

# Research Papers in Communication and Swallowing Disorders.



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The papers collected in this volume were submitted for their dissertation project by students graduating from the BSc (Hons) Speech and Language Therapy in 2016.

## Psychosocial impact of cochlear implant on young children: a literature review

Laura Ford, project supervisor Adam Brown

### Abstract

**Introduction:** Hearing is critical to child development and social functioning. Cochlear implants enable some deaf children to regain access to their hearing environment and consequently achieve great benefits in relation to speech perception and language development. However there is little research that investigates the social and psychological development of these children.

**Aim:** The purpose of this review is to examine and evaluate existing literature to investigate the psychosocial impacts of younger children wearing a cochlear implant.

**Methods:** The databases CINAHL plus, Scopus and Google Scholar were searched using primary and secondary search terms as well as relevant references of papers that met the inclusion criteria. Inclusion criteria for articles were: (1) Content which addressed self-esteem or social development (2) Papers from between the years 2000 and 2015 (3) Children aged 4-12 with a cochlear implant (4) Full text available in English (5) Children with no additional or known neurological, autism, cognitive deficit or learning difficulties. Eight studies satisfied all criteria and were evaluated.

**Findings:** Three main themes emerged from the literature: (1) Communication mode, (2) Age and age at implantation and (3) parent vs child perceptions. Parents place high value upon oral communication but there is not enough evidence to suggest that it affects psychosocial development. However both chronological age and age at implantation can be influencing predictors of psychosocial development. Parental views are generally positive towards all aspects for CI although parents score their children more positively than the children score themselves across psychosocial measures. However all studies vary in the inclusion criteria of participants and their setting.

**Conclusion:** This review highlights UK research is limited considering the psychosocial impact of cochlear implants of younger children. Future research needs to focus upon the factors that could influence parental response, mental health of children with cochlear impacts and focus more closely upon gender differences.

### Introduction

The first single-channelled cochlear implant device to be implanted in a child was in 1980 created by William F. House in Los Angeles, California. (Achbold et al. 1994). Cochlear implants replace the function of the damaged inner ear and thus provide a means of detecting sound. The implant then processes the sound waves and converts it into an electrical signal to send to stimulate the auditory nerve. Hearing impairments are frequently associated with an under developed vocabulary, lower attainment of academic achievement, decreased intelligibility due to difficulty with speech sounds and thus an increased difficulty in social functioning (Mayberry 2002; Connor et al. 2006; ASHA n.d.).

It is now well documented that children who are born with a severe to profound sensorineural hearing loss achieve great benefits from the implant of the device in relation to speech perception

and language development (Connor et al. 2006; Sahli and Belgin 2006; Sarant 2012; Yuhan 2013). The average pressure level of the voice from a distance of five feet is approximately 60dB for conversational speech (Northern and Downs 2002). The severe to profound hearing threshold levels lie between 70db to 110db.

Svirsky et al (2004) found that children who were implanted before they reached 2 years old obtained better oral language competence than those implanted at an older age. Due to the increasing evidence of the significant benefits from the use of cochlear implants, very young children are now being implanted at pre-verbal stage in order to facilitate understanding spoken language and the development of oral speech through the use of auditory information (Sarant 2012). However Thoutenhoofd et al (2005) highlighted the importance for future research to look more widely at the child's functional communication through the use of parental perception assessments (Thoutenhoofd et al. 2005).

Social functioning and development is key to children independently participating in social activities. Social development and language acquisition are entwined. It is therefore expected that children whose language development is delayed will also have fewer opportunities of social interaction and progression (Most 2007). Social maturation and peer engagement are essential for the development of self-esteem (Ryan and Deci 2000). However cochlear implanted children face an even greater demand in order for them to participate effectively in social communicative situations because of their hearing loss. If a child finds it difficult to enter into a new social group, this can potentially impact upon their social skills, their friendship circle and thus their psychosocial development.

Self-esteem is a key factor in psychological development. Hindley and Kitson (2001) have identified that there is considerable evidence that suggests deaf children are at greater risk of all forms of abuse than hearing children (Hindley and Kitson 2001, p.276). 'Rejection or victimization by peers may become a source of significant stress to children, contributing to feelings of loneliness and low self-esteem' (Welsh and Bierman n.d.). Therefore children with cochlear implants are more at risk of their implant impacting upon their psychosocial development. If a child cannot interact as well as their hearing peers they may become vulnerable to social segregation which could lead to a decline in their self-esteem.

This study seeks to review the research from studies which look specifically at the emotional and psychological consequences for children who wear a cochlear implant. It will explore possible relationships between wearing a cochlear implant and the impact on children's self-esteem identified through psychosocial indicators.

Despite extensive research in the relationship between CI and psychosocial elements this research has mainly focused upon the adolescent population with variable results. This review will focus upon children aged 4-12 years; within this age band children will progress through Erikson's industry vs inferiority stage. This stage has commonly been associated with the development of competence (Sokol 2009; Kivnick and Wells 2014).

'The average age of identification of deaf or hard-of hearing newborns has decreased over the last 20 years from approximately 30 to 48 months to 6 months or less' (Cunningham 2015, pp.1). Over the last twenty years, there has been a rise in the number of cochlear implantations. The focus of

this literature review will collate research from the years 2000 to 2015, this will ensure the research and conclusions from this review are as current and relevant as possible.

The rising numbers of cochlear implantation over the last twenty years and the aim of this literature review to collate research from 2000 to 2015, will ensure the research and conclusions from this review will be as current and relevant as possible. For the purposes of this review, studies which do not investigate or provide any evidence towards the impacts of self-esteem, and in children with cochlear implant will be excluded. This review hypothesises that cochlear implantation will impact on a child's psycho social development.

This review hypothesizes that for children who have a hearing impairment, wearing a cochlear implant will impact upon their psychosocial development and will seek to answer the following question: what is currently known about the psychosocial impact of young children who wear a cochlear implant?

## Methodology

### Search methods

A systematic search of the literature was conducted that included a combination of primary and secondary search terms. An initial review of the literature revealed that many studies referred to cochlear implant within their study but did not necessarily use them. Therefore primary and secondary search terms were formed to find the most relevant research. A primary search term was paired with another primary search term or secondary search term.

Search terms were entered into the electronic databases, CINAHL plus and Scopus. (refer to table 1) in August 2015. Studies were included if they were peer-reviewed articles published between 2000 and 2015; they addressed self-esteem, social development of children who have a cochlear implant, the children were aged between 4 and 12 and the paper was available in English. The terms were searched **Table 1: Search terms used in the review.**

| Concepts     | Cochlear Implant   | Children               | Social Psychology  |
|--------------|--|------------------------|--|
| Search words | Cochlear Implant<br>Cochlear Implantation<br>Hearing loss<br>Hearing impairment<br>Hard of hearing | Children<br>Pa*diatric | Social Psychology<br>Self Esteem<br>Self-esteem<br>Psycho-social<br>Psychosocial<br>Self satisfaction<br>Well-being<br>Quality of Life |

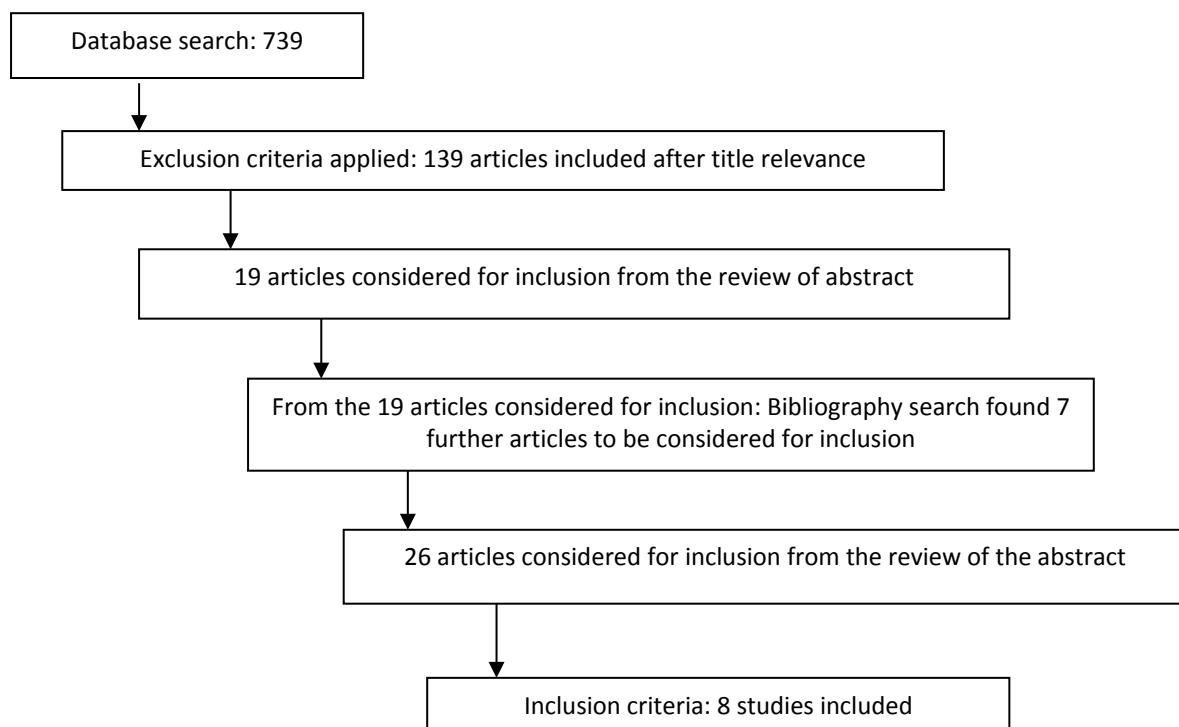
for in the abstracts of papers only, this is because titles can be limited and thus unreliable and full-text searches return many irrelevant publications. Papers were excluded if they referred to children who had a hearing impairment but did not have a cochlear implant.

**Table 2: Inclusion Criteria**

| Subject                           | Publication Details                         | Participants   |
|-----------------------------------|---|--|
| Self esteem<br>Social Development | 2000-2015<br>Full text available in English | Children aged 4-12 with a cochlear implant<br>Children with no additional or known neurological, autism, cognitive deficit or learning difficulties. |

This age band criteria was chosen due to much of the previous literature that focused on the psychosocial development of children who wore a cochlear implant, were of adolescent age, this period of development refers to the ages 10-19 years (WHO 2016). Therefore this review will explore children who wear a cochlear implant aged 4 to 12 years; primary school age as this set of participants are within the phase of industry vs inferiority of Erik Erikson's psychosocial stages. The participants are not to have any other additional diagnoses or learning difficulties as this would make this data unreliable due to additional difficulties can impact on the development of some children's social skills and it is pertinent that hearing loss and the use of cochlear implants are the subjects of exploration. The subject of the publication must be investigating the relationship between self-esteem/acceptance or social development of children who wear a cochlear implant because this is the integral topic to this literature review.

