and the surrounding environment.

7.2.3 Discussion of results

Two exchanges of note highlighted the challenging nature of communication among staff and clients. Both involved clients who were observed over multiple sessions or areas, and both indicate that the years of staff experience in the disability industry may be a factor in client-initiated communication. These are examples of a staff member knowing a client particularly well, when another staff member may not, highlighting the potential problematic use of redundancy (or use of familiarity among participants in lieu of AAC use), observed in these sessions.

The first client was observed over seven sessions, and supervised at different times by three different staff members. In that time, the client responded with occasional smiles and other forms of non-verbal communication to the various staff members, but displayed no verbal language skills. The client, confined to a wheelchair, displayed challenging fine and gross motor skills (such as struggling to hold items), and did not behave differently with different staff. Staff members would typically talk to the client, and get a smile in response, and it was very clear that the client understood what was being said, and would often laugh at humorous communication. One staff member joked with her that, “You need to get better staff. (That staff member) can’t even open your sandwich!”.

After observing this and other clients in various sessions over a total of three and a half hours in this study, the client finally responded verbally to the question, "What colour is that?", very quietly but very clearly, with the word, "Purple!". This occurred in the craft room, at the end of a session, where participants were quietly making craft items. Because of the quiet nature of this session, it is possible that client responses may sometimes not be heard, or that a client needs more time or a certain environment to use verbal skills, or that using verbal skills may be tiring or difficult for the client. Among the staff participants observed, that staff participant had the second most years of experience in the disability field and seemed to know the client well.

The second client was a wheelchair-bound client participant observed in all six off-site sessions as well as another three on-site sessions. The client was fed with a liquid, by a staff member at lunch/snack times through a drip in his side. Observations of this client off-site showed that he was non-verbal and non-responsive to questions or comments directed to him by staff. He was taken to the toilet, talked to, and staff helped him during ten-pin bowling, which involved pushing his hand against the ball to push the ball down a ramp. When the same client was cared for by a different staff member, on-site, the client raised his arm in response to the instruction, "Can you lift your arm? I'm just going to turn you around so I can get the right spot. I can't see here". The staff member then fed the client through the side-tube with a mixed liquid.

Noted conversation with the on-site staff member at the end of the session revealed that the staff member often saw this client respond to instructions and other communications, but noted that other staff had not seemed to see this. Other differences between the staff and environments of both sets of sessions were noted. This staff member (ad: see table 17) on-site had considerably more experience than the other staff members. Additionally, the on-site environment was quiet and seemed to be much easier to control in relation to client behaviour and situations, than the off-site sessions, which were open and potentially more distracting for participants. On-site sessions seemed to afford the staff members more time to communicate with clients positively, as shown in the data.

Throughout the studies undertaken in this thesis, and despite the difficulties of observing non-verbal communication, there were instances of unaided AAC serving

as communication exchanges. There was, however, no use of any personal aided AAC aids in any of the observed sessions, nor were staff or clients observed looking at or using publicly displayed AAC.

These observational data then, suggest a number of potential design directions that could be explored to address communication challenges. Off-site participants could benefit from the use of an aid that educates clients about acceptable social behaviour, or engages them in geographic location games to help them safely navigate public places. On-site participants could benefit from an aid designed to help pick warning signs (from a client) about toilet visits and behaviours of concern. The client could communicate their need or emotion to the staff member, instead of the staff member having to notice a slight change in behaviour in the client.

7.2.4 Summary of observations

An ongoing summary has been provided, so only a brief summary is necessary here. Overall, from the observation studies conducted, it has been noted that:

- There were 999 communication exchanges observed, using a written documentation method, and an ethological, or participant-observer technique depending on location.
- There were 19 on- and off-site sessions observed.
- Staff initiated communication three times as much as clients.
- Staff reprimanded clients more in off-site sessions.
- There was no observation of personal, or displayed aided AAC use, and very little use of unaided AAC, such as sign language.

The last dot point highlights the use of redundancy by participants throughout the observed sessions, in this environment of limited AAC use, as displayed in the IMM result in Figure 49.

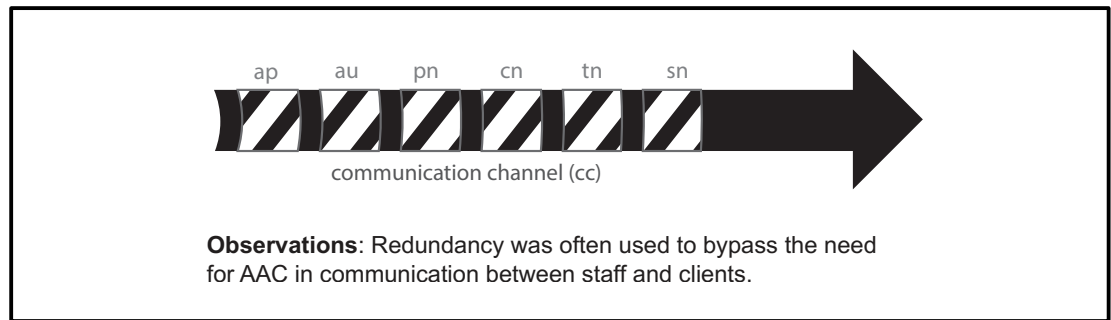


Figure 49: Example of an IMM result for observation study data.

Note here that the AAC bypass has been activated, in place of AAC use, and that this can lessen the effects of various forms of noise on the communicators (see chapter 5.2.5). While this result may show that staff are able to complete their tasks and tend to clients, the graphic is also of importance to clients and client-advocates, as a representation of the techniques needed to operate in an environment with limited resources, such as time to allow for AAC use. Redundancy is seen here as potentially beneficial to staff, but of more limited value to clients' short-, and long-term communication needs, and the latter's independence.

The observations reported in this chapter provide direct data about the nature and frequency of specific staff and client interactions. The remaining two studies in this research supply data from other participants, including parents and centre management. These studies also provided reflective information from staff about the analysed data to that point in the research.

7.3 Parent interviews

While the staff participants' perception of communication challenges were obtained in the focus groups and from subsequent information obtained from the posters, the nature of communication challenges and AAC use also needed to be explored from other participants' point of view. Specifically, I needed information about:

- Clients throughout the years as they grew from children to adults.
- Clients when they were away from the disability day-centre, on weekends, or after their centre visits.

With this in mind, I liaised with centre management in an attempt to recruit some parents of clients. Only two parents were able to find time for an interview, and both of them were recruited for this study.

Individual interviews were appropriate at this stage, because of the very small number of participants, and because there was now some knowledge gathered from previous studies. Semi-structured interviews were chosen for this study, to allow for focused but descriptive responses from parents, and for probing and requesting elaboration when appropriate. These types of interviews:

... combine features of structured and unstructured interviews and use both closed and open questions. For consistency, the interviewer has a basic script for guidance, so that the same topics are covered with each interviewee. The interviewer starts with pre-planned questions and then probes the interviewee to say more until no new relevant information is forthcoming (Preece et al., 2015, p. 299).

The two parents were unable to meet physically to conduct the interviews. A remote, telephone form of the interview technique was then conducted.

7.3.1 Method

Participants

Two parents of centre clients were recruited to take part in the telephone interviews for this study. Management had suggested that it would be difficult to recruit client family members, as there was a history of little parent involvement in the activities at the centre. Upon the recommendation of the centre management, I attempted to

contact six parents, over one week, but only two, both mothers, agreed to participate. The mother of a male client with Autism, Dyspraxia, and Diabetes was interviewed first. The mother of a female client with Prader Willi Syndrome was then interviewed. These impairments have been described in chapter 2.

Materials

Informed consent forms and information sheets (outlined in Appendix 2) were made available to staff management (three weeks before interviews took place), and these subsequently given to the two participants two weeks before the telephone interviews were conducted. In the information sheets, participants were asked to:

Give some thought to the kinds of difficulties you have experienced understanding your family member/client when they attempt to communicate something to you. I would also like you to think about the kinds of difficulties you think your family member/client has experienced when you have attempted to communicate something to them.

During each interview, a telephone with a speaker function was used, and each conversation was recorded with permission, using two audio recorders in different positions around the speaker. Each telephone interview was transcribed verbatim.

Procedure

Informed consent forms and information sheets were given to staff at the day centre to pass to interested parents. Once signed, consent forms were returned to me by staff management, and each parent was contacted by telephone twice (one call each day), once to set up an interview time, and the next to conduct the interview. Just before the telephone interview, audio recorders were tested and turned on, then the speaker phone feature was used on the telephone for the call.

Each interview began with me greeting and thanking the participant, then ensuring that the participant had read the information sheet, and was happy to conduct the interview at that time. I then reiterated the purpose of the study:

I'd like you to talk with me about communication difficulties you've had at home with (son or daughter). What sort of challenges have you had with (son or daughter) growing up, and with (son or daughter) as an adult? How have you overcome some of these challenges?

Both interviews were conducted at 8AM, three days apart, and were expected to take 30 minutes each. During each interview, I prompted discussion to keep each conversation on topic. After each interview, participants were thanked and audio recorders were turned off.

Results and discussion

Each parent began by giving a history of their child, including diagnoses and professional disability-support their child had received early in their lives, before moving on to examples of their child's behavioural incidents and communication challenges. Each parent outlined extensive use of communication aids as solutions to various communication difficulties throughout their child's life.

Both interviews were longer than 30 minutes (68 and 41 minutes respectively), at the request of each parent. Both parents now work in various roles within the disability industry.

Parent interview 1: Mother of male client

The mother of the adult male client described her son as being "diagnosed at three with ASD (Autism), and since that day, had none of the milestones (that children display as they grow intellectually)". She described early professional support as "seeing a speechie (speech pathologist) for a time" because his Autism and Dyspraxia affected his speech development.

Early in the interview, the mother began talking about AAC aids, and how important the use of these aids had been in their family. To address the challenges of anxiety in her child, for instance, she described how she:

Developed some Makaton/sign language, that sort of thing. Simple things like, 'Yes', and, 'No', to get his needs met. We did lots of daily schedules. We did, 'Today is Monday'. You really had to break down every step of the day

for him, and by the end of each day, you know, his anxiety was lower, and he understood what was happening, when it was happening, and in what order.

The mother described how the use of unaided AAC methods, such as gestures and facial expressions, were important tools to facilitate communication before other, more sophisticated aids were used later in the child's life. The client was described as being able to:

...understand the information but he just had difficulty processing, and of course because of the Dyspraxia as well, words were coming out all jumbled and back-to-front, and a speechie decided that he always had it in him but he just couldn't verbally express it. There was a lot of watching his body language and watching his facial expressions and then he'd actually take your hand and take you to something if you didn't understand. So he'd try to make you understand his environment or his needs or his wants.

With constant use of various types of communication aids, such as, "sign language, pictures on cards/key-rings/books", throughout the client's life, and, "lots of reward systems", the client, "took ten years 'til he said an actual word!".

Clearly, the use of communication aids (and early diagnosis and intervention: see chapter 2.2.3) had been extremely beneficial for this client. The mother said that an important part of the communication support, was that, "You have to make sure other people understand him, not just you". The mother described the advantage of her son, "being a visual learner", and offered the following advice about support for individuals with CCN:

If you put the effort in, and link with all the relevant professionals, speechies, OTs (occupational therapists), get the right information, online support groups, you can really learn things and really adapt it to your child and then work with him and get the right schools.

The mother used real objects (tangible symbols: see chapter 2.2), to help communicate effectively with her child, and outlined the challenging way she had to verbally communicate with her son, by having to be:

Very literal. Very specific. What we understand and what he understands are two different things sometimes. 'Go put your shoes on', and he gets 15 pairs

of shoes and just stands there looking at them. Two choices. 'It's your boots today or it's your shoes'. And physically show him the shoes and then you say, 'Good choice'. You've narrowed 15 down to two. Exhausting!

One of the aspects of the disability day-centre that the mother liked, and why she booked her son in there, was the use of the image-based activity schedules each day. This was an interesting comment, as I had only seen the text-based schedules in use at the centre. The conversation then turned to this use of communication aids in the centre, with the following exchange:

Prompt by me:

I'm not seeing a lot of communication aids in use at the centre with the other clients. Why do you think that is?

Mother's response:

I don't know. Maybe they're more verbal, or they are used to the routine, or they know how things work. It depends on what you're trying to teach. Social skills, travel training, taking part in the community, stranger danger and all those other things.

The next section discusses the interview with the second parent, before a summary of the parent interviews is presented. This is then followed by the final study in this chapter: staff interviews.

Parent interview 2: Mother of female client

The mother of the female client described the early part of her daughter's life as challenging, because she had "no family or friends who I could lean on for any help", and she'd often think, "Where do we go from here?" Because there wasn't much support for Prader Willi Syndrome (see chapter 1) at the time, this was especially challenging.

As with the first interview participant, this mother outlined the importance of liaising with professionals for support and information:

Back then, we also had one day a week where a physiotherapist, a speech pathologist, and an occupational therapist would go to the same place.