The steps in the filtering of the literature found from the initial search are shown in figure 1.

**Figure 1. Flow diagram of Literature search**

The initial title screen searches depicted relevance to the study being carried out. The abstract was then considered as to whether to be included or not included in this research. All abstracts were reviewed and relevant publications were then selected. The reference lists of the selected articles were then also reviewed to enable similarly affiliated papers to be revised. The reference search found a further 7 appropriate articles for inclusion. Of the total 739 abstracts that were found during the database search of CINAHL and Scopus, and also using Google Scholar for the bibliography search, 26 were considered to be potentially appropriate. Of these, 8 articles met the inclusion criteria (see figure 1).

## **Results and Discussion**

### ***Quality of the research***

#### Study Design

All eight studies that were included within this literature review are cross sectional studies, using a survey research design method. This allowed the researchers to compare multiple variables of potential factors that influence psychosocial development of children who wear a CI.

#### Aims of studies

There was a variance in the aims across the eight cross sectional studies included. Two studies investigated peer relationships of deaf children with a CI (Bat-Chava and Deignan 2001; Martin et al. 2011). Anmyr et al (2015) investigated the personal and social resources of children with a cochlear implant. Four studies (Huber 2005; Huttunen et al. 2009; Loy et al. 2010; Warner-Czyz et al. 2011) explored and examined the quality of life of these children. Huttunen et al (2009) included exploration of the child's family as well as the child, investigating specifically the benefits of CIs. Furthermore there are disparities in the use of the phrase "quality of life" amongst these studies. Two studies refer to health related quality of life (Huber 2005; Warner-Czyz et al. 2011). HRQoL is a medical term fundamentally formed from the approaches health status and health value/preference/assessment (Khanna and Tsevat 2007). HRQoL is described as a patient reported outcome measure often used to measure the functional, physical, social and emotional well-being of a person throughout intervention processes (Fallowfield 2003). Whilst Nicholas and Geers (2003) explored the psycho-social adjustment of CI children, the child's scale of self-esteem and examined parental satisfaction with implantation. See table 3 for the overall measure each study employed.

#### Participants and Recruitment

The studies analysed all recruited participants between the ages of 4 and 12 years, although three studies (Loy et al. 2010; Martin et al. 2011; Warner-Czyz et al. 2011) all additionally included a 13 to 16 years group. As these older sub groups of participants did not meet the inclusion criteria for this literature review these findings were excluded. All studies explicitly gave the gender proportion of their participants; overall there were 240 females and 207 males identified. An uneven representation highlights how results cannot be generalised to either gender effectively. In previous

research there has been evidence supporting females displaying consistently higher rates of peer competence and prosocial behaviours than males (Walker 2005). Social competence has been related to psychosocial development; a deficit in social competence can lead to peer rejection which can thus lead to social withdrawal and lower self-esteem (Welsh and Bierman n.d.). The higher number of females in the studies may lead to underestimates of the psychosocial effects of CI on the entire CI population.

A total of 447 CI children were recruited across the eight studies. The studies differ in their method of recruitment. All the studies offered a diverse sample of geographical participants and most studies recruited their participants through organisations already involved with the child, either SLT involvement, or audiology centres. These groups of participants can therefore be described as samples of convenience. However Anmyr et al (2015) participants were a purposive sample; from a subset of a project the researchers had previously investigated. This was an exploratory cross sectional study that aimed to improve the knowledge about daily functioning and attitude towards children with CI's and hearing aids. The participants were conveniently selected from a paediatric and adolescent cochlear implant and habilitation unit from Stockholm (Anmyr et al. 2012). Conversely two studies recruited their participants through summer camps for those with CI's. Nicholas and Geers (2003) recruited through an all-expenses paid for, 4 night summer camp. Similarly, Warner-Czyz et al (2011) required CI users and their family to spend 5 days at a summer camp but at the expense of the family, this recruitment process could be more bias towards more affluent parents.

Therefore it is important to consider the composition of the samples could bear influence and confound the results of these studies, particularly the summer camp recruitment as this form of sampling was aimed towards CI children who were amongst alike peers, which could have positively influenced self-image.

#### Measurement tools

The studies analysed in this literature review (refer to table 3.) are varied in the method of assessment tool to investigate the psychosocial impacts of cochlear implants.

Measuring psychosocial differences in children is complex, due to methodological and developmental factors. Niparko (2006) identified challenges that can be faced when measuring children's HRQoL. The saliency in the domains of psychosocial developments and the suitability of these domains to be considered throughout child development. Additionally, the measurement of self or proxy assessments must also be considered.

It is uncertain whether reliability and validity studies were carried out on all the instruments used (Margalit and Efrati 1996; Goodman 1997; Waad and Hult 2001; Martin et al. 2011; Archbold and Lutman 2013). Due to the diversity in geographical origin of these assessment instruments, it is possible that an instrument that is valid and reliable in one cultural context may not necessarily maintain its consistency for children with CI. However an extensive discussion of these instruments is unattainable in this review.

**Table 3. Studies meeting all inclusion criteria**

| Author                       | Instrument  | Data Type                                     | Perspective | Overall measure   |
|------------------------------|---|---|-------------|---|
| Bat-Chava and Deignan (2001) | Child Behaviour Checklist 1   | Quantitative: Highly structured questionnaire | Parents     | Psychosocial functioning  |
| Huttunen et al (2009)        | Children with cochlear implants: parental perspectives 2                                      | Quantitative: Highly structured questionnaire | Parents     | Generic HRQoL   |
| Nicholas and Geers (2003)    | Pictorial scale of perceived competence and social acceptance for young children <sup>3</sup> | Quantitative: Highly structured questionnaire | Self        | Perceived Self-Competence and social acceptance   |
|                              | Meadow-Kendall Social-Emotional Assessment <sup>4</sup>                                       | Quantitative: Highly structured questionnaire | Parents     | Child's Adjustment: Subscales; social adjustment, self-image, and emotional adjustment.   |
|                              | Parents and Their Implanted Child: Views and Experiences <sup>5</sup>                         | Quantitative: Questionnaire                   | Parents     | Ratings of Satisfaction with Cochlear Implantation Components: Communication, General functioning, Self-reliance, Wellbeing and happiness, Social relationships, Education, Process of implantation, Effects of Implantation, and decision to implant |
| Huber (2005)                 | KINDL-R6  | Quantitative: Highly structured questionnaire | Self        | Generic HRQoL and disease specific CI module  |
| Warner-Czyz et al            | KINDL-R:<br>The Kiddy KINDLR,<br>The Kid KINDLR <sup>7</sup>                                  | Quantitative: Highly structured questionnaire | Self        | Generic HRQoL and disease specific CI module  |

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<sup>1</sup> (Achenbach 1991)

<sup>2</sup> (Archbold and Lutman 2013)

<sup>3</sup> (Harter and Pike 1984)

<sup>4</sup> (Meadow-Orlans 1983)

<sup>5</sup> (Archbold and Lutman 1998)

<sup>6</sup> (Ravens-Sieberer and Bullinger 2000)

<sup>7</sup> (Ravens-Sieberer and Bullinger 2000)



|                        |  |   |         |   |
|------------------------|--|---|---------|---|
| (2010)                 |  |   |         |   |
| Anmyr et al<br>(2015)  | Children's sense of coherence <sup>8</sup>   | Quantitative: Highly structured questionnaire | Self    | Socio-emotional                                 |
|                        | Network Map <sup>9</sup>   | Qualitative                                   |         | Social networks                                 |
|                        | Strengths and Difficulties Questionnaire <sup>10</sup>   | Quantitative: Highly structured questionnaire |         | Mental Health                                   |
| Loy et al<br>(2010)    | KINDL-R:<br>The Kiddy KINDLR,<br>The Kid KINDLR <sup>11</sup>                                  | Quantitative: Highly structured questionnaire | Self    | Generic HRQoL and disease specific CI module    |
| Martin et al<br>(2010) | Pictorial scale of perceived competence and social acceptance for young children <sup>12</sup> | Quantitative: Highly structured questionnaire | Self    | Perceived self-competence and social acceptance |
|                        | Child behaviour scale <sup>13</sup>  | Quantitative: Highly structured questionnaire | Parents | Prosocial, withdrawn and aggressive behaviours. |
|                        | Interaction Quality Index (IQI) and the Prosocial Behavior Index (PBI) <sup>14</sup>           | Quantitative: Structured observation          | Parents | Peer Task Measures                              |

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8 (Margalit and Efrati 1996)

9 (Waad and Hult 2001)

10 (Goodman 1997)

11 (Ravens-Sieberer and Bullinger 2000)

12 (Harter and Pike 1984)

13 (Ladd and Profilet 1996)

14 (Martin et al. 2011)

## ***Findings of the Studies***

The scrutiny of the eight papers included in this literature review showed that authors were concerned to comment on a number of recurring issues in their findings and these could be summarized in the form of three main themes as shown in table 4.

**Table 4. Recurring themes identified**

|                              | Theme                |                             |                               |
|------------------------------|----------------------|-----------------------------|-------------------------------|
|                              | Communication Method | Age and Age of Implantation | Parental views vs Child views |
| Bat-Chava and Deignan (2001) | ✓                    |                             | ✓                             |
| Huttunen et al (2009)        | ✓                    |                             | ✓                             |
| Nicholas and Geers (2003)    | ✓                    | ✓                           | ✓                             |
| Huber (2005)                 | ✓                    | ✓                           | ✓                             |
| Warner-Czyz et al (2011)     | ✓                    | ✓                           | ✓                             |
| Anmyr et al (2015)           | ✓                    | ✓                           | ✓                             |
| Loy et al (2010)             |                      | ✓                           | ✓                             |
| Martin et al (2011)          |                      | ✓                           | ✓                             |

## ***Findings***

From investigation of the qualitative and quantitative analysis of the studies it was possible to extract the main influencing factors of psychosocial aspects within cochlear implanted children that will be explored further within this literature review; communication method used, age and age at implantation, CI child vs parental perception.

Before the themes are explored in more detail there are some important observations to be made about the conflicting findings that have emerged. Investigation of the data highlighted child self-scores and parent perception results do not match; with some studies highlighting parents score their children higher than the children rated themselves. Huber (2005), identified that in HRQOL there was a negative correlation between self-rating and proxy rating; the greater the parent rated their child the poorer the child rated and reversely. This could impact the results of the following themes greatly and therefore the data of child and parent results have been discussed separately to support the exploration of child vs parent perceptions.

## ***Communication method***

The method of participants communication use differ across the studies. All studies excluding one included the participant's current communication method. Across these studies the predominant communication method was oral and total communication.

Of all the studies included four indicated whether their participants used either oral communication or total communication as their method of communication (Bat-Chava and Deignan 2001; Nicholas and Geers 2003; Warner-Czyz et al. 2011; Anmyr et al. 2015), 210 used oral communication and 117 used total communication. Huttunen et al's (2009) participants' communication mode was determined by the knowledge of the speech therapist used within the data collection process; of the 31 participants 24 used oral communication and 8 used sign language. In contrast Huber's (2005) participants predominately used sign language. As will be indicated in the results the type of communication method a child uses to interact may play an integral role in the increase of self-esteem.

### Child Results

Warner-Czyz et al (2011) found better oral communication facilitated personal independence highlighted by the significant relationships between communication and the quality of life sub scales.

However Nicholas and Geers' (2003) results demonstrated that self-image or being well adjusted was unrelated to an increased level in the child's communication mode in class. It also highlighted no statistically significant correlations were found between the child's social-emotional scores and communication outcome measures. Their study employed a large sample; 89 of their participants were within the educational placement of total communication classrooms and 92 participants were within predominantly oral classrooms. Subsequently a greater sample of results were considered.

Furthermore, Huber (2005) asserts that the ability to hear and understand spoken language only influences self-rating positively if the child is living within a primary hearing environment. However this factor was not explored by the other researchers and is not explicitly demonstrated within the results of her study, thus no statistical data is provided to support the claim.

### Parent Results

Bat-chava et al (2001) demonstrated there is a very strongly statistically significant relationship between oral communication skills and whether the CI child's peer relationship had improved since implantation. Similarly, Huttunen et al (2009) found better oral communication facilitated personal independence highlighted by the associations found between communication and the quality of life sub scales using the two-tailed spearman's rho;

- self-reliance: moderate correlation
- social relations: strong correlation
- education: strong correlation
- The child's oral communication ability after implant: moderate correlation

Parents also indicated that they were more content with their child's communication and education when their child used spoken language. In contrast to the child self-score, Nicholas and Geers' (2003) results from the parent's views and experiences demonstrated a very strongly statistically significant

correlation across the outcome measures speech perception, speech production, oral language and total language.

### Discussion

There is not enough statistical evidence to support the claim: oral communication as a main communication mode is integral to children with CI's self-esteem. Although Warner-Czyz et al (2010) found oral communication facilitated higher independence this is what would be expected within usual developmental norms. As children develop their language, they are more likely to develop their social competence which consequently, as Lau (2014) suggested, can facilitate a growth in independence as they access and develop their language system. (Huber 2005; Percy-Smith et al. 2008; Sarant 2012) All three authors assert a child's primary communication environment could positively influence self-esteem. If a child grows up amongst deaf parents this may positively influence their self-esteem, as other communication methods become their primary form of communication. Supporting this, Mayberry (2002) indicated that verbal skills were better from deaf children with deaf parents. This therefore aids the finding that oral communication is not necessarily integral in the self-esteem of CI children.

In contrast, all parental studies that explored communication mode, including Nicholas and Geers (2003) found either statistically significant relationships or correlations to sub scales of psychosocial domains. Thus parents place high value upon oral communication and relate it positively to psychosocial skills. Nevertheless Bat-Chava et al (2001) parent's reported they noticed a change in their child's personality, although this could have been due to the children having more access to the hearing world with 92% of children using oral communication and thus being able to participate by entering a wider variety of social environments. Nicholas and Geers (2003) parent's views and experiences of their children revealed communication across all domains are essential for and improved psychosocial skills. These results are potentially more credible as the communication domains such as oral language, the written word and creative expression are easily observable due to their overt characteristics, and furthermore the large sample size Nicholas and Geers (2003) employed has evidently obtained more data results for comparison. Warner-Czyz et

al (2009) support this by asserting parents can evaluate objective aspects of their child's behaviour however show reduced skill on less observable features of a child 'such as self-esteem, emotional or social functioning, the domains more commonly to be affected by hearing loss' (Warner-Czyz et al. 2009, p.1424).

It must also be considered that parents can provide an in-depth perception of their child that no other professional would be able to do; as Huttunen (2009) asserts parents are naturally to have the closest bond to the child (Huttunen et al. 2009). Parents are able to pinpoint changes in personality as found by Bat-Chava (2001) as well as subtle changes in behaviour. It is possible that additional factors play a role in parents perceiving oral communication more positively. None of the researchers included the parental acceptance of deafness or the parent's communication patterns with their CI child within their studies. This could influence psychosocial adjustment and is a consideration to be explored in future research.

### ***Age and Age at Implantation***

Four studies (Nicholas and Geers 2003; Huber 2005; Loy et al. 2010; Warner-Czyz et al. 2011) were found to identify age as a prominent component in the areas of psychosocial development in children who have CI's. Age at implantation was also indicated as a factor to consider in the analysis of self-esteem in children.

#### Child Results: Age

Two studies found a negative correlation between the child's chronological age and the HRQL evaluation. Warner-Czyz et al (2011) and Loy et al (2010) concluded the younger children, aged 4–7 group, scored an overall mean rating which was significantly more positive than that of the two older sub categories of groups aged 8-11 and 12-16 years. Similarly, Nicholas and Geers found that age was a significant predictor of a better self-image, with younger children (8 years) revealing a greater self-image than older children (9 years) ( $p < 0.01$ ). Anmyr et al (2015) utilised three socio-emotional self-report measures in their study; children's sense of coherence, the network map and the strengths and difficulties questionnaire, however no significant difference was found between CSOC, social network closeness or SDQ score and age of participant.

Huber used a normative hearing sample of the standard population mean scores for identical aged school pupil samples (8-12 years) in Germany for comparison purposes. She contrasted her results with the standardised sample of hearing children, her results revealed the sample of CI children aged 8-12 results were significantly lower in the overall score of self-rating in comparison to the standardised hearing children ( $p < 0.001$ ).

#### Child Results: Age at implantation

Of the six studies that included children's self-perception, three studies did not investigate the impact of age at implantation (Huber 2005; Loy et al. 2010; Anmyr et al. 2015) and two out of the three studies that did explore this dimension, did not find any significant results.

Nicholas and Geers (2003) did not find any significant relationship between age at implantation and psychosocial impact, however it was identified that children who had had longer use of the updated SPEAK speech processor within their cochlear implant had a better self-image rating ( $p < 0.003$ ) and that children who are implanted at an earlier age are more likely to have better auditory perception, language acquisition and thus speech intelligibility (Nicholas and Geers 2003). As previously stated Warner-Czyz et al (2011) demonstrated that their sample of 4-7 year old group scored significantly more positively on the KINDL-R assessment than their older peers. Additionally the youngest CI sample (4-7 years) had received their CI at a younger mean age compared to the 8-11 and 12-16 groups (0.9 to 3.2 years younger than the two older sample groups). However they also had less experience (on average 2.1 to 4.4 years) with the CI compared to the two older samples.

However Martin et al (2011) found that duration and age at implantation were highly correlated variables. The younger the child at implantation, the longer the child had been using the implant. The children who had used their implant for longer scored higher in spending a longer period of time in interactive and collaborative play with their hearing peers and displayed more prosocial

behaviours ( $p < 0.05$ ). Duration of implant use was particularly associated with a larger rate of peer entry success. It was also highlighted that duration of implant use had a significant effect upon the CI child's perception of cognitive competence ( $p < 0.01$ ) and perception of maternal acceptance ( $p < 0.05$ ). Correspondingly, Warner-Czyz et al's (2011) study also indicates that between age at CI activation and duration of use is very strongly statistically significant.

#### Parent Results: Age and age at implantation

Martin et al (2011) was the only study to investigate both age and age at implantation from parental perception though they found no significant correlation or relationships. However this could be due to the small sample size with a total of ten participants and restricted age range of five to six.

#### Discussion

Younger CI users reported better self-scores of self-esteem than their older CI peers. This could relate specifically to the developmental age of the child. Chronological age could impact on how the CI users positively and negatively feel about the device and its use in everyday life, as well as intellectual, social and emotional development (Warner-czyz et al. 2013). Differences in the developmental stages can have a huge impact on how children see the world and themselves. Children aged 4-7 will have a differing outlook on life and possibly a lower intelligence level in comparison with children 8-12 years. Therefore different levels of insight and self-awareness between different chronological ages, could affect results.

Anmyr et al's (2015) investigates mental health as well aspects of psychosocial development. Fellingner et al (2008) evaluated the mental health and quality of life in a sample of deaf pupils. Like Anmyr et al (2015) they also used the SDQ and found both proxy samples rated deaf children as having significantly greater difficulties on the SDQ than their peers from normative samples (Fellingner et al. 2008). 'Deaf children are at greater risk of developing mental health problems than their hearing counterparts' (Hindley and Kitson 2001, p.272). It's clear from the research that the SDQ measurement tool has primarily been used for aiding mental health diagnosis, assessing emotional, behavioral problems and pro-social behaviour. It is therefore appropriate that Anmyr et al (2015) explored elements of mental health and is thus pertinent for exploration in future research, with little current literature investigating mental health in CI children. Interestingly, no single study indicates whether the CI child is the parent's first deaf child, with 'approximately 90-95% of deaf children are born into hearing families' (Hindley and Kitson 2001, p.273). Previous literature has identified that the family's response and how families can prepare with stressful events can have a powerful impact upon the deaf child's psychological development and mental health (Hindley and Kitson 2001). It would therefore be a crucial element of the psychological development of CI children to explore further, as well as the response of the parents and whether this factor can impact upon this child's mental health.

As Huber (2005) included, comparing CI participants with a normative hearing sample or using hearing controlled samples ensures for wider exploration and enables a greater focus to be brought upon the difference between for example a normal hearing 10 year old and a cochlear implanted 10 year old. Other studies researching deaf children have also illustrated the need for inclusion of a

contrastive hearing sample group; obtained through data of normative hearing samples (Keilmann et al. 2007; Fellinger et al. 2008; Percy-Smith et al. 2008).

Although many of these study did not find a relationship between age of implantation and stronger psychosocial skills this could be due to the small sample sizes. Only Nicholas and Geers (2003) and Warner-Czyz et al (2011) have a sample size that exceeds 100 participants. The greater the sample size the more precision can be given to results, as it allows for more power to detect differences. Warner-Czyz et al (2011) identified that their younger sample have a greater positivity surrounding their HRQOL. Although Warner-Czyz et al (2011) did not correlate the difference between age at implantation and chronological age, it was found there was a very strongly statistically significant correlation between age at CI activation and duration of use using a correlation analysis; much like Martin et al (2010). This was found by comparing the overall rating of HRQoL on the generic instrument and the overall rating on the CI module.

Early identification of a hearing loss allows for a more rapid response in preventative measures against the child losing access to the hearing world. The earlier the intervention process begins, the faster the child can gain access to language which ought not to hinder their language development significantly. This may also provide a greater acceptance to the use of a CI for children as they use it from a younger age in everyday living and thus have more potential to embody the device as part of themselves and as part of their own self-image, rather than viewing the CI as something that separates them from normally hearing peers (Percy-Smith et al. 2008). Therefore although there is not enough evidence to suggest that age or age of implantation does affect the self-esteem of CI users directly, it is possible that the longer the duration of use of a CI is an indicator of greater self-esteem; which future research should explore.