Twenty years ago I did feel I was in the unknown, so that was good!

The advantages of using communication aids, to encourage interaction and to combat her child's anxiety, were also discussed:

She also had different pictures back then to start. I used to have pictures of her wanting food, or when she was tired, sick. The basics. You know, 'Help mum', or, 'My toys', and we used to stick little pictures all over the bathroom and her bedroom to avoid just saying to her, 'What was that again'? In order for her to say what she wanted, she would elaborate with the pictures and it avoided her getting stressed and having a tantrum and at that age that's not fair. So we used pictures and sign language, and as she came into the three and four Kinder, her development of the sign language was even better than me to be honest! She picked it up - she was just amazing!

Use of unaided AAC, and a commitment to respectful attention, was another key to helping her child:

We always enabled her to try and explain everything, and we always had facial and eye contact. She was never ignored and we always made sure she could see our facial expressions, so everyone knew: 'This looks really important', or, 'She's angry', or we could see what was making her upset. As a family we got together to learn about the different body language she had when she was trying to explain something and be part of the conversation with her.

As a young adult, the client also had issues about understanding puberty and body changes, and this was an issue where communication augmentation helped:

She's a young lady, so those more personal discussions. That has been the most complicated. To discuss certain developmental issues. In terms of pain, for example. I had to come to a really little child. She is also diabetic so I know her monthly cycle. So I'll look at her and say, 'Have you got a sore?'. And she'd nod and give me the sign for, sore, or sign for, sick, and then I'll put her to bed or have her rest next to me to have that comfort. I think a lot of

other parents would be in the same situation as myself when you're dealing with the same sensitive issues.

This mother described the process of transition (from a special-needs high-school to the current disability day-centre), as being a difficult time, but said both institutions made the process "really seamless". Near the end of high school, mother and daughter went on occasional organised visits to the disability day-centre, which over time transitioned into longer and more frequent visits:

We started the year before and top marks to the school for what they did, and this is why I admire the day centre she goes to now. They also informed us they had one-day transitions and they weren't going to leave it 'til the last month in December. What they did at the day-centre was introduce more in the full last term. They didn't just give you one week for a couple of days. They actually had a whole term of your child getting used to the fact that this is going to be a new place for them. The whole communication from them and the fact that service was offered just made the transition easier.

Some of the challenges and solutions outlined above reflect similar issues that were discussed and observed in earlier studies at the disability centre. The development of more image-based timetables (rather than the text-based timetables currently used), the employment of rewards systems, and the use of individually-tailored communication picture books seem to be beneficial AAC systems that are worth exploring in future study.

With a description of both parent interviews, and illustrative examples of the transcribed conversations within each study, the next section summarises both, before staff interviews are presented.

7.3.2 Summary of parent interviews

As is evident from the discussions from both telephone interviews, there were similarities in the strategies of both parents, when attempting to communicate with their children. Both mothers:

- Sought out health-care professionals and information to assist in their children's care and their own knowledge.

- Insisted that early and subsequent constant use of varied Unaided and Aided AAC had helped their children deal with anxiety, speech development, safety and health issues, and general confusion.
- Specifically used sign language, pictures, timetables, schedules, token and reward systems, as well as verbal speech to communicate with their children.
- Talked about the beneficial, but typically tiring and challenging nature of using various AAC forms each day.
- Gave a lot of attention to their children, and tried to be patient and consistent in their care.
- Praised the actions of the disability day-centre.
- Are currently employed in the disability industry.

As outlined by the two parents in this study, sourced or invented solution strategies, designed in order to target communication difficulties, have been used throughout their children’s lives. An idealised, and simplified IMM representation of this is shown in Figure 50, and the employed strategies summarised in Table 19.

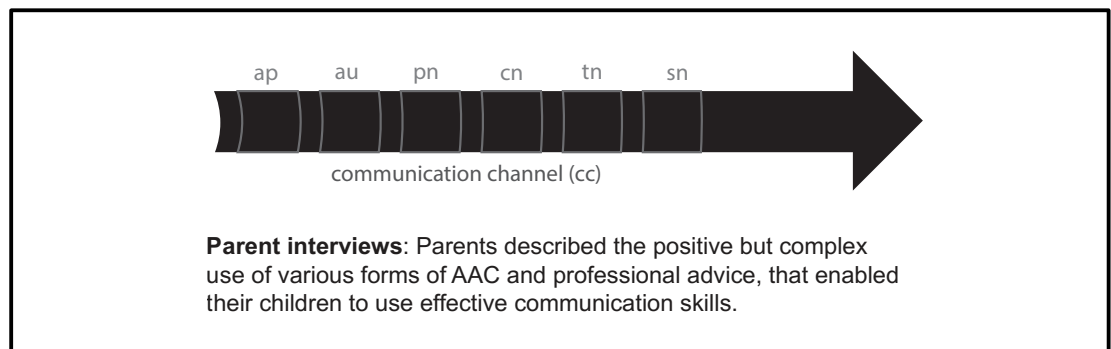


Figure 50: Example of an IMM result for parent interview data.

Table 19: Communication challenges and solution strategies.

N	Description / topic	Solution strategy	Parent #1	Parent #2
1	Inability to communicate verbally	Used simple manual sign language to get needs met	✓	✓
		Used pictures of objects and activities: Parent/client pointed to pictures to discuss needs	✓	✓
		Liaised with professionals for support/information (In kinder/school/day-centre)	✓	✓
2	Anxiety about change	Used timetables/schedules to communicate structure of daily activities	✓	✓
		During instruction or activity, broke down task to smaller, more understandable tasks	✓	✓
3	Slow development of speech	Gradually faded back sign language and encouraged more speech	✓	
		Buildup of single word sentences to multi-word sentences using repetition & practice	✓	
		Used token and reward systems on phone apps (animations) / pictures (stars)	✓	
4	Confusion about tasks / activities	Parent was verbally literal and limited choices for client. E.g.: "Get shoes" meant client would choose all his/her shoes. Instead: "You have a choice of these TWO shoes" (and show actual shoes)	✓	
5	Confusion about puberty body changes	Verbal explanation of pain and changes in simplified terms – as, sore, or, sick. Also used sign language for same terms		✓
6	Safety	Verbal explanation/discussion of cause and effect of being lost or hurt	✓	
		Registered client with police in case client wandered away from home	✓	
7	Health issues	Explanation of positive aspects of medicine in simple terms – verbal and with pictures	✓	✓
		Verbal explanation of overeating as being dangerous - and using weight-limiting fun activities		✓
8	Difficulty interpreting emotions	Attempt to clearly show other people's emotions and their causes: e.g. face pictures featuring changes		✓
		Verbal explanation of human behavior: Pictures showing crying as sadness, laughing as happy		✓
9	Communication between school/parent	Used communication book (pictures and simple words) to report daily behaviour/incidents		✓

Where the archival study investigated the presence of aided AAC aids at the centre, staff interviews were designed to gather staff opinions about the use of communication aids in the centre. The staff interviews were also designed to gather feedback about data presented to them from the studies to that point. This study is now presented.

7.4 Staff interviews

As I did not attempt to ask staff earlier in the focus groups about AAC use in the centre, it was important at this later stage to learn more about their attitude towards AAC methods. I met the majority of these staff participants at the start of each focus group, and had not at that time established a rapport with them, so the slight risk of sounding accusatory, by suggesting that communication aids were not used, was not taken. After spending more time with the participants in the course of the research, I felt that staff interviews could provide answers to the AAC-related questions. A structured, group interview was deemed suitable for this study, as enough information had by now been obtained to design appropriate questions. and a group of staff were interested in the results, and available for a short time during their staff meeting.

The purpose of this final study was to:

- Determine individual staff attitudes about the nature of communication at the centre.
- Determine staff attitudes about the accuracy of the data from the previous studies to that point.
- Further investigate the *use* of AAC in the disability day centre.
- Gather data about the administrative operation of the disability centre.

7.4.1 Method

Participants

Participants in this study were all staff members at the centre, including a selection of staff workers and team leaders. The centre director was not available for the final staff interview, but presented the initial opportunity for me to take part in this particular method ahead of time. Over a third (n=12) of the total staff members at the centre (n=30) participated in the staff interview. A breakdown of the staff who ultimately participated is outlined (Table 20):

Table 20: Breakdown of staff participants.

Type of participant	Team leader	Staff participants from off-site observation sessions	Staff participants from on-site observation sessions	Staff participants from focus groups	New to research
Number of participants (n)	2	1	2	5	2

Materials

Informed consent forms, information and interview protocol sheets were designed and given to the centre director to distribute to interested parties (See Appendix 2). Interview protocol sheets were designed to be used on-line (email) or on paper (printed), depending on the preference and availability of participants. There were also three slight variations to the protocol, with:

- Staff workers to answer three questions about communication challenges and AAC.
- Management and team leaders to answer questions about the above, plus administrative questions.
- The centre director to answer the above questions, plus another about staff demographics.

Staff interview protocol sheets are presented in Appendix 3.

In consultation with the Centre Director, an in-house presentation was arranged in order to show participants the research data to date, and for staff participants to complete the staff interview protocols in person. This was an attempt to gather the greatest number of completed interviews. Pens were provided to participants to fill out the interview protocols.

Procedure

Consent forms, information and interview protocol sheets were emailed to the Centre Director ahead of time. These printed paper and electronic forms were intended to give a choice to participants about how they would fill these out, but only two protocol sheets were filled out, scanned and sent back to me over the subsequent six weeks. To ensure that additional sheets were completed, and to provide staff with information gathered from this study so far, I decided to organise a presentation and gathering, so participants could fill these forms out in person. An afternoon staff meeting was organised by the Centre Director to take place two weeks later, two months after the initial forms were presented to the Centre Director. The Director was not able to be present for the final display of data, or the group interview that took place after this presentation, so did not fill out a questionnaire. It is therefore not necessary to further describe the extra questions intended for the director.

At the beginning of the meeting, I greeted staff, thanked them for their time, and gathered signed consent forms from all present 12 staff participants. Two of the attendees had already filled out and sent forms by email, but wanted to see the presentation of data. I then presented research data in a 20-minute electronic presentation, using a projector in the craft room at the disability day centre. After the presentation, staff were presented with the interview protocol sheets, and spent approximately 20 minutes filling these out. After the sheets were collected, staff were thanked and all left the room.

Results and discussion

Analysis of the data gathered from completed protocol sheets revealed a number of attitudes about communication and AAC at the centre. Each section below outlines responses from one of the three questions from the interviews. The responses to further questions, given only to team leaders, are then briefly presented.

Question one

Question one began with:

How would you rate the *usefulness* of communication (AAC) aids for adults with Complex Communication Needs? (1/10 is *no use* and 10/10 is *essential*).

Most participants (ten of the 12) agreed that communication was very useful, and responded with a score of eight out of ten and higher. Their contextual written comments, addressing the next part of question one, “Please describe the reasons for your rating above”, are below:

Basic communication is a must for any person.

Communication is essential.

Everyone has a right to say what they need. Communication is 100% needed.

All clients have the right to communicate.

Two participants responded with a rating of five out of ten for the usefulness of communication. While one of them had no written response to the reason for their rating, the other wrote about their lack of experience, rather than aids being unimportant:

I have found communication aids useful in the instances I have used them. I haven't had opportunities to use them with every client. During program, it isn't always possible to spend the time on them.

Question two

Question two was as follows:

While there seems to be AAC stored in the centre, they seem to be little used, including picture-based cards and individual communication booklets. To what extent would you say this is an accurate representation of the use of these aids in the centre?

Nearly half of the staff (n=5) explicitly agreed that the above statement was accurate, with half of the staff (n=6) not directly answering the question, and one (n=1) stating that the above statement was not accurate. Of the six participants who

did not directly state that the above statement was accurate, five still outlined various reasons for the lack of AAC use without explicitly answering with a yes or no response. Ten of the 12 participants agreed in some way that there was little use of AAC in the disability day centre, with comments such as, “True”, “Fair”, and, “It is accurate”, or with explanations such as:

Some staff will or do not use. (Lazy).

Many staff can’t be bothered or do not see the importance in clients making choices.

The other two participants responded, with one feeling “Ill qualified to comment”, as the “majority of my work is off-site”; one disagreeing, but also writing: “Where are they? Because I don’t know”.

The next part of question two was:

Why do you think this may be the case? Please elaborate.

Three participants declined to comment, but all other participants (n=9), responded with many different reasons for what they believed was a lack of AAC use in the centre. Table 21 breaks down the responses into category. Note that participants listed more than one reason in their response.

Table 21: Participant explanations for lack of AAC use at centre.

Reasons for lack of AAC use in centre	Number of participants (n)
Too time consuming to use	5
Staff Laziness	4
Too costly to produce	2
Too many clients to use aids	1
Lack of training / knowledge in aid use	6

Some of the written comments associated with these responses were as follows:

It is easier for staff if clients don’t make choices - too time consuming and inconvenient.