As illustrated in the result older children have lower self-esteem than their younger CI peers. However it must be considered the older the child, the more experience they have had living with a CI and the longer they have been within the education system. It has been found that bullying most commonly peaks at ages between 11 to 14 (Eslea and Rees 2001; Fried and Sosland 2011). Thus these children are at greater risk of mistreatment which could consequently affect their self-esteem.

The younger CI peers have also had earlier implantation and thus these children may have grown up with their CI integrated within their self-image throughout life. Marschark et al (n.d.) suggested children up to the age of eight could have an advantage with adapting to CI input due to greater plasticity younger auditory systems tend to have. During the ages of 3 to 5 children are more likely to be freely interacting with one another and noticing similarities rather than differences with one another (Warner-czyz et al. 2013). Consequently this could have influenced the outcome of results as older children will be very aware of social pressures and want to belong to a society and fit in (McLeod 2008); which could negatively influence their self-confidence or image. Younger peers are generally implanted at a much younger age before audition begins for normally hearing children and so it would be beneficial to consider whether the decreased level of self-esteem of older children be counteracted by early implantation.

## ***CI Child vs Parent perception***

Two studies considered only the parental perception (Bat-Chava and Deignan 2001; Huttunen et al. 2009), three studies considered the child perception (Loy et al. 2010; Warner-Czyz et al. 2011; Anmyr et al. 2015) and the remaining three studies explored both child and parent perceptions (Nicholas and Geers 2003; Huber 2005; Martin et al. 2011). Huber (2005), Martin et al (2011) and Nicholas and Geers (2003) all identify within their studies that child and parent perceptions differ.

### Results

Bat-Chava and Deignan (2001) investigated the parent's perspective of their child's psychosocial skills. Their methodology included both qualitative and quantitative procedures to obtain their results. As a whole the responses from the parents in this study indicated a positive view of their child's psychosocial development, with the CI providing a greater accessibility to social relationships due to an enhancement in oral communication and thus the ability to integrate more easily with hearing peers. Although it was also indicated that CI may cause a residual lag in oral communication for these children if implanted at a later age.

Huttunen et al (2009) also investigated the parent's perspective of the child's communication, general functioning, self-reliance, wellbeing and happiness, social relationships and education, and themes related to the family; effects of implantation and supporting the child.

Significant relationships were found between communication mode (oral communication) and self-reliance, social relations, education and effect of implantation. An additional sub sample between speech intelligibility and parental views highlighted that parental perception of their child's spoken language are actually realistic to their child's development ( $r = 0.710$ ).

Nicholas and Geers (2003), Martin et al (2011) and Huber (2005) all considered both parental and child perspectives. Huber's study found that children aged 8-12 responded with a significant decrease in self-rating compared to that of the normally hearing sample ( $p < 0.001$ ). Strong negative correlations exist between an increased level of health related quality of life and the agreement of the parental and child rating. The greater the parent rated a particular subdomain the poorer the child rated and reversely, demonstrating that the parents rating was very strongly statistically significantly different in comparison to their child's own self-rating.

Nicholas and Geers (2003) analysed the responses from both parent and child. The subtests correlations obtained from the picture assessment of self-image for children with cochlear implants (PASI) were significant and positive, as were the correlations obtained from the Meadow-Kendall scale, measuring the parental views and experiences. However the correlations analysed between child and parent scores were nonsignificant.

Martin et al (2010) controlled gender after analysis found differences across peer competence and children's self-esteem in the PPCSA assessment, with girls displaying greater rates of peer entry and prosocial behaviour. The CI children's perception results highlight duration of CI is a strong predictor



of social competence after controlling the variables for gender. Duration of CI was found to strongly correlate with the variables interaction quality, prosocial behaviour, self-esteem, cognitive competence and maternal acceptance, suggesting, that children who have had their CI for a longer period of time have better views of themselves in relation to the social, emotional and cognitive dimensions of their social interactions (Most et al. 2012). Strong correlations were also found between self-esteem and the variables: Interaction quality, prosocial behaviour and peer group entry. Therefore in this study CI children with greater self-esteem had better interaction quality, prosocial behaviour and skills in peer group entry. Furthermore Martin et al (2010) employed the CBS to score parental perceptions however after correlation of the parent's ratings of their children's social competence and the children's observational scores, they found they were unrelated to the child's self-esteem or any other predictors of peer succession.

Anmyr et al (2015) and Warner-Czyz et al (2011) investigated only the child's perception. Significant negative correlations between the CSOC and the SDQ ( $p < 0.01$ ) were found across all subscale domains. Closeness in the friends and associations segments did not correlate to either SDQ total or any subscale scores, or to the CSOC scores (Anmyr et al. 2015). In contrast to Warner-Czyz et al (2011) who found a positive correlation between the generic HRQoL and the HRQoL on the CI module ( $r = 0.19$ ,  $p = 0.03$ ) suggesting coherence between them. These scores were analysed via the Games-Howell post hoc and revealed the 4-7 year sample's overall mean rating on the generic KINDL-R was significantly more positive than that of the 8-11 sample ( $p < 0.05$ ). Both sample groups: 4-7 years and 8-11 years indicated correlations between the auditory history variables age at activation and duration of use.

## Discussion

Parents of deaf children have been previously recorded to have exceedingly high expectations once their child has been implanted. This is due to the anticipation that their children will have access to all sounds and will often expect them to gain language as quickly as their peers (Hindley 1997). Therefore parental expectations should be an area for future research to consider as this would help explore parental perception scores against how realistic their expectations are.

As previously discussed; parents may not always be the most reliable source for their child's own view of their self-esteem as their perceptions are more likely to be subjective. As recognised by Bat-Chava and Deignan (2001) parents whose children have had more successful experience with their cochlear implant may have been more inclined to participate in the study than those parents whose children have struggled with oral communication and peer interaction since receiving their implant. Therefore it is possible there be a partially predisposed outcome of parental opinions across all studies and thus it may not be a typical or representative portrayal of the effect of wearing a CI.

Bat-chava and Deignan (2001) and Huttunen et al (2009) all demonstrate significant correlation to oral communication against specific domains of psychosocial factors. It is possible that parents liken child success to oral communication due to the positive impacts of socialising that associates with oral communication. This outcome supports the growing literature describing the increased benefits of CI in the areas of oral communication and socialisation (Lau 2014).

All participants were recruited through organisations the family were already receiving support from. This could suggest that parental expectations for their children are not typically associated with the child's well-being but perhaps to how effectively the child can communicate. Huber (2005) was the only study to find a very significant difference to the child rating response. This may relate to how parents cope with the knowledge that their child is deaf. Hindley and Kitson (2001) explore in their chapter that some parents can struggle to come to terms with and understand their child's deafness if not enough social support is offered (Hindley and Kitson 2001). This could relate to Huber (2005) findings that the parents may be unaware of their child's current difficulties. It would therefore be appropriate in future studies to consider the support provided to parents and explore the comparisons between parental perception results and amount/quality of support provided to them.

This is in contrast to Warner-Czyz et al (2011) who felt there is a lower reliability of child responses, particularly on the CI module. Warner-Czyz et al (2009) questioned whether younger children are capable of responding accurately to such psychosocial assessments. Younger children with under developed cognition may not have the ability to successfully understand and answer some of the more complex self-score questionnaires (Goodman 1997). Nicholas and Geers (2003) adapted the PSPCSA adding new items that were more suitable to the linguistic abilities of younger children who have a CI. Additionally the questions provided were evaluated and determined to be appropriate by teachers of the deaf, and these were aided by drawings and supportive verbal statements for clarification. The test was also administered in the communication mode of the child's choice. This is the only study that provides additional support for the children to help facilitate their additional needs in language. This could suggest that the Nicholas and Geers (2003) self-score results are more reliable as the children were able to clarify the questions and their understanding, meaning their answers have greater accuracy.

Collection of assessment from both parental and child self-assessment helps refine and categorize data when exploring the psychosocial impact of younger children. The assessment instruments used for self-scoring were all quantitative measures which benefits data summary however it is unclear whether children with CI could have answered these accurately, therefore parental insight is beneficial.

## **Conclusion**

This review aimed to advance what is currently known about the psychosocial impact of young children who wear a cochlear implant.

## ***Communication method***

There is not enough evidence within these studies to support the statement; oral communication is integral for CI children as their primary mode of communication in facilitating psychosocial development, in relation to the child's own self-rating scores. However parents place high value upon oral communication, in particular towards the improvement of social competence. Parents believe if their children use oral communication they are more independent and are more likely to integrate and interact with their peers, parents and the wider world. Although there is controversy

surrounding the reliability of parent's perceptions, this outcome adds to the wider literature that oral communication is important for children who have a cochlear implant. Further research would be important to consider whether the primary home communication mode of younger children with a CI impacts upon their psychosocial development. Collection of data regarding the family history would also be beneficial to allow contrasts to be made against children who have deaf or hearing parents.

### ***Chronological age and age at implantation***

There is not enough evidence to suggest both chronological age and age at implantation affect psychosocial development however this review has indicated they can have an influence upon the prediction of psychosocial development. Younger CI children who have received intervention at an early age have more positive self-scores than older CI children. This study considered children as young as four; children at this age are at a vastly different developmental stage than children aged twelve. Children of twelve years are more likely to have experienced difficult social situations and mistreatment in contrast to their younger peers, which would explain the foundation for this outcome.

### ***Parent vs Child perceptions***

Parental views are generally positive towards all aspects of CIs however they score their children more positively than the children score themselves across psychosocial measures. However with some controversy between the high scorings of parents, parent's perceptions cannot be relied upon independently as a single predictor of CI children's psychosocial development and must be considered amongst additional data.

### ***Limitations of the present review***

This systematic review has several limitations. Firstly this review was restricted to including studies only available in the English language, it is therefore possible that some pertinent studies may have been excluded. Another limitation are the small size of the sample groups included within the studies; with four of the eight studies having a sample of between only 10 and 25 participants, which may have made it more difficult to detect differences and thus draw conclusions. A difference in gender was also clear in two studies (Nicholas and Geers 2003; Martin et al. 2011), with females having more positive scores recorded from both parent and child. However as the distribution showed there were more females than males in the entire cohort of participants this may have led to an overestimation of self-esteem and psychosocial development.

### ***Further Research***

There is a need for future research to consider a larger population of younger CI children. In addition to this it would be beneficial for researchers to consider exploring more rigorously the relationships between the parental expectation, the amount/quality of support provided to parents following a diagnosis of deafness of their child and the family's home environment; whether the child's parents

are deaf or hearing. This would provide a greater insight into the reliability of parental responses to their children's psychosocial development.

Furthermore, due to already known associations found between bullying and mental health (Ybarra 2004), mental health particularly self-esteem, anxiety and loneliness are areas that could be investigated further to extend the knowledge of psychosocial development in children who wear cochlear implants. Finally it would be valuable to compare CI between genders to evaluate whether females do precede males in psychosocial development.