Staff busy: Too many clients in programs. New staff or staff not understanding the need.

Time, staffing levels, complacency.

Info isn't exchanged between staff.

No knowledge of these aids.

Time restrictions.

Question three

This was a two-part question, with the initial part asking:

Do you know of any AAC aids you don't have access to in the centre? Why aren't these included in the centre at the moment?

Four participants declined to write responses for this question, with the rest of the participants (n=8), offering suggestions for possible new AAC aids, mostly for the use of electronic devices, such as electronic tablets, audio aids, writing machines and speaking programs.

Four participants specifically addressed the second part of the above question, with responses including: "budgets", "cost and time", "inconsistence", and "Hidden, no purpose. Too much to sort through".

The second part of question three was:

Please suggest additional AAC tools you may like to incorporate. What characteristics would you like to see in these aids?

Half of the participants (n=6) declined to comment in this section, with the remaining participants suggesting aids such as "electronic/tablet" and "audio tools".

Characteristics staff would like to see included aids that are "more streamlined" and "more accessible to others, group specific and themed". A more detailed response from one staff participant was:

Sensory-room clients to be given choices by showing them cue cards: e.g. sleeping bag / beanbag vs. chair. Also perhaps audio tools where staff can

record their prompting to the client with their own voice so client is used to the sound.

Extra questions for team leaders

While the previous, three-question protocol was made available to all staff members, a revised version was given to team leaders, who were asked to complete an additional 11 questions. These extra questions related to funding and administrative issues, and were intended to gather more information about the centre and the clients, while these busy participants were gathered together for the presentation and group interview. As these additional questions were only completed by one team leader, an outline of gathered data is now summarised according to topic.

Funding and application:

The team leader noted that clients (or their carers) approach the centre to take part in activities, through word-of-mouth or after seeing some advertising for the centre. To apply for inclusion at the centre, candidates must fill out a form to receive funding from the Department of Human and Health Services (DHHS), through the centre, or by having the funding transferred from previous service providers. Some funding for AAC, for each client, is available through the NECAS scheme (Iacono et al., 2013).

Clients and staff:

The centre does not have a maximum number of clients it can accommodate, but does have to have correct staff/client ratios. Some support is available to help clients, including speech pathology, occupational therapy, general practitioner services, psychology, and some clients do live in shared accommodation and not with their parents. There are rare moments when a client is assessed by a speech pathologist for communication assessments.

7.4.2 Summary of staff interview

Participant responses suggest that communication and AAC is seen as important in the centre, but that accommodations to include aids in daily activities are not taken for a variety of reasons. Staff participants were interested in the thesis data presented to them, but were not presented with results from the IMM, as the model was not developed at that time. Staff reactions to the data presented in this way

could be an extension of this research beyond the thesis, as could their use of the IMM to reflect on their interactions with each other and the clients.

In Figure 51, an IMM result summarises the various forms of communication interference suggested by staff participants in this section, where a lack of training for AAC (ap), and limited time (tn), means that AAC is seldom used (au) at the centre.

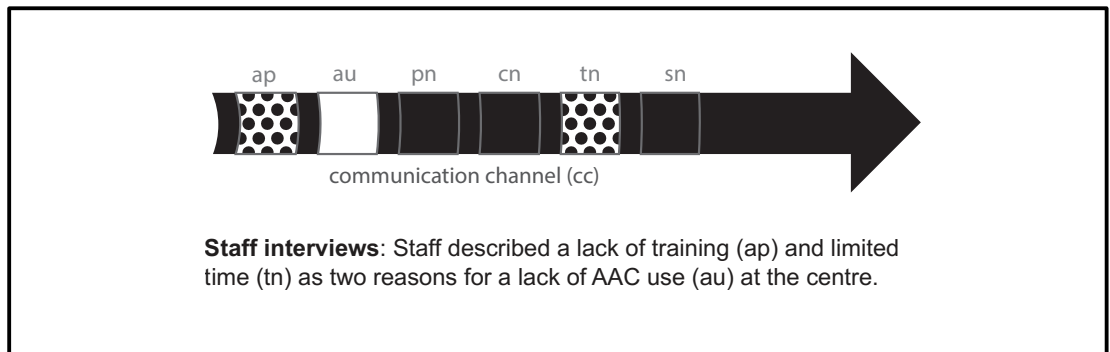


Figure 51: Example of an IMM result for staff interview data.

Chapter 8: General Discussion and Conclusion

8.1 Summary of main findings

This thesis has focused on, noise, specifically on the forms of noise that affect the communication of adults with CCN. The word, noise, comes from the Latin for nausea (Oxford University, 2017), an appropriate word given the myriad of health issues that adults with CCN face in their lives. Use of the IMM then, can be said to be highlighting forms of nausea, in an effort to understand and reduce its effect on these people. Part of this noise is language, which Foucault describes as infused with power, and disabling.

This research extends knowledge about CCN, and AAC. It extends the use and features of existing communication models with the development of the IMM, used to identify and present visually the noise in complex communication.

The results of the empirical studies confirm aspects of the literature review, notably that adults with CCN are vulnerable individuals in our society, and that AAC is problematic. The literature described the former's impairments as varied and debilitating, and their external environment as potentially disabling them further. This disablement is noted as being a historic, and fundamental influence on our society, described in disability studies and communication theories.

As I discussed in chapter 2, despite the complexity and challenges in AAC use, there is consensus in the literature that AAC is beneficial. In that chapter, and in chapter 4, I also discussed the importance of effective personal communication skills. As the empirical studies showed, with very little aided and unaided AAC used at the centre, the impaired participants were not given the opportunity to communicate with AAC support, thus, according to researchers and activists outlined in chapter 3, disabling the clients. While it was not possible to observe the clients' communication ability with AAC use, it was clear that this lack of use denied them the chance to fully express themselves, regardless of ability.

The archival study showed that, while aided AAC aids were stored, they were seldom used at the centre, even though the two interviewed parents believed strongly in the benefits of constant and varied use in their homes. While some aided AAC aids were displayed on walls and doors in the centre, these were never referred to during the course of my research, and the use of the more structured

forms of unaided sign language only infrequently used for a small number of individual words in the observed sessions. This sign language was employed by a client whose mother was interviewed in this research, illustrating that her insistence on teaching AAC methods to this client enabled some use of the method in these instances.

My observations showed that staff reprimanded clients more often in off-site, rather than on-site, activity sessions, and staff initiated communications three times as often as clients. The need to manage client behaviour did support the literature about adults with specific impairments, and the predominance of staff-initiated messages was a further indication of the one-sided nature of communication in a busy environment with little AAC adoption. Foucault's theory about the imbalances of power using language (chapter 3.1.4) is relevant here, but so too is the use of appropriate medicalisation in the care of the clients (chapter 3.3.3). The staff focus groups and group interview revealed many communication challenges, including issues with personal and instructional conversations with clients, and a lack of staff information exchange.

Some of this communication interference can be attributed to participant impairment, where clients struggle with a perception of their personal state or role at the centre. Other results point to a lack of resources, notably time, displayed in the IMM as temporal noise. Some staff did suggest this as a reason for the lack of AAC use, in the group interview. As outlined in chapter 1, staff supervise groups of clients with varied impairments and potential behavioural issues in activities, and they are expected to attend to their clients' needs, including food, personal care, and entertainment.

The idea that time is an overlooked and valuable resource in the AAC process is important. The lack of available time could explain why AAC is seldom used at the centre unlike at home, where busy parents still focus their attention on the one person. Note here that some aided AAC was designed and stored at the centre, indicating that staff participants at least saw the value in the development and existence of these devices.

Staff participants noted that they needed to improve their client-information exchange with other staff, and more time (and staff) to do this could help clients. Other comments made in the group staff interviews alluded to this lack of time as

being a limited resource beyond the confines of the day centre. The low number of visits from busy professionals, who assessed clients' communication abilities, pointed to stretched institutional resources as well. More of these assessments would help to determine appropriate AAC for use by selected clients at the centre. If Foucauldian power imbalances do shape the communication environment at the centre, it is in part caused by the limitations put on centre staff in the control of their resources by government institutions.

The primary way in which staff participants attempted to overcome this lack of resources, was by relying on their knowledge of clients in their communication with them, without using a short-term need for typically time-consuming AAC use. This has been described as redundancy in chapter 4 and the AAC bypass in the IMM. Staff were able to understand the nuances of a client's communication idiosyncrasies from the latter's limited verbal and non-verbal cues, based on these shared experiences. My observations showed that such shared experiences did facilitate some forms of communication, for example, when a client was able to follow instructions or indicated a basic understanding of a message (chapter 7.2.3). Yet, as discussed, it was unclear whether the use of AAC by the client could have enabled them to communicate more effectively about their own wants and needs with unfamiliar partners, and redundancy did limit clients' communication independence away from staff members who knew more about them.

The ability to describe the interference caused by this lack of resources, and the effects of shared knowledge, are made easier with the use of the IMM: part of the contribution of this thesis. This novel, physical, diagnostic tool, was developed from a synthesis and extension of the existing communication-theoretical literature, my knowledge of design, and other insights gained during the process of writing this thesis.

As well as extending knowledge of both the disability and communication fields, the IMM serves to fill a need exposed by gaps in the existing literature. If AAC is seen as beneficial, and subsequently not used, then we need a way to describe the challenges of communication by, and the environment of adults with CCN living in this vacuum of AAC use. As applied research, the IMM provides an interactive, practical application for this, providing a simple way of identifying noise in communication at various stages, and the typical way in which communication

partners sometimes rely on shared experiences rather than therapeutic communication aids. Figure 52 shows a summary of IMM results from the various studies outlined in this thesis.

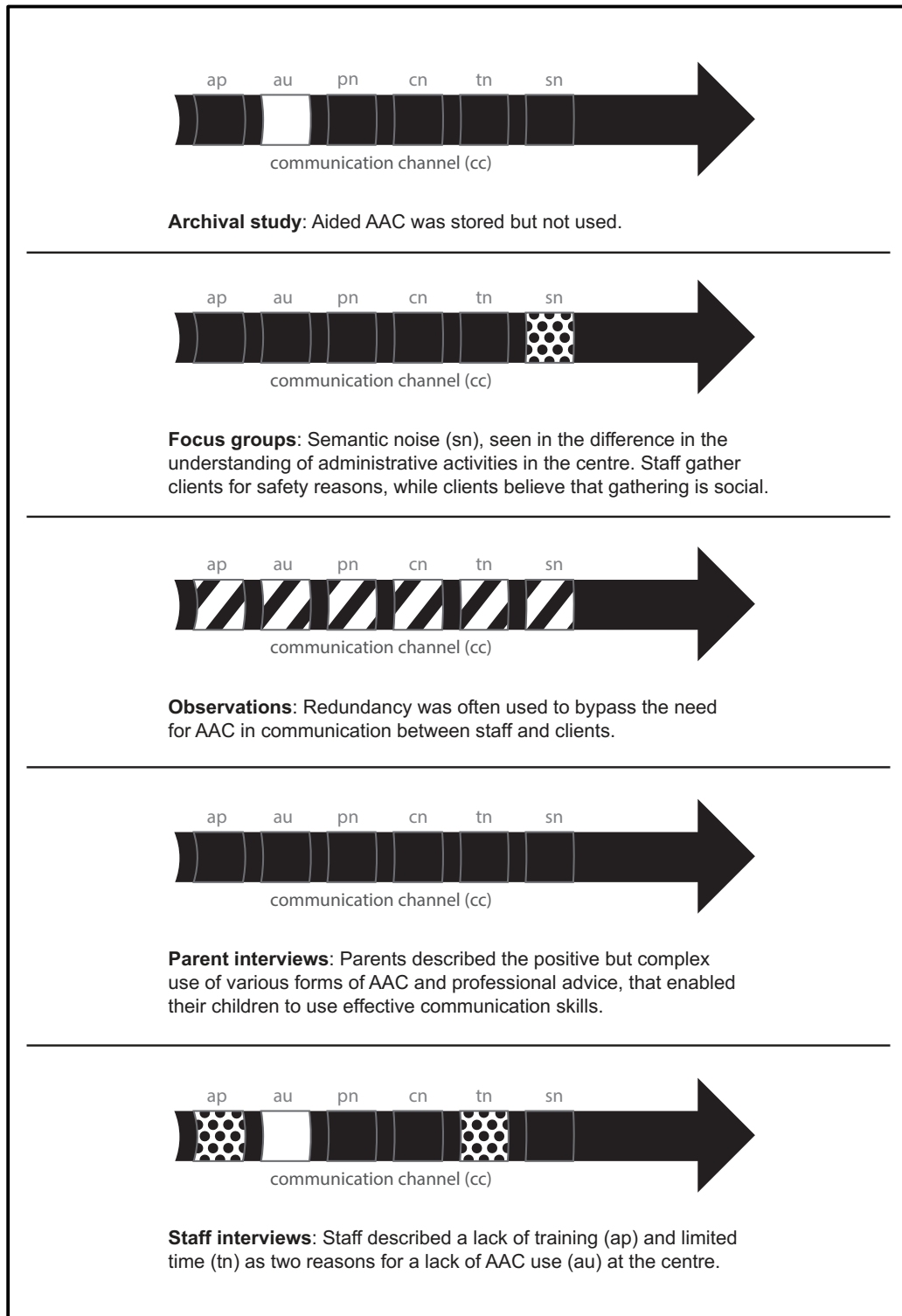


Figure 52: Summary of IMM result examples from empirical research chapter.

8.2 Theoretical implications

As well as adding to knowledge about adults with CCN, this thesis provides a modern application for and extension of Marxist and Foucauldian theory, in descriptions about power imbalances. Discussions in the literature point out that appropriate use of AAC methods can be beneficial, and the external nature of disablement is distinct from a person's impairment. So, while AAC methods can be complex and problematic, but useful, denying that use for adults with CCN can be considered disabling and oppressive.

The analysis of the environment at the disability day centre also provides a new perspective on one communication theory in particular: Muted Group Theory. While this theory has in the past detailed the plight of minority groups, it has not specifically described adults with CCN. The word, muted, here is particularly relevant for them, used in the past to describe a metaphorical muting of the opinions and inclusion of some groups. As suggested in this thesis, with CCN adults, this muting refers more literally to the potential cessation of their communication entirely.

This muting is evident in the design of the IMM. In addition to the difficulties the message sender has with internal challenges/noise, other potential forms of interference are present. Any of these forms could mute the sender (represented with the introduction of white graphic areas into the black communication channel in the IMM), from their inappropriate preparation and use of AAC, to the types of noise present in their environment or with other communication partners.

8.3 Future work

As the research in this thesis investigates communication in one disability day centre, the addition of more centres to the research could determine whether the activities in the existing centre are typical. The inclusion of more participants would also be beneficial. For example, if direct contact could be made with clients, instead of with other participants on their behalf, client perspectives could be included. Additional parent involvement could determine if the opinions of the two mothers in this thesis were also typical.

With regard to empirical methods, ethics arrangements limited the use of some data gathering techniques in this thesis, so, for example, the future use of video recording

could provide more substantial information about communication exchange, especially with the non-verbal communication of participants.

In relation to design, further development of the IMM would be prudent, with the use of additional aspects of the Interactive Design process, and the involvement of IMM users. Furthermore, the current model shows general, simplified communication interference, with no further detail in that information noting whether this is from a certain environment, or message receiver. More design iteration could enable different or more information to be gathered from the model. Different colours could be used to highlight various parts of the tool, and user instructions could be added to help with operation.

Other possibilities exist, including experimentation with physical materials and software development for the model's construction. Physical materials would influence the efficiency of the interactive components and the clarity of visual elements. Other designs may have potential for further development, including the previous rod/tube design shown in Figure 13, and the mocked-up, rectangular design shown in Figure 16. Digital software, such as a mobile application for a tablet, could provide opportunities to expand the interactive nature of, and information displayed in the model.

While the IMM was used throughout this thesis to offer simple, alternative analyses of results, the model was not user-tested. One such test could offer a comparison of its diagnostic capabilities with analyses of real communication, audio or video recording staff/client interactions for that purpose. This analysis could provide information to researchers about the challenges in communication environments, enabling a clearer understanding of where the breakdowns occur in complex communication. In turn, government departments, and policy-makers could be given a visual report showing the impact of these communication challenges on impaired, and disabled individuals.

The aim of the research in this thesis was to investigate communication breakdowns among adults with CCN. As part of this aim, the following three questions were posed that the research sought to address. Firstly, why are AAC aids and techniques seldom used in the disability day centre? Secondly, what communication challenges exist in that environment of limited AAC use? Finally, can a designed

artefact be used to identify and simply describe communication breakdowns in these complex CCN environments?

Each of these questions have been addressed in turn. For the first question, the research in this thesis supports the reviewed literature: AAC is complex and problematic, CCN users of such devices have a myriad of impairments and needs, and resources to appropriately provide and support AAC for people with CCN are lacking. For the second question, the literature and empirical studies have identified and corroborated various communication challenges, brought about by a mixture of internal and external forces, described in various degrees of separation as impairment and disablement.

I have designed and presented a solution to the problem posed by the third question, developed as a synthesis of information presented in the thesis. This physical, interactive artefact, the IMM, can be used to identify and describe communication breakdowns, or noise, using visual clues to simplify aspects of these dynamic, complex environments.

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Appendices

Appendix 1: Ethics clearance

Ethics final report

Dear Deirdre Barron,

Re: Final Report for the project (Report Date: 18-03-2016)

2013/147 'Communicating with pictures: designing meaningful images for adults with complex communication needs'

The Final report for the above project (Report Date: 18-03-2016) has been processed and satisfies the reporting requirements set under the terms of ethics clearance.

Research Ethics Team

Swinburne Research (H68)
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Ethics modifications and extensions

From: Keith Wilkins on behalf of RES Ethics
Sent: Tuesday, 2 February 2016 4:59 PM
To: Deirdre Barron; Shaun Britton
Cc: Darren Tofts; Gitte Lindgaard; RES Ethics
Subject: SUHREC Project 2013/147 Ethics Clearance for Modifications/Extensions (4)

To: Assoc Prof Deirdre Barron/Mr Shaun Britton, FHAD

Dear Deirdre and Shaun

SUHREC Project 2013/147 Communicating with pictures: designing meaningful images for adults with complex communication needs

Assoc Prof Deirdre Barron, FHAD; Mr Shaun Britton et al

Approved Duration Extended to: 31/03/2016.

Modifications/Extensions: June 2014, November 2014, September 2015, February 2016.

I refer to your request for further modification to the above project protocol and an extension of ethics clearance. The request documentation as emailed today, re change in supervision and additional participation and consent arrangements, was put to a SUHREC delegate for consideration.

I am pleased to advise that, as modified to date, the project may continue to end of March 2016 in line with standard ethics clearance conditions previously communicated and reprinted below.

Please contact the Research Ethics Office if you have any queries about on-going ethics clearance, citing the project number. A copy of this email should be retained as part of project record-keeping.

As before, best wishes for the project.

Yours sincerely

Keith

Keith Wilkins
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Appendix 2: Project information statement and consent

Project Information Statement

Project Title:

Communicating with pictures: Designing meaningful images for adults with complex communication needs.

Investigators: Dr. Darren Tofts, Dr. David Austin, Mr. Shaun Britton

Principal Investigator:

Dr. Darren Tofts (xxxx@swin.edu.au)

To:

Research participants, including staff at xxxx centre, the guardians & families of clients, and clients at the centre.

Project Summary:

This research project is a collaboration between xxxx and Swinburne University of Technology. The research will investigate the use of Augmentative and Alternative Communication (AAC) aids by adults with an impairment. These aids include any communication materials used in the xxxx day-centre, such as activity schedules, shopping lists, timetables, safety signs and the individual communication pictures in symbol sets.

Your Involvement:

Data will be gathered in a number of ways.

- Initially, **documentation** of the existing AAC at the xxxx centre will take place. The documentation will be in the form of note-taking and photography of signage and symbol-sets. We may need some assistance from staff to help direct us to that material or to document any individual communication aids that currently exist. This will take no more than 10 minutes. Please note that no photographs of any participants will be taken.

In addition, we are conducting:

- Focus groups, with staff and family members / guardians**, as a means of understanding the communication needs of clients and staff. Possible follow-up interviews, with questions of clarification, may be necessary.
- Observation** of staff and clients during their day-to-day activities. This will involve a researcher quietly observing and taking written notes about the communication interactions between staff members and clients.

Focus groups will consist of:

- Preparation for the focus group, where participants will be invited to identify and note down the kinds of communication problems they have experienced in their interaction with clients at the centre and elsewhere. This covers both client-initiated and staff-initiated communications. Family / guardians of clients at the centre will be asked independently to do the same in preparation for their focus group.
- Separate focus groups, run for staff and for family members / guardians, expected to take one hour and involve 5 to 10 participants each time. Participants will be asked to attend one focus group. If the number of participants signing up for participation in the focus group exceeds 10, we will conduct a second focus group.

- Possible follow-up interviews:

One individual interview per participant, expected to take no more than 30 minutes.

We will request your permission to audio record each session. As a result of this research, we will be creating communication interventions for the centre that may facilitate communication and increase the well-being and engagement of your clients/family members.

Observation will consist of:

- The observation of staff members working with their key clients. Observation will involve a researcher sitting away from the participants, writing notes about certain aspects of the communication between the participants. Each observation will be up to 30 minutes. Breaks will be taken between observations.

We will request your permission to take notes during these sessions.

Data Usage and Confidentiality:

All audio-recorded data will be stored on password-protected computers and in locked cabinets at Swinburne University, only accessible to the researchers. During the data analysis, the researchers will remove all data that could identify a participant. Photographs will only be published with the participants' explicit consent. Once the project is complete, all data and analyses will be retained in a location requiring password authentication – at least five years from date of the last publication, and can only be accessed by the investigators. After this period data will be destroyed using confidential waste disposal techniques. The researcher will delete any data remaining on data collection devices. Some de-identified data may be retained for possible re-analysis or inclusion in meta-analyses.

Collected project consent forms will be stored securely in an alternative location to data collected from observations and interviews. Only the above named investigators will have access to the secured consent forms.

Privacy Protection:

The information collected in this project will be treated as confidential and used for research purposes only. We will present the results of the study at conferences and publish the findings in academic journals. No individual person will be identifiable in research reports. We will use code names for participants in all written work and public presentations.

Voluntary Participation:

We do not expect any risks to participants. However, participants may withdraw their consent to participate and discontinue participation at any time. If you feel uneasy and wish to terminate your involvement you should feel free to withdraw consent at any time and no further questions will be asked. If you are happy to proceed we will be asking you to sign an Informed Consent Form before conducting the focus groups, interviews and observation...

Thank you for reading this and for your participation.

Further Information about the project:

Any questions regarding the project entitled *Communicating through pictures: Designing meaningful images for adults with complex communication needs* can be directed to the Chief Investigator: Darren Tofts, Faculty of Health, Arts and Design, Swinburne University. Contact: xxxx

This project (SUHREC Project 2013/147) has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the conduct of this project, you can contact: xxxx.

Consent form: Focus groups

Informed Consent Form (Focus groups)

Swinburne University of Technology. Faculty of Health, Art & Design

Project Title:

Communicating with pictures: Designing meaningful images for adults with Complex Communication Needs.

Investigators:

Dr Darren Tofts, Mr Shaun Britton

Principal Investigator:

Darren Tofts (xxxx@swin.edu.au)

1. I consent to participate in the project named above. I have been provided with a copy of the project information statement and this consent form and any questions I have asked have been answered to my satisfaction.

2. ***Please circle your response to the following:***

- | | | |
|--|------------|-----------|
| ▪ I agree to take part in a focus group | Yes | No |
| ▪ I agree to provide follow-up information if needed | Yes | No |
| ▪ I agree to allow the focus group/follow-up session to be audio recorded. | Yes | No |

3. I acknowledge that:

- (a) my participation is voluntary and that I am free to withdraw from the project at any time without explanation;
- (b) the project is for the purpose of research and not for profit;
- (c) any identifiable information about me which is gathered in the course of and as the result of my participating in this project will be (i) collected and retained for the purpose of this project and (ii) accessed and analysed by the researcher(s) for the purpose of conducting this project;
- (d) my anonymity is preserved and I will not be identifiable in publications.

By signing this document I agree to participate in this project.

Name of Participant: **Signature:**

Date..... dd/mm/yyyy

Variations to consent according to study

Observations (For neurotypical participants)

Please circle your response to the following:

- | | | |
|---|------------|-----------|
| ▪ I agree to take part in an observation study | Yes | No |
| ▪ I agree to provide follow-up information if needed | Yes | No |
| ▪ I agree to allow the observation to be recorded as written notes. | Yes | No |

Observations (On behalf of clients by Centre Director)

1. I consent to the centre clients to participate in the observation research as part of the project named above. (This consent is given based on the National Statement on Ethical Conduct in Human Research document, Chapter 4.5.) I have been provided a copy of the project consent information statement to which this consent form relates and any questions I have asked have been answered to my satisfaction.

2. ***Please circle your response to the following:***

- | | | |
|--|------------|-----------|
| ▪ I agree that the clients can take part in an observation study | Yes | No |
| ▪ I agree to allow the observation to be recorded as written notes. | Yes | No |
| ▪ I agree to make myself available for further information if required | Yes | No |

3. I acknowledge that:

- (a) the Swinburne project is for the purpose of research and not for profit;
- (b) any identifiable information gathered in the course of and as the result of my/our dependent participating in this project will be (i) collected and retained for the purpose of this project and (ii) accessed and analysed by the researcher(s) for the purpose of conducting this project;
- (c) the client's anonymity is preserved and they will not be identified in publications or otherwise without my express written consent.