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## **Effectiveness of a consultative model of service delivery for intervention for late talkers: a review of the evidence**

Rosa Stoppard-Holden, project supervisor Jenny Ford

### *Abstract:*

**Introduction:** The current NHS has a quality drive to provide economic and effective healthcare. A core component is a shift to preventative and integrated working. In relation to speech and language therapy, there is an emerging discussion around intervention provided through a consultative model. Late talkers are at risk of later developing language impairment. Analysis of research into current interventions and models of provision including parent-based intervention (PBI), could begin to indicate whether a consultative model is an effective means of providing input to late talkers.

**Method:** A systematic and multi-faceted approach was adopted to locate all relevant literature. Database and bibliographic searches were conducted and inclusion and exclusion criteria were used to ensure that only applicable resources were used. A total of 19 studies were evaluated to analyse key themes, including PBI. A further 12 studies were discussed to review established frameworks, such as Sure Start, highlighting themes i.e. integrated working.

**Literature review:** Key themes emerged including approaches used and the frequency of intervention. In discussion of direct and indirect intervention, clinic versus PBI is the main debate in the literature. The findings indicate that PBI is effective, although there is little indication of outcomes for receptive language. Classroom-based intervention could be another effective means of indirect intervention, although additional research is needed.

**Conclusions and implications:** Intervention is effective for improving vocabulary, language use and social skills. Strategies targeted at an appropriate level for the child and intervention in a natural environment, are the key factors which make intervention effective for late talkers. Parents offer a cost effective, accessible means of providing intervention within these parameters. Whilst additional research needs to be conducted to provide validity, the findings from this review indicate that a consultative model could be an effective means of administering intervention for late talkers.

### **Introduction:**

This review will look at the role of speech and language therapists (SLT) in providing intervention for late talkers and analyse whether a consultative model could be an effective alternative to direct intervention.

### ***Late talkers; characteristics and outcomes:***

Language development includes acquisition of expressive skills such as vocabulary, syntax (word order), morphology (word structure i.e. plurals, tense), as well as receptive language



(understanding), pragmatics (use of language) and phonology (speech sounds). These factors can be delayed in late talkers.

Late talkers (Ellis and Thal, 2008), late language emergence (Rice, Taylor and Zubrick, 2007), developmental expressive vocabulary delay (Desmarais et al, 2007; Desmarais et al, 2008; Appendix 1) and other terms are used synonymously, referring to children 18-35 months with a primary language delay. It can occur secondary to another condition including; autism, hearing impairment, developmental, neurological or behavioural difficulties. However, in the absence of another condition it is referred to as primary language delay (Rescorla, 2011; Paul and Rhea, 2001). This review will consider primary language delay.

There is considerable variation in assessments used to establish a diagnosis; the MacArthur Communication Development Inventory (CDI) (Fenson et al, 1993), Language Development Survey (LDS) (Rescorla, 1989) and the Ages and Stages Questionnaire (ASQ) (Bricker et al, 1995) are commonly used (appendix 2).

In literature late talkers are described as a heterogeneous group (Desmarais et al, 2008), varying in characteristics such as; receptive language (Ellis and Thal, 2008), delayed phonological acquisition (Carson et al, 2003) and use of communicative intent (Paul, 1991).

Research evidence shows that late talker's catch up with peers on vocabulary (Rescorla, 2011; Rice et al, 2008), but continue to have persistent difficulties with syntax and morphology (Rescorla and Turner 2015; Moyle et al, 2007).

Research indicates a positive correlation between the number of risk factors and the likelihood of persistence (Olswang et al, 1998; Hawa and Spanoudis, 2014; Zambrana et al, 2014). Salient factors which influence persistence include; socio-economic deprivation (Locke et al, 2002), receptive delay (Henrichs et al, 2011) and genetic factors (Bishop et al, 2003), amongst others (appendix 3).

Late talkers are at risk of; poor educational attainment (Johnson et al, 2010; Scarborough and Dobrich, 1990; Snowling et al, 2001), social (Knox and Conti-Ramsden, 2003; Lindsay et al, 2007; Horowitz et al, 2006), behavioural (Snowling et al, 2006.) and emotional (Botting and Conti-Ramsden, 2000; St Clair et al, 2011) difficulties.

Furthermore, research has found a positive correlation between specific language impairment (SLI) and language delay (Rescorla, 2005, Tager-Flusberg and Cooper, 1999, Redmond et al, 2011). Rescorla (2002) hypothesises that children with receptive delay are likely to be diagnosed with SLI by 5 years. While the correlation is noteworthy, this review will analyse intervention for late talkers at risk of later language impairment. SLI is an identified impairment, therefore affecting the role and approach of an SLT.

### ***Overview of intervention:***

Early intervention is short term input that will have long term impact for language delay, the aim being to obtain age appropriate language scores (Olswang et al, 1998).

Literature considers direct (by SLT to the child) versus indirect (input through a trained other) intervention. Parent-based intervention (PBI) is the most commonly discussed indirect intervention; where under guidance from an SLT parents provide input (Baxendale and Hesketh, 2003). SLT assistants (SLTAs) and teachers are not consistently discussed for late talkers (Boyle et al, 2007; Boyle et al, 2009; Dickinson et al, 2009). In a meta-analysis, Law et al (2004) conclude there was little difference in outcomes obtained through direct and indirect intervention.

Pickstone et al (2009) and Marhsall and Lewis (2014), discuss child and environment focused intervention, rather than direct and indirect. Child focused intervention targets areas of need in relation to a child's linguistic, social and cognitive skills; whereas environment focused adopts strategies which influence the environment around the child in order to support language development (Pickstone et al, 2009). Environment focused intervention involves resources – books and TV, as well as adapting others' communication, as a means to facilitate language (Roulstone et al, 2011. Neuman, 1999. Pickstone et al, 2009). Although environment focused intervention is important to consider, this review will analyse indirect intervention through trained others.

The aims and outcomes of studies are measured by specific criteria. Efficacy trials examine results at an individual level; analysing whether specific intervention improves a desired outcome in a controlled environment. Effectiveness trials produce results at a whole population level; measuring whether an intervention could be effective in practice (Gartlehner et al, 2006).

### ***Overview of policies:***

Policies influence and impact upon the provision, format and availability of intervention for children with speech, language and communication needs (SLCN). The Bercow Report (2008) highlighted the need for effective support; recommending collaborative working between agencies to ensure that a child's needs are met. It triggered the Better Communication Action Plan; in turn prompting the Better Communication Research Programme (Department of Education, 2009 - 2012) and the Better Communication Report (Department of Children, Schools and Families, 2008). Notable outcomes have been Every Child a Talker (ECAT) and The Child Health Promotion Programme; which aim to raise awareness of children's speech, language and communication skills (DCSF, 2008. RCSLT, 2011).

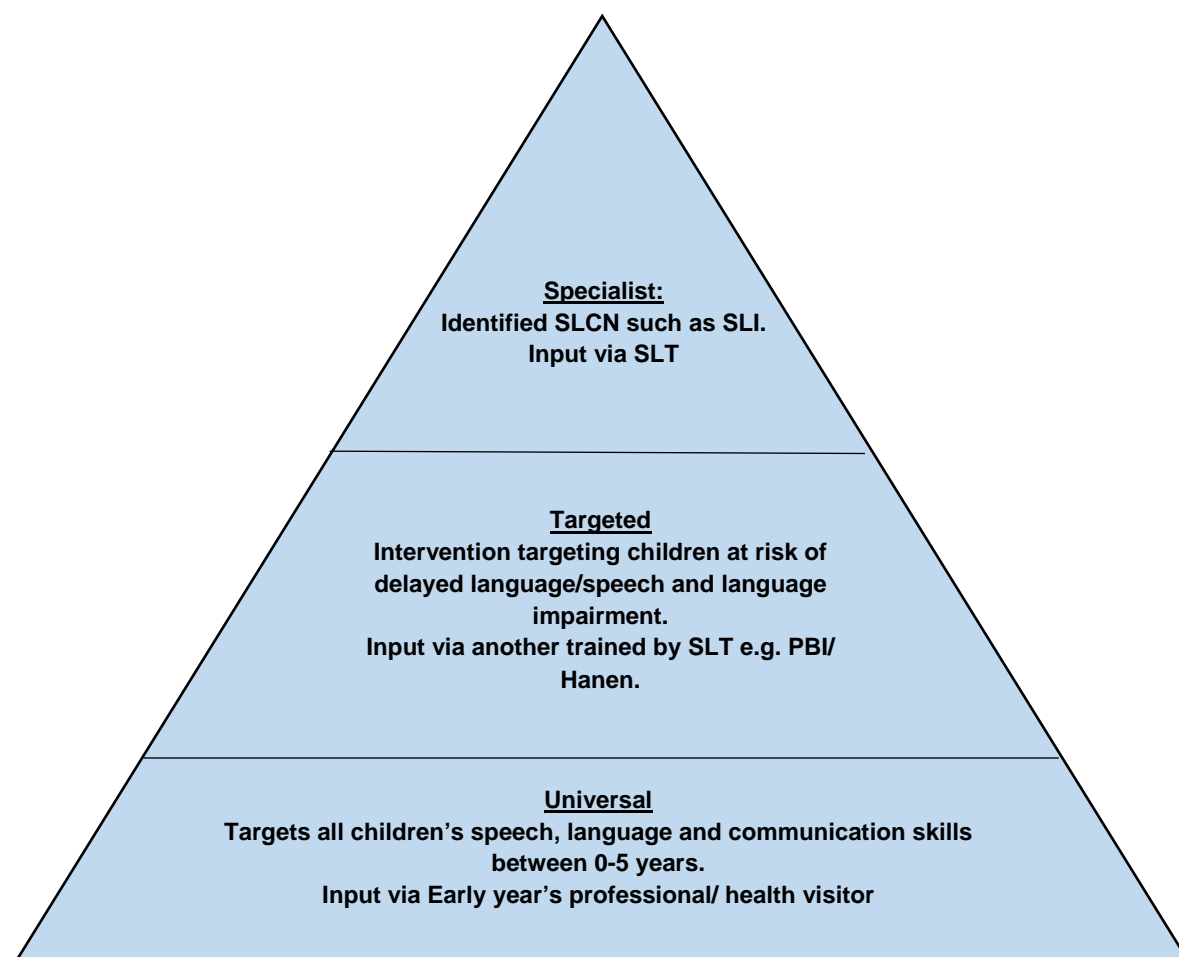
Concurrent themes of the NHS five year forward view are to adopt a preventative and integrated approach towards healthcare (Department of Health, 2014). Given the present climate there is a consensus for a sustainable and cost effective approach to intervention. To achieve this there is a quality drive affecting healthcare professionals; clearer outcomes measures, more effective early intervention (Duncan Smith and Allen, 2008) and the promotion of skills (Field, 2010).