Parent/staff interviews

Please circle your response to the following:

- | | | |
|--|------------|-----------|
| ▪ I agree to take part in an interview (telephone/email/face-to-face) | Yes | No |
| ▪ I agree to provide follow-up information if needed | Yes | No |
| ▪ I agree to allow the interview to be recorded by audio/written notes | Yes | No |

Appendix 3: Staff interview protocol

Protocol for staff

Purpose of the interview:

The purpose of this interview is to gather data from staff about communication patterns and the use of communication aids in the centre, as well as document comments and clarification about research findings so far. To this point, the following research has been conducted with participants at the centre:

- Documentation of current communication aids
- Focus groups for staff
- Observations of staff and clients
- Interviews with parents

As outlined in the Project Information Statement, this interview should take no more than 30 minutes. Thank you for your time today.

Communication:

1. How would you rate the usefulness of communication (AAC) aids for adults with complex communication needs? (Please place an x in one box: 1 is no use and 10 is essential).

1 2 3 4 5 6 7 8 9 10

Please describe the reasons for your rating above.

2. While there seems to be AAC stored in the centre, there seems to be little used, including picture-based cards and individual communication booklets. To what extent would you say this is an accurate representation of the use of these aids in the centre?

Why do you think this may be the case? Please elaborate.

3. Do you know of any AAC aids you don't have access to in the centre? Why aren't these included in the centre at the moment?

Please suggest additional AAC tools you may like to incorporate. What characteristics would you like to see in these aids?

Additional questions in protocol for centre management

Client funding and support:

4. How are clients chosen to attend the centre? How do they apply?
5. Do you have a maximum number of clients you can safely accommodate at the centre?
How many is that please?
6. What sort of funding exists to supply AAC aids to client? Please elaborate.
7. What sort of funding exists to support client attendance at institutions such as the disability day centre?
8. What sort of support do clients receive from external agencies?
9. How often does DHS do assessments and visit clients? Please put an x in one box.

Weekly Monthly Annually Other

If 'other', please outline.

Appendix 4: Change of thesis title

09 June 2017

To: Shaun Britton

Student ID: xxxx

Dear Shaun,

Subject: Change of thesis title

I am writing to advise you that your application to change the title of your thesis was approved in accordance with the provision of the Research Training Statement of Practice.

The approved new title is, as requested:

A diagnostic tool for the identification of noise in Augmentative and Alternative Communication: A case study about adults with Complex Communication Needs.

The previous title was:

Communicating with pictures: Designing meaningful images for adults with Complex Communication Needs.

Yours sincerely

Graduate Studies

Swinburne Research

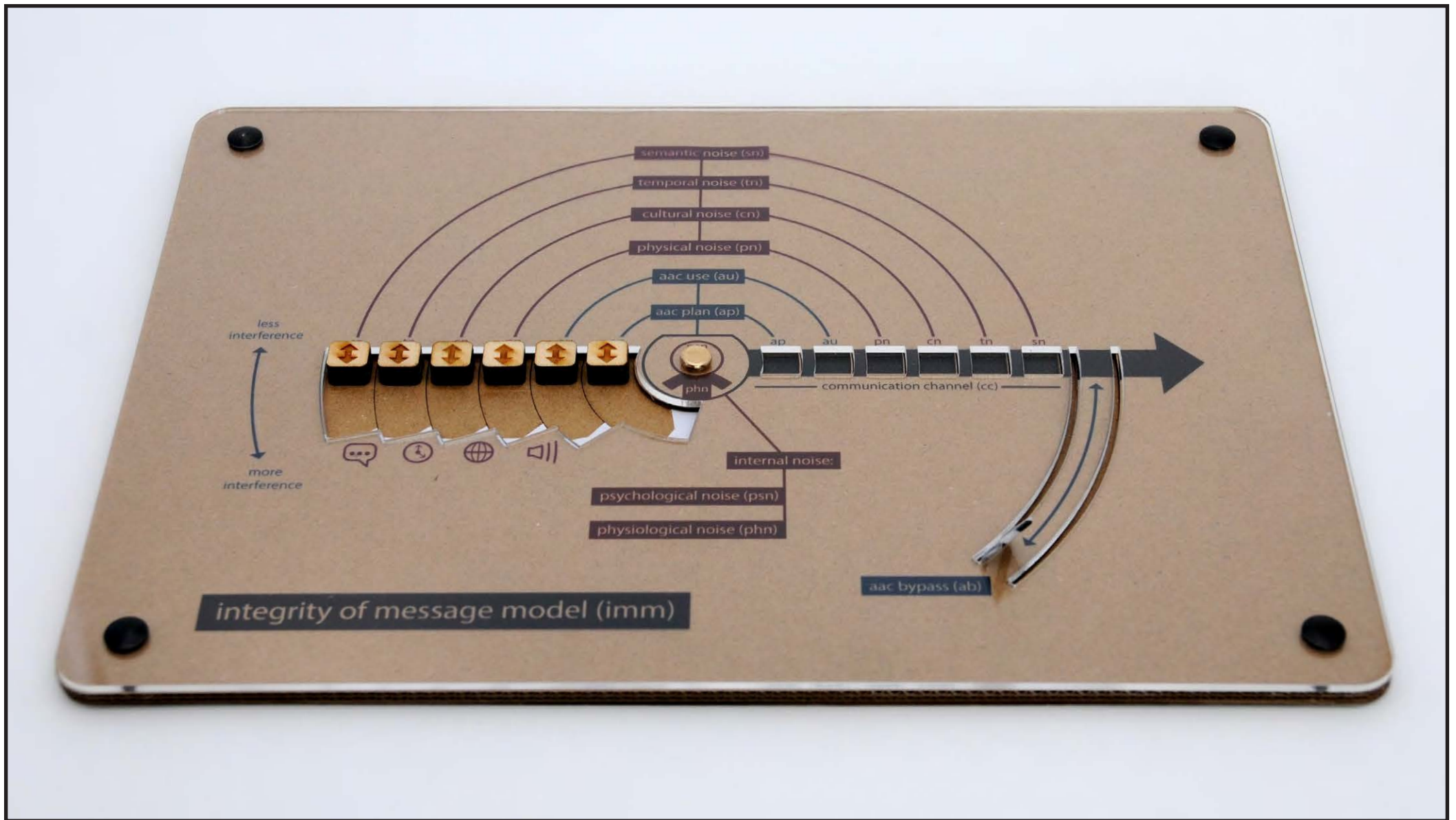
Swinburne University of Technology

Tel +61 3 9214 3886

Email: HDR@swin.edu.au

Appendix 5: Further documentation of the IMM physical prototype

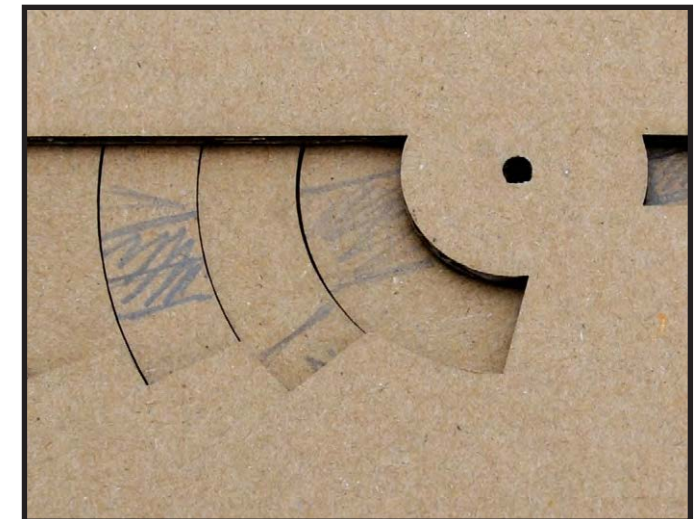
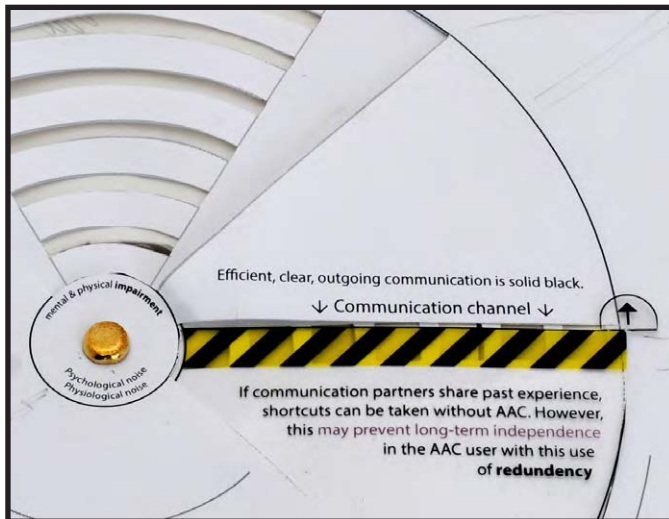
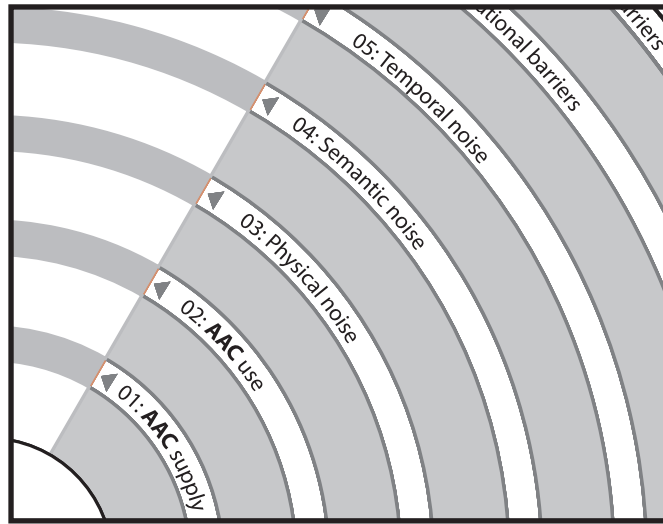
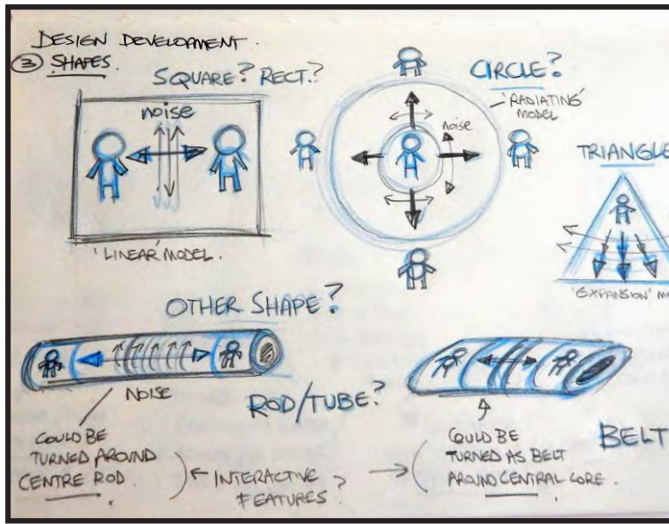
Please see the supplementary photographic record in the attached document.



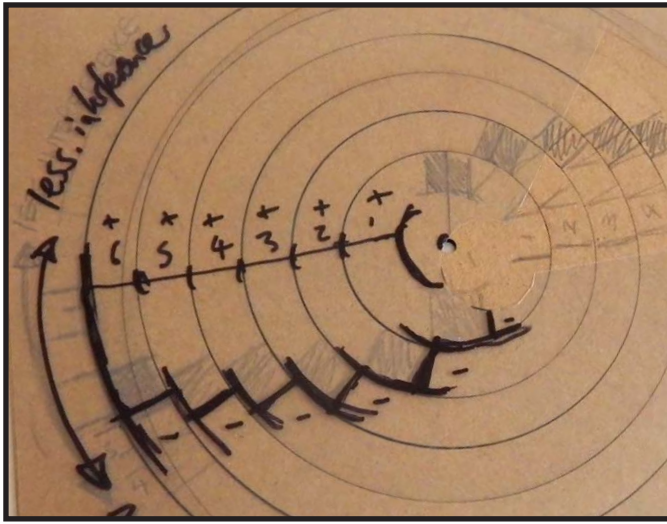
Appendix 5: Integrity of Message Model (Physical prototype).

Contents

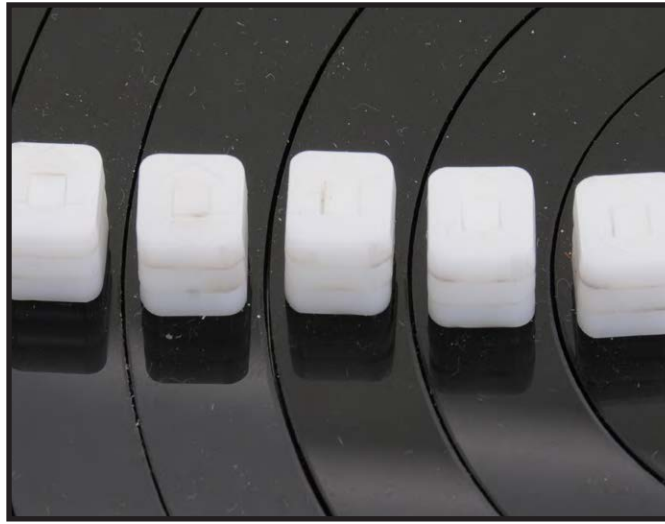
1. Design process: Idea to prototype.
2. Design process: Refinement of prototype.
3. Materials used in design process.
4. Body-shape experimentation.
5. Handle/layer experimentation.
6. Information experimentation.
7. Overview of model.
8. Construction process.
9. Handle operation.
10. AAC bypass operation.



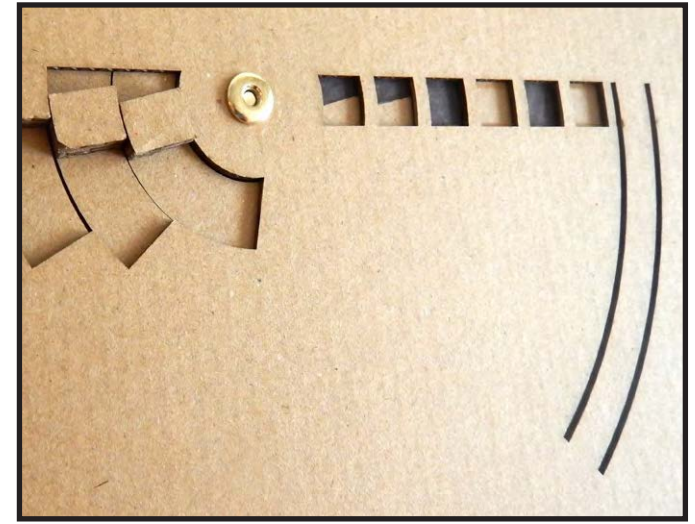
Design process: Idea to prototype.



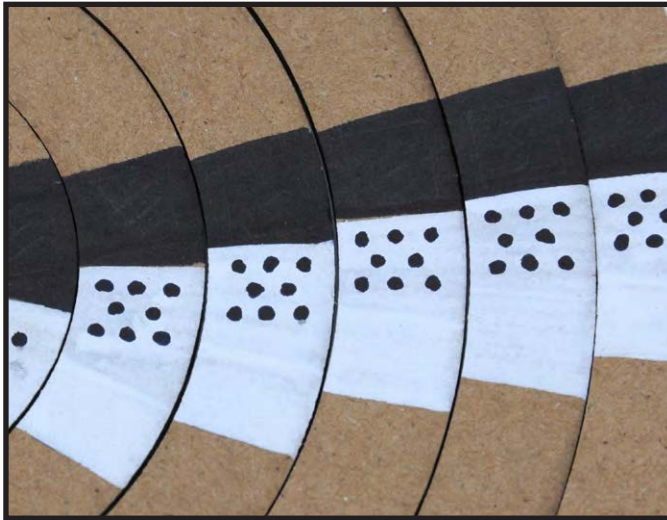
7. Iterative design over laser-cut prototype.



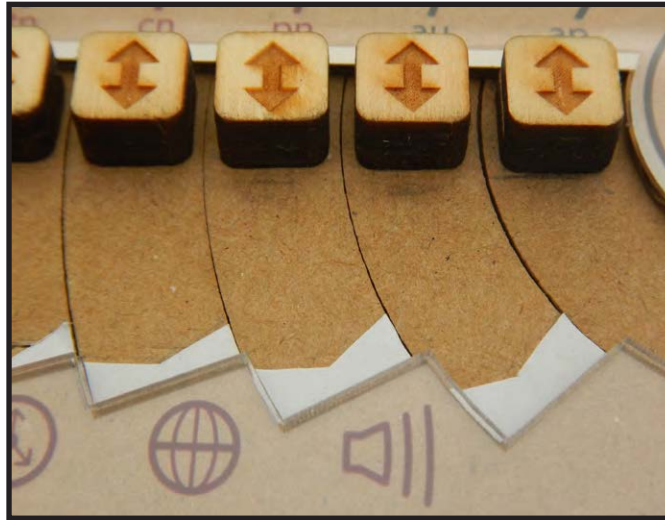
8. Experiments with laser-cut materials.