A further initiative of the plan, is the move towards a public health model (DfH, 2014); in terms of SLT this has been discussed within literature (Locke et al, 2002; Law et al, 2011). This is crucial for SLT; as previously held clinical models, with caseloads defined by severity, are no longer practical. Instead specialist knowledge of SLT must be redistributed to support not only those identified with SLCN at more severe levels, but also those at risk (Law et al, 2013).

### **Commissioning of SLT:**

A key consideration for change towards a public health model, is the shift in commissioning of SLT services. The model from Every Child Matters (DCSF, pg. 21. 2003), was adapted by Gascoigne (2006) to illustrate the commissioning and role of SLTs in the 'pyramid of need' (pg.10). Figure 1 illustrates an adaptation of Gascoigne's (2006. pg. 10) model in relation to the themes of this review.

**Figure 1: commissioning of SLT in related to late talkers.**



A primary prevention approach is comparable to the universal level, targeting the whole population to prevent possible difficulties in the future (Law et al, 2013). The healthy child programme falls within this level, whereby health visitors are trained to identify and offer speech and language support to parents in the early years (RCSLT, 2011). The targeted service level, encompasses core prevention and initial intervention, to reduce or prevent a specified difficulty, such as language delay (Law et al, 2013). This review discusses themes consistent with this stage. The specialist tier encompasses specific interventions to reduce the effect of an impairment and increase the person's ability to participate (Law et al, 2013).

Gascoigne (2006) recommends that research should analyse the impact of SLTs training others to implement therapy; as well as the need for delegation of skills to a wider workforce. This rationale is supported by the predicted shortfall of trained professionals over the next decade (DfES, 2004 as cited by Gascoigne, 2006, pg.18). A more accurate definition of the consultative model is also recommended, in relation to a shared skill mix and integrated working. This underpins the rationale for the aims of this review. Within this review a consultative model will be defined as; an SLT training others to provide intervention within the child's natural environment (Law et al, 2002. Gascoigne, 2006).

### ***Aims and objectives:***

This review will respond to the following questions:

- 1) Is intervention necessary for late talkers?
- 2) Is effectiveness influenced by who delivers intervention?
- 3) What are the implications of findings for practice?

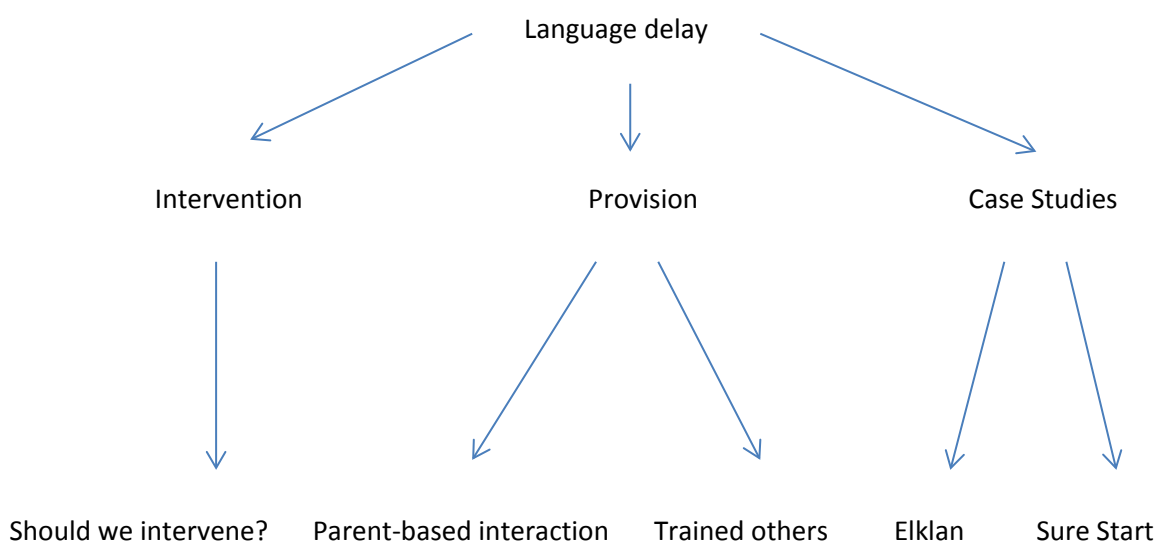
The review will evaluate literature to answer the initial two questions; and discuss the implications for the third.

### **Literature Review:**

#### ***Search Strategy:***

Literature, to identify if a consultative model could be effective intervention for late talkers, was located through a multi-faceted approach. Background reading around language delay was conducted to inform search terms and possible themes (figure 2). Additional reading and searches were then completed. Core authors/papers were consulted to gain background knowledge and inform future searches (figure 3).

***Figure 2: Initial background reading.***



**Figure 3. Key authors**

| <b>Themes:</b>                     | <b>Key authors:</b>                                       |
|------------------------------------|---|
| <b>Language delay</b>              | Bishop and Leonard (2000)<br>Desmarias (2008)<br>Rescorla |
| <b>Intervention and Provision:</b> | Law et al 2004, 2010                                      |
| <b>Case Studies</b>                |   |
| <b>Sure start:</b>                 | Anning and Ball, 2008.                                    |
| <b>Elklan:</b>                     | Elklan – Evaluation reports                               |

Search terms were developed and adapted throughout (table 1), including additional specific searches relating to themes, to locate relevant literature in answer to this review. Bibliographic searching was also conducted to ensure all potentially relevant literature was elicited. The following databases were used: PubMed, CINAHL, Jstor, PschINFO, Cochrane, Scopus, Academic Search Premier (EBSCO) and LexisLibrary. Specific journal searches provided additional literature: International Journal of Language and Communication Disorders.

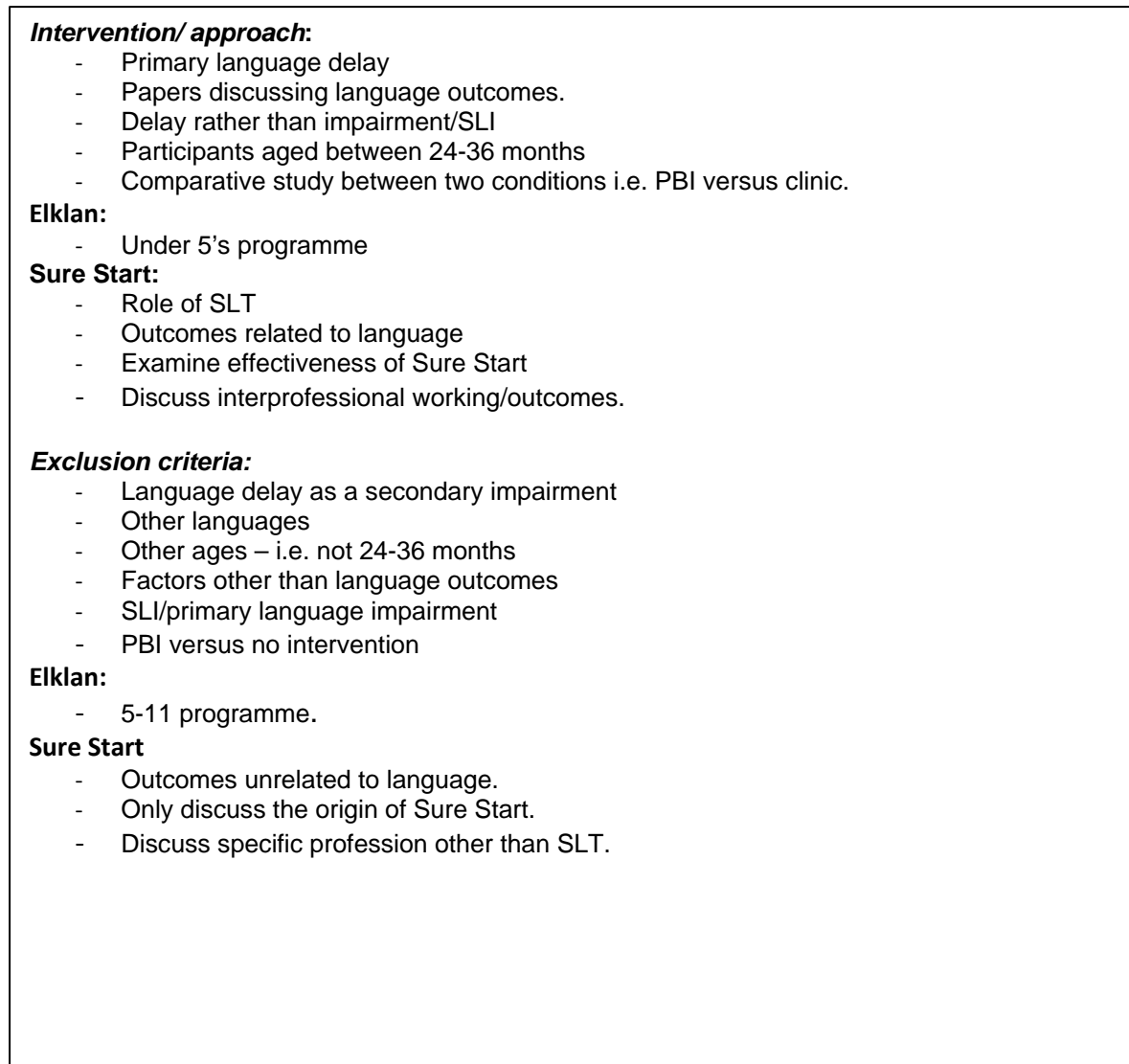
**Table 1: Search terms**

| <b><u>Language delay</u></b>                           |
|--|
| - Delayed language                                     |
| - Language delay                                       |
| - Late talkers   |
| - Early language delay                                 |
| - Early intervention and language delay                |
| - Speech and language therapy AND language development |

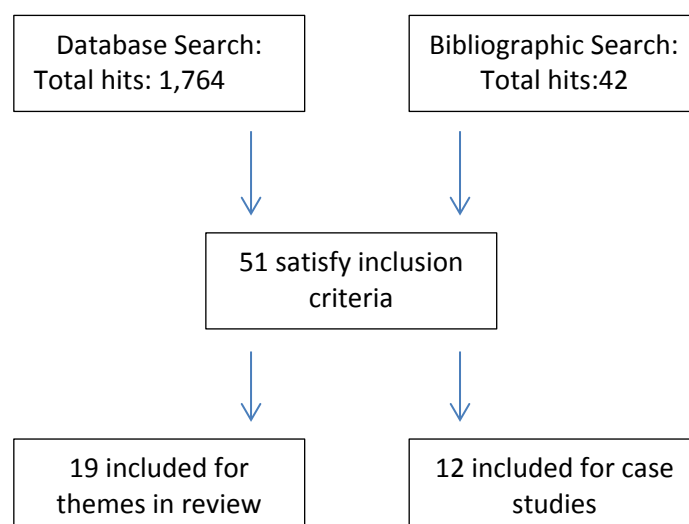
| <b><u>Intervention</u></b>  | <b><u>Approach:</u></b>   | <b><u>Case Studies:</u></b>   |
|---|---|---|
| <ul style="list-style-type: none"> <li>- Is SLT effective?</li> <li>- Dosage for SLT.</li> <li>- Intervention AND language delay</li> </ul> | <ul style="list-style-type: none"> <li>- Parent based intervention</li> <li>- Direct versus indirect AND speech and language therapy.</li> <li>- Hanen</li> <li>- Classroom based intervention and language delay</li> <li>- SLT AND language delay.</li> </ul> | <p data-bbox="989 282 1070 315"><u>Elklan</u></p> <ul style="list-style-type: none"> <li>- Elklan</li> <li>- Elis and MacLan</li> </ul> <p data-bbox="989 421 1126 454"><u>Sure Start:</u></p> <ul style="list-style-type: none"> <li>- Sure Start</li> <li>- Sure start children's centre</li> <li>- Sure start AND effective</li> <li>- Sure start AND inter-professional working</li> <li>- Sure Start AND Language Development,</li> <li>- SLT AND Sure Start.</li> </ul> |

A total of 1,764 titles and abstracts, and 42 articles were obtained through bibliographic searches. Inclusion and exclusion criteria (figure 4) were applied to identify those relevant to the research question. A final total of 51 studies were identified as potentially relevant. Additional reading of the papers illustrated some articles did not meet inclusion criteria. This review critically analyses a total of 19 papers in themed discussions. It will examine case studies of specific established programmes to inform the conclusions of this review and possible clinical implications. 12 papers were used to discuss case studies; Elklan and Sure Start Children's Centres (SSCC) (figure 5). Additional papers were read, and are referenced to provide background or further information to findings below.