9. Refining final body of model.



10. Experimenting with model features.

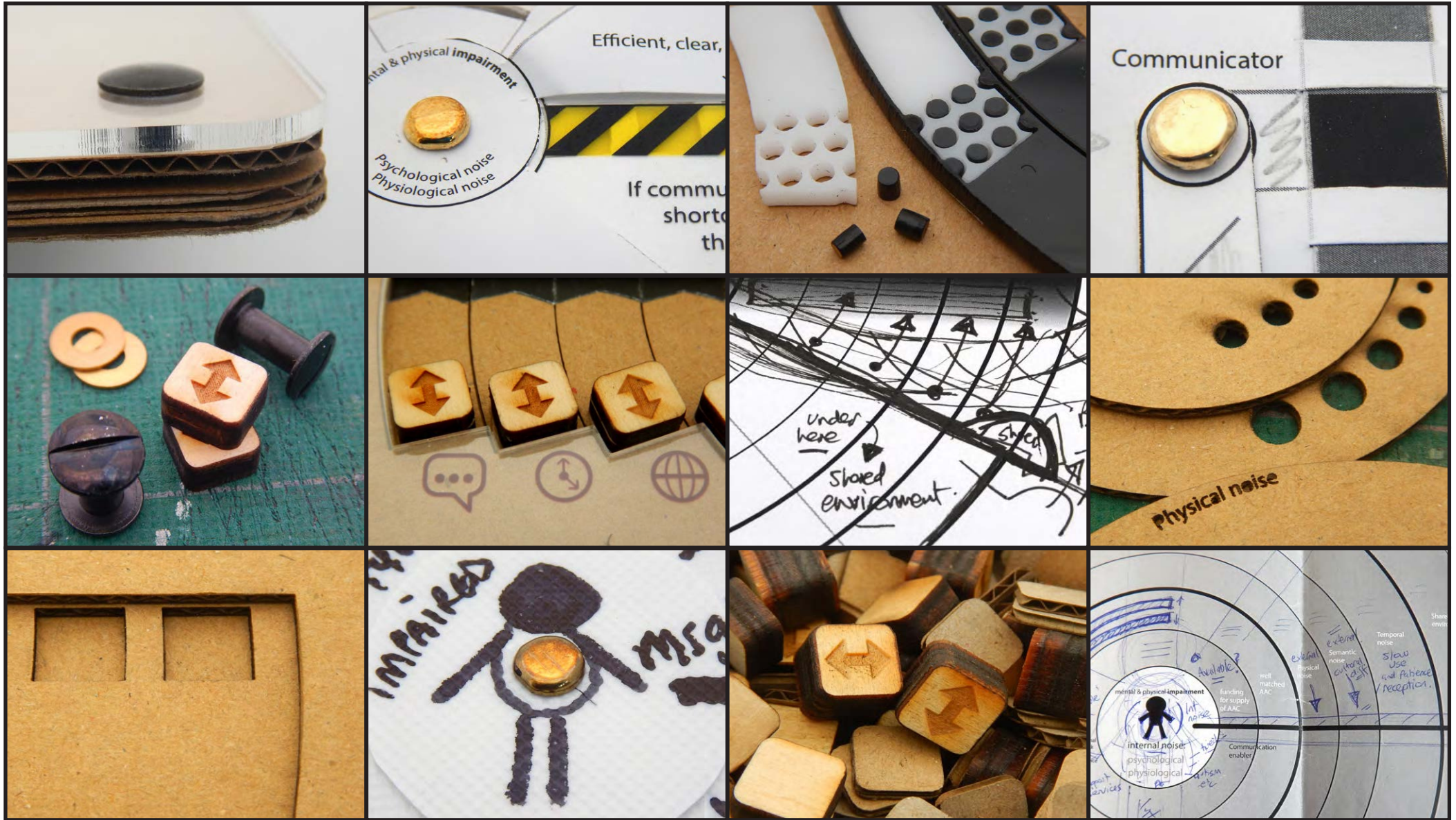


11. Finalising model details.

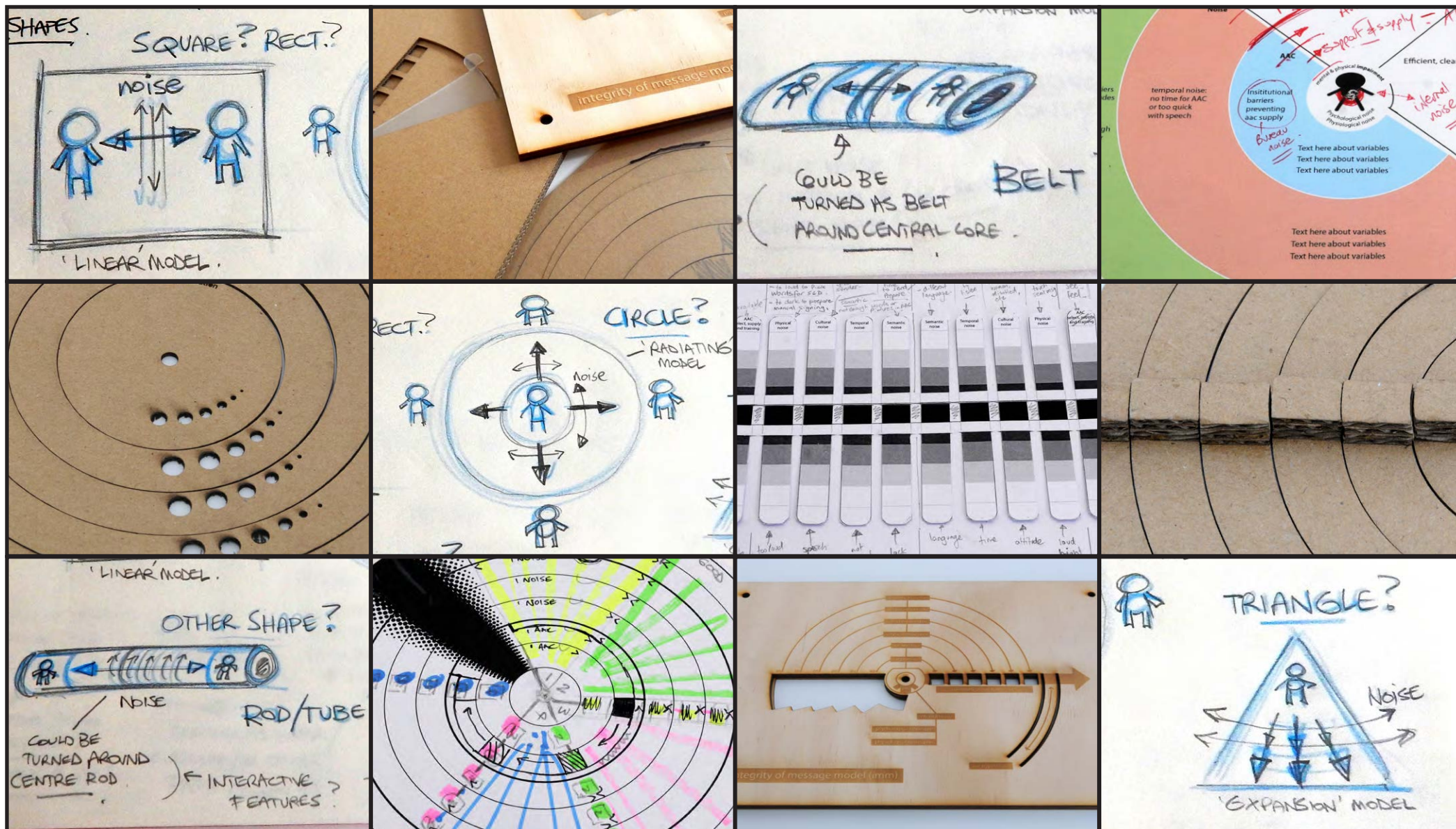


12. Manufacture of multiple models.

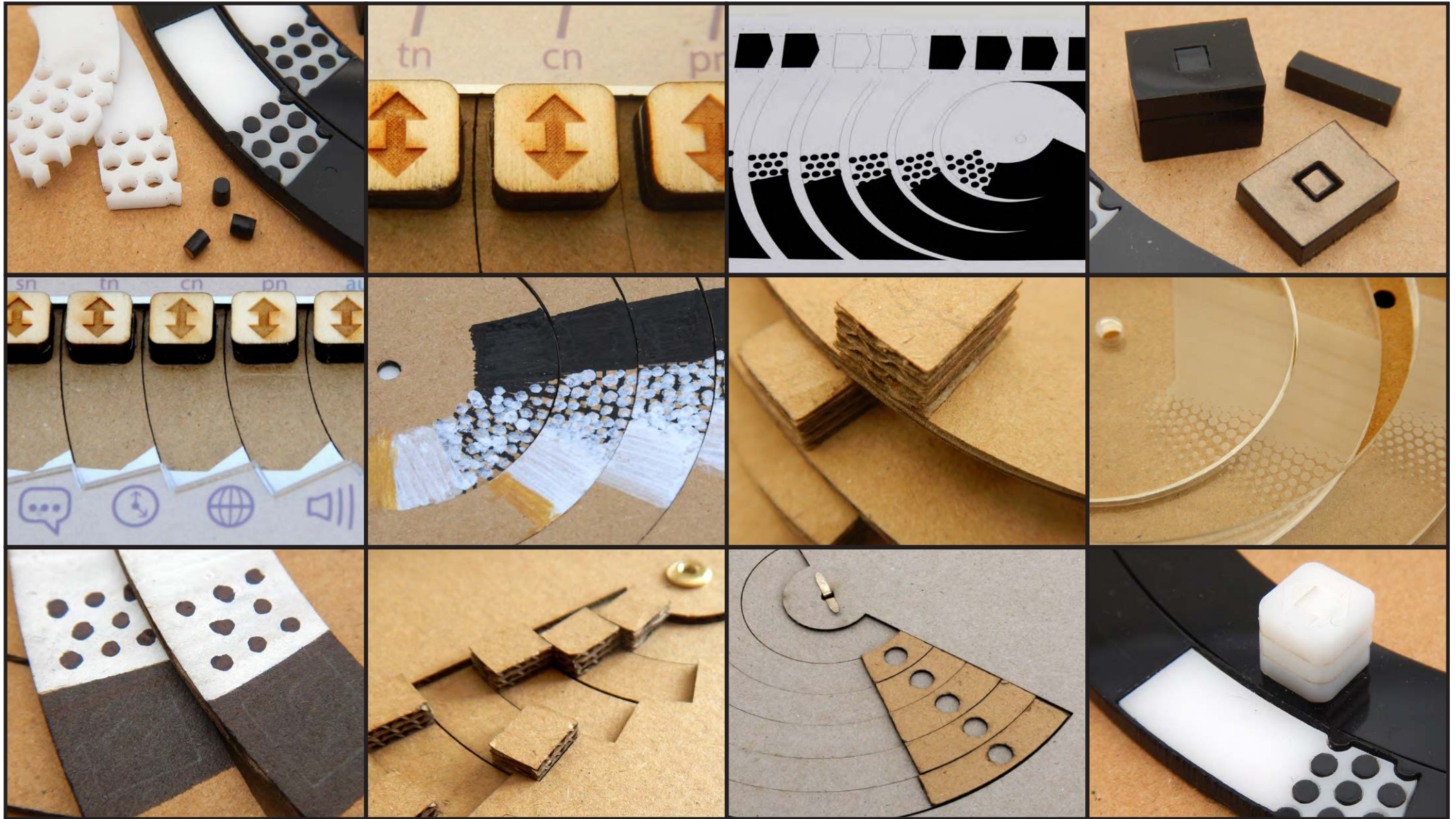
Design process: Refinement of prototype.



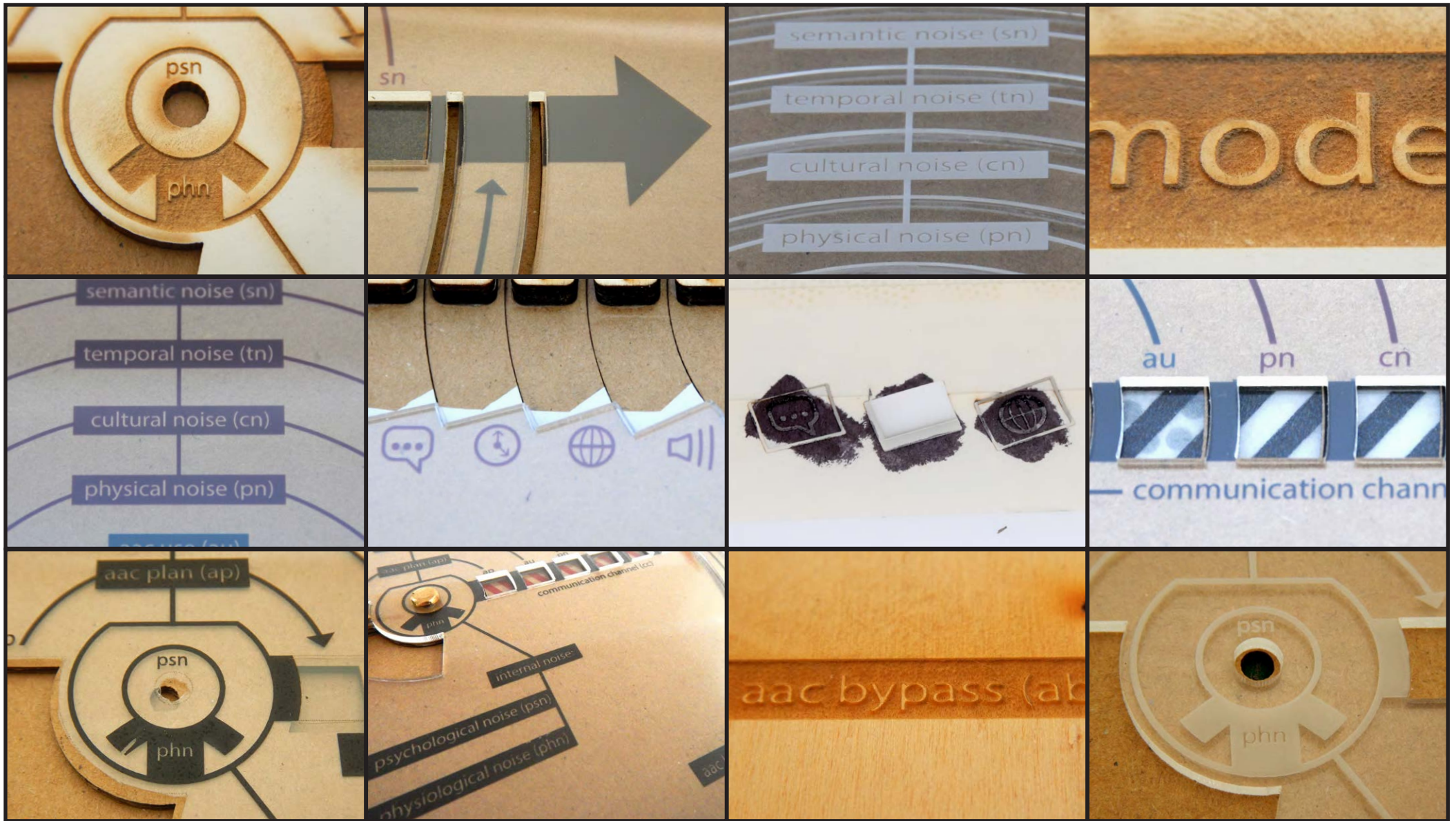
Materials used in design process. Paper, cardboard, acrylic, plastic, timber, fasteners, washers, tape.



Body-shape experimentation: Square, circle, triangle, tube, and belt-shaped design ideas.

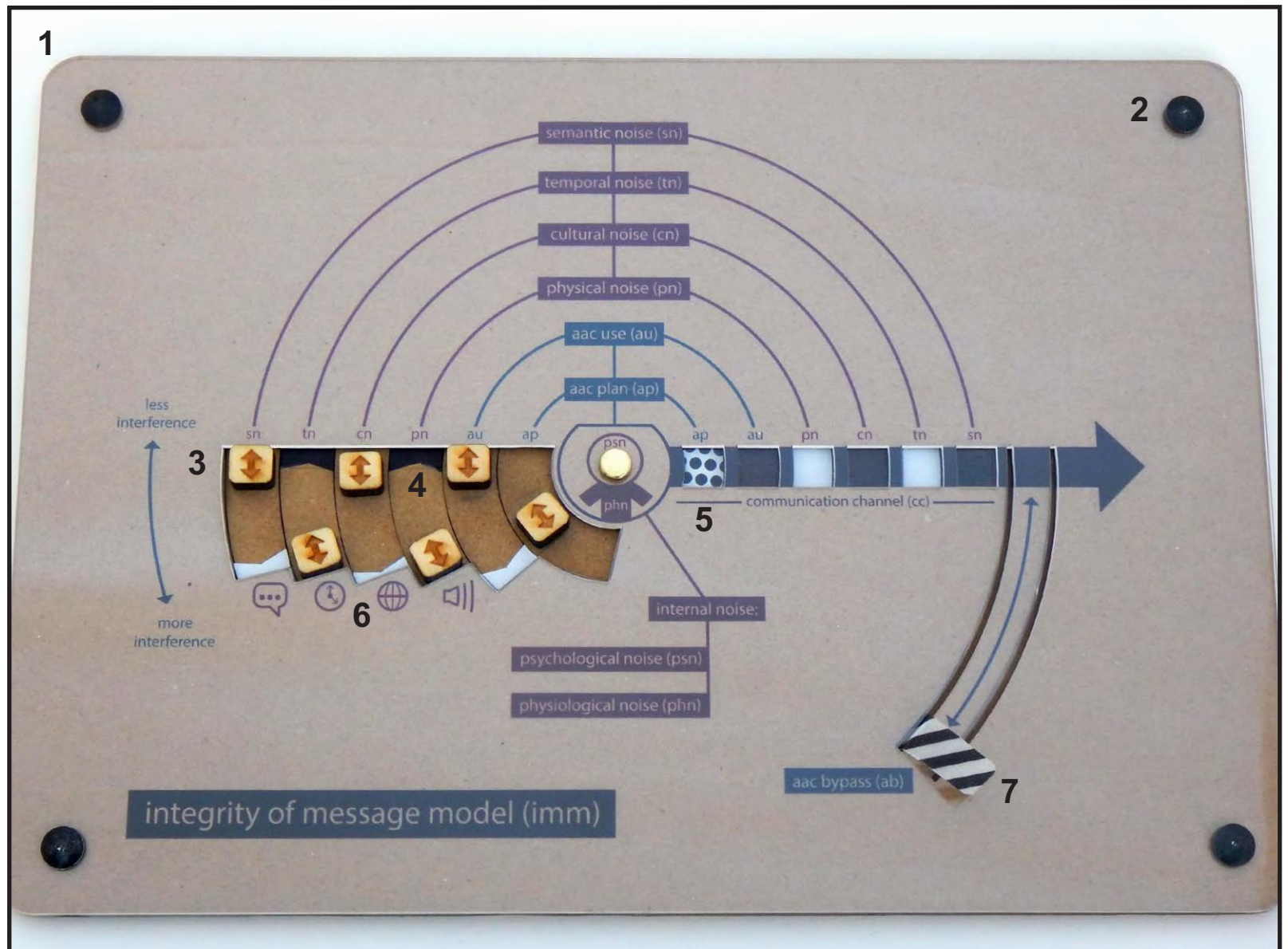


Handle/layer experimentation. Layers: Cardboard, acrylic, timber. Detailing: Inserted acrylic, paint, stickers.

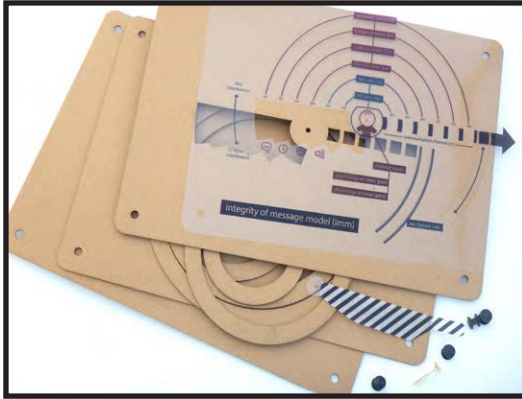


Information experimentation. Details added with embossed acrylic, card, timber, or inserted printed plastic.