**Figure 4: Inclusion AND exclusion Criteria:**



**Figure 5: Approach to systematic review:**



## Evaluation and Critical Analysis:

### *Speech and Language Therapy - What works?*

Is intervention appropriate?

The appropriacy of intervention for late talkers is debated in literature, as research indicates the majority of late talkers catch up with peers (Johnson et al, 1999; Girolametto et al, 2001).

Paul (1996) proposed a 'wait and see' approach, advocating intervention as unnecessary for children who solely have an expressive and receptive delay in a "stable" environment (Paul, pg. 204, 2004). van Kleeck et al (1997) criticised these findings based upon the evidence, information provided about participants and assessment measures used. However Whitehurst et al (1991) also advocates this. Despite identifying a positive correlation between intervention, homebased milieu approach, and an increased vocabulary, no long term benefits of intervention were identified when participants were reassessed at 5 years; therefore Whitehurst et al (1991) discredited the need to intervene. Robertson and Weismer (1999) and Girolametto et al (1996) criticise the reliability of these results on the grounds of no random assignment and a limited sample.

In a random control trial (RCT), Glogoswka et al (2000) found no significant difference in results between intervention and a no intervention condition. The reliability of these findings are criticised in relation to: the therapy activities provided (Broomfield and Dodd, 2011), heterogeneous nature of the group, outcome measures used and low frequency of intervention (Pring, 2004; Law and Conti-Ramsden, 2000).

Buschmann et al (2008a) propose intervention should be offered as early as possible, arguing that a 'wait and see' approach is unjustifiable. In a RCT, Robertson and Weismer (1999) compared the effectiveness of clinic based intervention to a delayed treatment group. In the trial 10 participants, aged 24-36 months, were randomly assigned to an experimental condition; of SLT delivered language intervention over a 12 week period. 11 participants were assigned to delayed treatment group. The authors highlight the effectiveness of intervention; identifying short term gains on measures of mean length of utterance (MLU), diversity and number of words produced, intelligibility of speech, as well as evidence of improved social skills. They advocate that therapy should provide a facilitative function; supporting the social interactionist approach towards language development which reinforces the correlation between social and language domains. Additional systematic reviews and literature provide clear evidence that SLT is effective for late talkers (Enderby and Emmerson, 1996; Law, 1997; Law et al, 2004; Law et al, 2010; Olswang, 1998; Nye et al, 1987).

Receptive delay is largely overlooked in research and in instances where results are discussed conclusions are contradictory. In a meta-analysis, Law et al (2004) found no statistically significant data, for children with a receptive delay, between those who received intervention and those in control groups. In comparison, a RCT found that children with a receptive delay made more significant improvement following intervention compared to children with expression and speech difficulties (Broomfield and Dodd, 2011). Broomfield and Dodd (2011) evaluate children with



language impairment therefore results cannot be generalised to late talkers. Receptive delay will be discussed later in this review.

A further element to the debate are secondary outcomes if intervention is not provided. Olswang and Bain's (1991) discuss that whilst children may 'catch up' with peers, other related skills may be negatively influenced by delayed language. These include: social-emotional development, their relationship with parents and phonemic segmentation.

The aspects intervention should target are also debated, including; pragmatic elements (Paul, 1991), phonological discrimination, word retrieval, language processing, verbal memory (Rescorla, 2009), and syntactical elements (Rice, 2000). These are important to consider, as research indicates that measures of vocabulary spontaneously improve, whilst deficits persist on measures of syntax and morphology (Rice et al, 2008. Rescorla, 2011).

There are clear indications that intervention is beneficial for late talkers; however additional research is needed to examine receptive delay and long term outcomes, to provide holistic evidence for intervention (Paul et al, 1991; Law, 1997).

Does the approach towards intervention matter?

Intervention approach is another variable that is discussed and should be taken into account. In a systematic review, Cable and Domsch (2011) highlight two main approaches to intervention; focused stimulation and modelling of target words.

Eight key studies adopted a focused stimulation approach, the majority of these also discussed PBI as a modality of intervention (Baxendale and Hesketh, 2003; Wilcox et al, 1991; Lederer, 2001; Girolametto et al, 1996; Robertson and Weismer, 1999; McDade and McCartan, 1998; Gibbard et al, 2004; Gibbard, 1994). Focused stimulation facilitates language through turn taking, modelling, expansion of utterances, following the child's lead and language at an appropriate level (Manolson, 1992). The Hanen Programme for Parents is the most prevalent example of this (Manolson, 1992).

Focused stimulation advocates facilitating language development in a natural environment. This utilises communicative opportunities (Cable and Domsch, 2011) and increases exposure of target words in a range of linguistic frameworks and contexts, increasing the likelihood of generalisation and linguistic awareness of terminology (Wilcox, 1991). It also supports the Royal College of Speech and Language Therapists (RCSLT) guidelines for intervention to be provided in a natural environment (RCSLT, 2005).

Outcomes include; increase in vocabulary and complexity of language used (Gibbard, 1994; Lederer, 2001; Girolametto et al, 1996; Robertson and Weismer, 1999), as well as some evidence of improved receptive language (Baxendale and Hesketh, 2003), and social skills (Lederer, 2001). In a RCT, Girolametto et al (1997) identified phonetic development of late talkers as a secondary gain; specifically syllable structure and phonetic inventory. However the variation in method, measures

and modalities of the studies, mean that results cannot be specifically attributed to focused stimulation (Cable and Domsch, 2011).

The other approach is modelling of target words. Four studies adopted this approach (Ellis Weismer et al, 1993; Girolametto et al, 1996; Lederer, 2001; Robertson and Weismer, 1999). In this approach selected target words are modelled by a parent or clinician in a natural environment (Cable and Domsch, 2011), although studies vary on whether the child is required to imitate the word. Target words are selected using criteria: age appropriate, capacity to be understood, can be represented by a real object, and contains sounds within the child's phonetic inventory (Cable and Domsch, 2011). Results indicate some evidence of children acquiring target words. Similar to above however, results must be treated cautiously and their potential to be generalised is limited, due to variation in measures and approaches (Lederer, 2001; Girolametto et al, 1996).

Primary research around approaches for late talkers is limited, however there is evidence that intervention in a natural environment at a level appropriate for the child could be effective.

Does the frequency of intervention matter?

There is debate over the frequency of direct intervention (Law et al, 2014; Dockrell et al, 2014; Barratt et al, 1992; Warren et al, 2007; Zeng et al, 2012). However, there are few primary studies which investigate the impact of frequency (Barratt et al, 1992), the majority of papers discuss it indirectly or evaluate this variable via research around other areas of intervention.

Barrett et al (1992) carried out a RCT; 18 participants received an intensive weekly course of nursery visits, four times a week for three weeks each month over a six month period. In the other condition, 21 participants received a visit to nursery once a week for 40 minutes over a six month period. Greater improvements were observed for children in the intensive group. In a summary paper, Dockrell et al (2014) advocate a positive correlation between dosage and impact of intervention, despite results not being statistically significant. In contrast, Zeng et al (2012) in a review of research, argue that there is a threshold, whereby intervention is effective once over a certain quantity, after which the emphasis of efficacy is placed upon quality. A further debate is whether dosage has become more a matter of economic rather than clinical concern (Zeng et al, 2012; Dockrell et al, 2014).

Both frequency and approach are influenced by the nature of intervention. In terms of approach, direct intervention can be more difficult to conduct in a natural environment. In addition a rationale for PBI is that strategies can be provided consistently in all environments (Manolson, 1992). Therefore PBI may be more effective in administering a high intensity, cost effective and natural intervention.

There is clear evidence to suggest intervention is appropriate for late talkers. The approach and frequency of intervention require further research to inform the decisions made by individual service providers.

## ***Provision for intervention – who should provide intervention?***

Clinic versus Parent-Based Intervention:

This section will analyse evidence to inform whether a consultative model for intervention with an at risk population is effective.

For late talkers, PBI versus clinic is the main debate for provision. The effectiveness of PBI therapy as opposed to no intervention is well evidenced within literature (McDade and McCartan, 1998; Buschmann et al, 2008b; Ciccone et al, 2012; Gaines and Gaboury, 2004; Lederer, 2001; Girolametto et al, 1996; Whitehurst et al, 1991; Ward, 1999). PBI outcomes include an increase in: parent-child interaction, vocabulary, confidence, social skills and multi-word utterances (Ciccone et al, 2012). Parents who participated in this service delivery model found it to be effective (Ciccone et al, 2012; Lederer, 20001). In a review Girolametto (2010), advocates PBI as effective in targeting preschool children to achieve short term goals. They attribute effectiveness of the PBI strategies to the fact that they target pre-linguistic communication including: joint attention, communicative intent, vocabulary, syntactical aspects and emergence of early sentences.

Four studies compare the effectiveness of clinic versus PBI (summarised in table 2). All studies used a pre and post-test design, with only one study not incorporating random assignment (Gibbard et al, 2004). Specific aspects discussed varies between studies, including: Hanen (Baxendale and Hesketh, 2003), video based PBI (van Bakolm et al, 2010) and applying cost effective analysis to results (Gibbard et al, 2004). Therefore direct comparison of results must be approached cautiously.