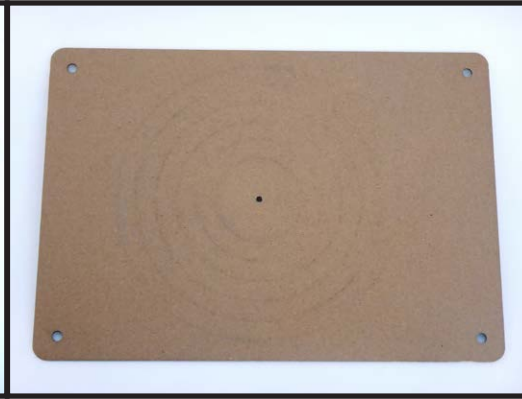
1. Model has curved corners and uses lightweight materials for ease of use
2. Metal fasteners hold the various parts of the model together
3. Timber handles used to manipulate graphic areas of communication channel
4. Black and white arrow stickers show where to position handles
5. Windows cut through cardboard and acrylic allow results to show as halftone or solid colour
6. Icons display alternative, graphic descriptions of layers
7. AAC bypass handle allows the bypass to be positioned in front of the channel



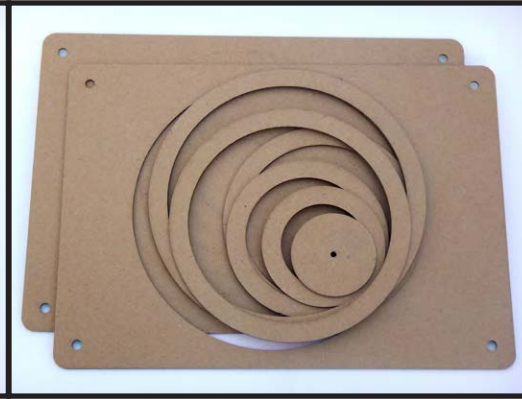
Overview of model.



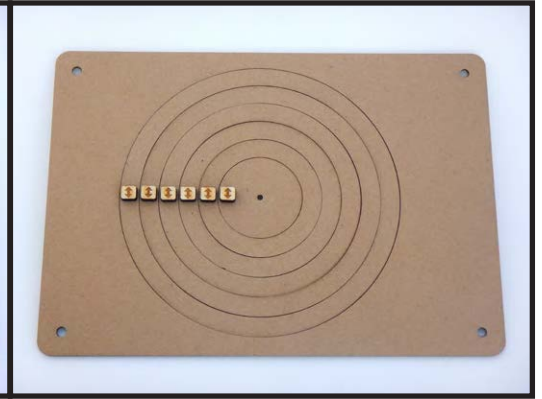
1. Gather pieces together.



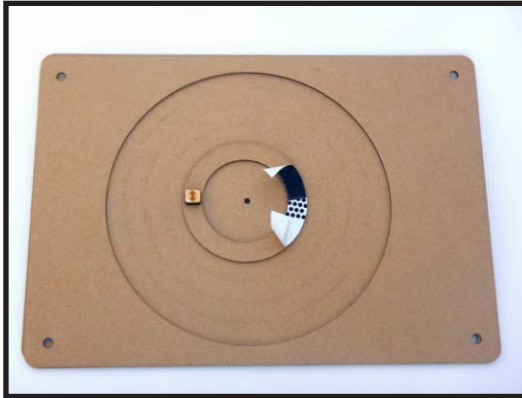
2. Start with back plate.



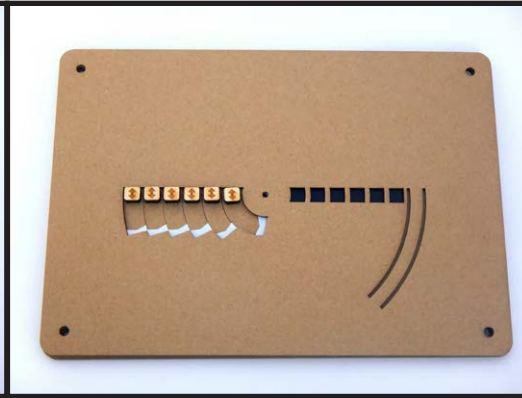
3. Add layer frame and layers.



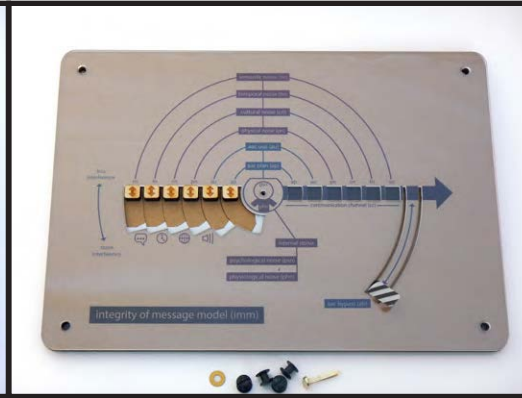
4. Add handles to layers.



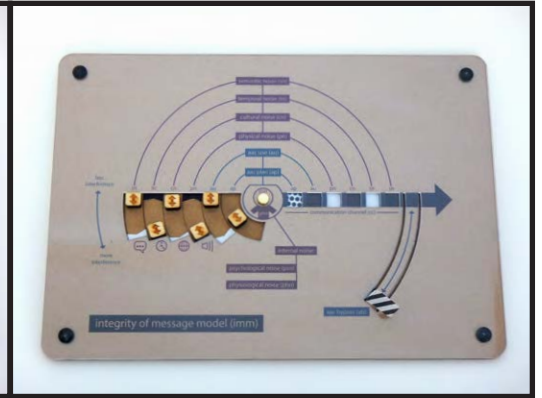
5. Apply stickers to layers.



6. Add top plate.

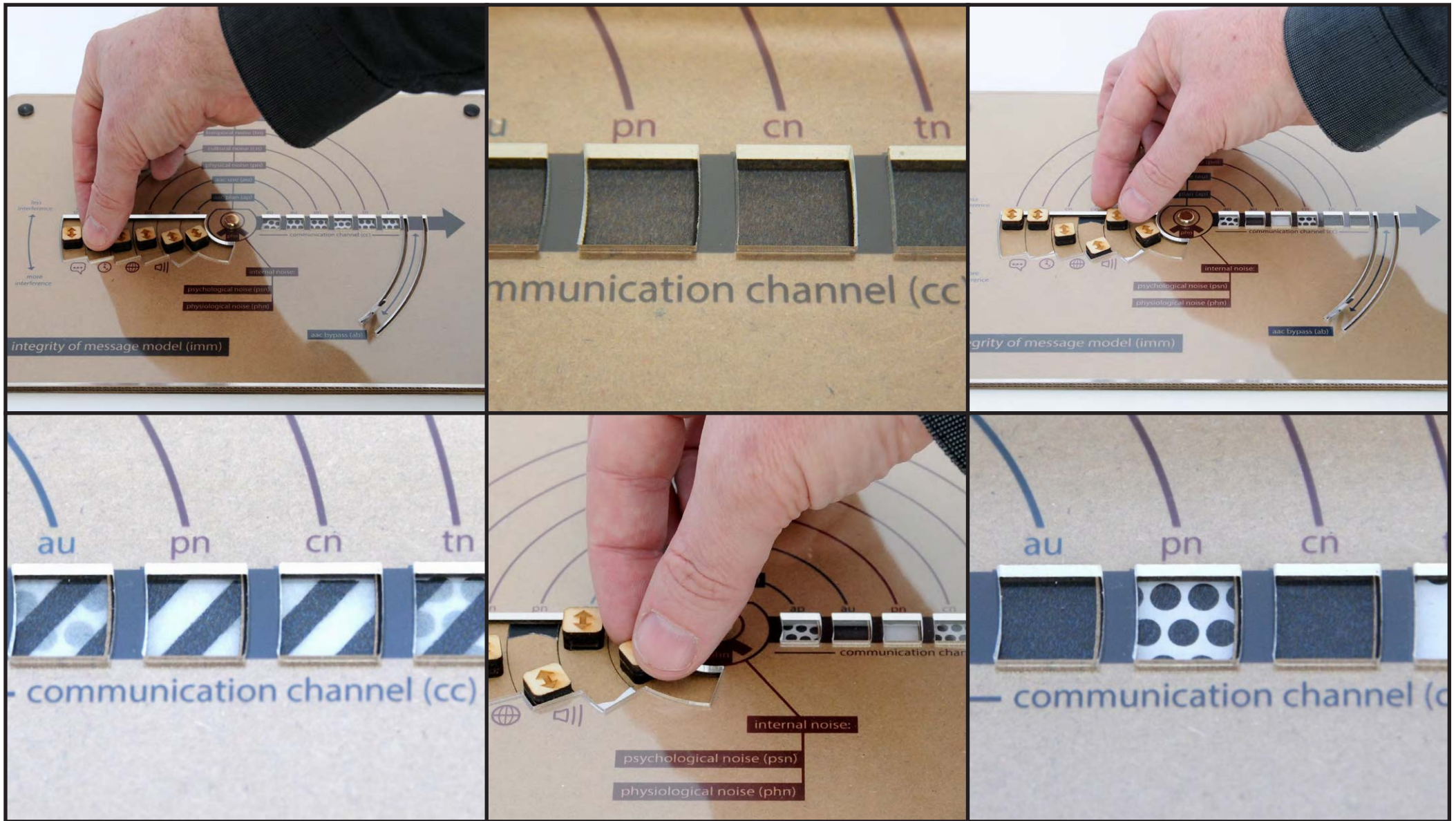


7. Add plastic, acrylic front, bypass.

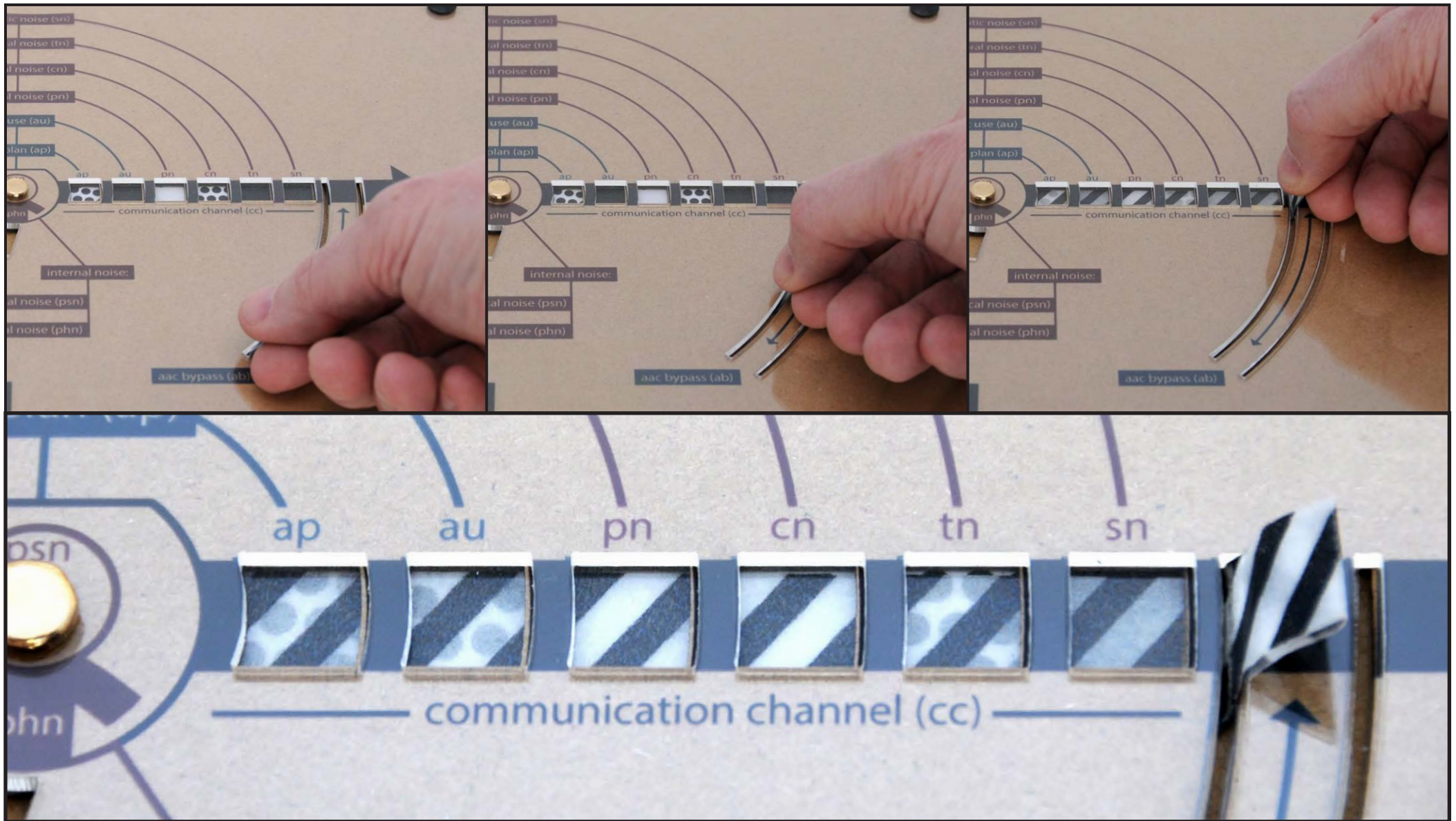


8. Fasten pieces together.

Construction process.



Handle operation. Handles manipulated to affect noise in communication channel.



AAC bypass operation. AAC bypass handle manipulated to cover communication channel.