Results from the four studies indicated that PBI is the most effective intervention for language delay; obtaining the highest scores on measures of syntax; grammaticality, MLU, receptive language and conversational coherence (van Bakolm et al, 2010. Gibbard, 1994. Gibbard et al, 2004. Baxendale and Hasketh, 2003). One study examined evidence of long term effects, finding conversational coherence and MLU remained high for children in PBI condition (van Bakolm et al, 2010). The authors argue PBI is more effective as language is facilitated in a natural environment and across daily routines (Gibbard, 1994. van Bakolm et al, 2010. Girolametto, 2010).

***Table 2: Clinic versus parent based interventions.***

| Article:  | Method:   | Criteria:   | Outcomes  |
|---|---|---|---|
| <p><b>Gibbard, 1994.</b></p> <p>Only the second tier is discussed. Tier one examined clinic versus no intervention.</p> | <p><b>1. Parent Language Group</b><br/>– n = 9<br/>Fortnightly for 6 months amounting to 11 sessions.</p> <p><b>2. General cognitive support parent group</b>, n = 8<br/>Fortnightly for 6 months amounting to 11 sessions.</p> <p><b>3. Direct SLT group</b>, n = 8.<br/>Weekly 30 min direct 1:1 over 6 month period.</p> | <p><b>Criteria:</b><br/>27-39 months.<br/>Limited language - fewer than 30 words. Measured on McCarthy Scale of Children's Abilities,</p> | <p>PBI language group gained a higher mean score than SLT 1:1.</p> <p>PBI cognitive support had lowest score overall.</p> <p>Results were not statistically significant except MLU measure.</p> |

|   |   |  |   |
|---|---|--|---|
| <p><b>Baxendale and Hesketh, (2003)</b></p> <p>Hanen Programme</p>                              | <p><b>Clinic</b> – n= 18<br/>45 min sessions across 8-12 week block</p> <p><b>Hanen Parent Programme</b> – n = 19<br/>11 weeks, 8 group sessions lasting 2 hours and 3 home visits.</p>                                     | <p><b>Criteria:</b><br/>31-43 months</p> <p>Expressive and receptive delay, measured on Pre-school language scale.</p> <p>Diagnosed with language impairment.</p> <p>There was no control group</p> <p><b>No therapists had received Hanen Training.</b></p> | <p>Children with receptive/expressive delay showed greater improvement in the Hanen group.</p> <p>Children with expressive delay showed improvement at a faster rate in clinic.</p> <p>Results from Hanen were higher than clinic, however not to be significant.</p> <p>Hanen was found to be more expensive to implement due to two therapists being required to run the group rather than one in a clinic situation.</p> |
| <p><b>Gibbard et al, 2004.</b></p> <p>Cost effectiveness and outcome measures were applied.</p> | <p><b>Treatment:</b><br/><b>PBI</b> n= 10<br/>11 fortnightly sessions lasting 90mins.<br/><b>Direct SLT (general care).</b> n= 11.</p> <p>Procedure over 12 months, following NHS Portsmouth SLT protocol.</p>              | <p><b>Criteria:</b><br/>22-36 months<br/>Limited expressive language i.e. fewer than 30 words.</p> <p>No previous SLT input.</p> <p>Receptive language 2SD below the norm.</p> <p>No random assignment.</p>  | <p>Both showed evidence of improvement.</p> <p>PBI made greater gains on: vocabulary, phrase length and MLU.</p>  |
| <p><b>van Bakolm et al, 2010</b></p> <p>PBI through home based video training</p>               | <p><b>PBI</b> n= 11<br/>13 weeks, 6 biweekly home visits lasting 90mins.</p> <p><b>Clinic:</b> n= 11<br/>12 weeks last 45mins.<br/>Parents remained outside the room.<br/>No specific goals were identified for clinic.</p> | <p><b>Criteria:</b><br/>26-37 months.</p> <p>Expressive delay 10 months and receptive delay 4-6 months.</p> <p>Random assignment.</p>  | <p>Both showed evidence of improvement.</p> <p>No differences on MLU or receptive language.</p> <p>PBI group statistically significant improvements were observed on measures of grammaticality.</p>  |

Despite results favouring PBI, both conditions elicited improvement. Disparity in scores between both conditions, in some studies, were not statistically significant (Baxendale and Hasketh, 2003;

Gibbard, 1994). When directly compared, the effect size for expressive vocabulary outcomes was minimal (Law et al, 2004).

Confounding variables, such as socio-economic status, maternal education, age and gender were matched within each condition with the exception of one study (Baxendale and Hesketh, 2003). Despite this being controlled, participants were predominantly middle class; research highlights that the group most at risk of language delay are those from lower socio-economic backgrounds (Hart and Risley, 2003). In addition to limited sample sizes, this means results cannot be reliably generalised to the whole population.

Another limitation is the inconsistency between treatment conditions; with PBI receiving proportionally more input (Baxendale and Hesketh, 2003). In van Bakolm et al's study (2010) duration of treatment was equally distributed, results obtained were comparable to those of the other studies. However parents were not allowed to attend clinic sessions, therefore strategies could not be generalised outside of clinic. In practice parents attend clinic sessions so strategies can be generalised. Furthermore, higher results cannot be solely attributed to who administered input, due to confounding variables such as no specific goals being set in clinic. The frequency that parents employ strategies needs to be controlled in order to add validity to the application of these results. For the implications of these findings to be thought of as reliable, conditions need to reflect clinical practice (Gartleher et al, 2006).

While the above studies adopt PBI groups, there is minimal discussion of group application as a method for intervention. In a pre and post-test design investigation, Lederer (2001) advocates group PBI sessions; allowing integration of social and facilitation skills and opportunities for parent-peer support. Their survey also identified that parents reportedly preferred this model over an individual PBI session.

Research indicates PBI is an economical (Gibbard et al, 2004) and effective intervention for late talkers (Baxendale and Hesketh, 2003; Gibbard, 1994; van Bakolm et al, 2010). Comparative analysis between studies must be treated cautiously, due to variation in: methodologies; focus of intervention: application of Hanen; outcome measures and criteria. Furthermore the limited number of studies means that results cannot be reliably generalised. If these studies are to be considered valid, they must also highlight those children most likely to meet criteria for SLI at a later stage (Weismer, 2000). Baxendale and Hesketh (2003) summarise whilst PBI was effective, it may not be the most effective intervention for children with a severe language delay.

If PBI is adopted as the main intervention for late talkers, continued reviews from SLTs may be important to consider (Fey et al, 1993). Boyle et al (2009) and Fey et al (1993a, 1993b) found that SLT based intervention results across language measures had fewer variations, which gave greater consistency and comparable outcome measures. This is a paramount consideration in the NHS using outcome measures as a driving force for commissioning, to find the best and most cost effective interventions (Washington et al, 2013).

#### Classroom-based intervention:

Classroom based intervention is another means of providing intervention in a natural environment. In a RCT, Wilcox et al (1991) compared 10 participants in a classroom and 10 in a clinic based intervention. They found children in the classroom condition generalised more language. This finding was attributed to exposure to target words in a variety of contexts and linguistic frameworks, modelled by both teachers and peers. These findings are important to note, however it is the only study so far that analyses classroom intervention for late talkers.

There is concurrent evidence that for late talkers a consultative model could be effective. However, further research needs to be conducted into: dosage, control of variables; such as frequency parent employ strategies and classroom-based intervention, to provide validity to these findings.

### ***Frameworks: what has already been done?***

This section will analyse examples of specific established programmes which illustrate how findings of this review could be applied to practice.

#### Elklan

Elklan offers accredited training programmes to education staff, SLTs, SLTAs and parents, to support children with SLCN, aged under 5 and 5 to 11, within a classroom setting. The training provides information, advice and resources on how to support children's language development. The main aim of Elklan is to facilitate and support development in a language friendly environment (Lyon and Hess, 2007).

The rationale behind the under 5 course is based upon the Bercow review (2008) and supports the recommendations of ECAT, which aims to ensure parents receive training to facilitate language development.

#### Outcomes:

After receiving training for the under 5's course, the majority of parents (39/45) surveyed observed a positive impact upon their child, including an increase in: child led, imaginative and vocal play, and commenting on what they were doing. In addition children: asked more questions, spoke more during play, repeated and copied parents' utterances (Marr, 2013).

Professional reported outcomes include; improved confidence and knowledge to provide support, ability to adapt communication and work independently with children with SLCN in a classroom (MacKay and Aitken, 2010), and across agencies (Elklan, 2009). Reported statistics show that prior to training 23% felt able to support children with SLCN, whereas following training 100% felt able to (Elks, 2010). In addition there was a reported increase in; accuracy in observations, information sharing and personalising targets (Elks and McLachlan, 2010).

#### Evaluation:

No peer reviewed studies which discussed the effectiveness of Elklan were found. Published evaluations are predominantly produced by Elklan itself. Therefore observer bias cannot be ruled out and is likely to affect how outcomes are reported. The evaluation reports are based upon surveys completed prior to and following training. The majority of reported outcomes relate to confidence and skill development, rather than effectiveness related to language outcomes. Establishing the validity of the above outcomes is difficult to definitively state. However, Elklan is a leading provider of training to practitioners and parents, and is well established in SLT. It provides a clear example of how training can be implemented by SLTs to practitioners and parents in natural settings.

#### Children's Centres

A desired outcome of SSCC, was to facilitate collaboration between professionals and across agencies, working with pre-school children towards a shared goal (Edgley and Avis, 2006). A key goal of SSCC has been to ensure children have improved speech, language and pre-literacy skills (Anning and Ball, 2008). In addition, it aims to reduce the number of children aged 4 requiring specialist intervention for SLCN (Turner et al, 2004). SSCC achieve this through; home visits, outreach services, support for families, and ensuring that children are provided with play, learning and childcare experiences (Melhuish and Hall, 2007). This approach targets the home environment, development of parent skills and the child's health (Anning and Ball, 2008), through inter-professional working (Morrow et al, 2005. Malin and Morrow, 2007).

#### Outcomes:

Kane (2008) highlights a key limitation in structure of SSCC is that no designated plans were produced to evaluate its effectiveness. As a result of variation between centres analysis of its effectiveness is complex (Melhuish et al, 2010, Rutter, 2006).

The effectiveness of SSCC is discussed within the literature (NESS, 2005; NESS, 2007; NESS, 2008; Belsky et al, 2006; Rutter, 2006; Melhuish, Belsky and Barnes, 2010). The main outcomes include improved: social behaviour, child independence, self-regulation, and positive parenting (Camps and Long, 2011; Melhuish et al, 2008).

The outcomes, role and involvement of SLT in SSCC have been relatively overlooked (Fuller, 2010). Fuller (2010) proposes this is partially due to the short timescales of government evaluation to inform succeeding policies. An online mixed method survey, investigated the practice of SLTs in SSCC, findings include: increase in preventative practice, new and different interventions such as indirect were offered. However no effectiveness analysis is applied, therefore the impact upon language development cannot be reliably stated (Fuller, 2010).

In terms of professional working SSCC increased: inter-professional working and development (Malin and Morrow, 2007. Morrow et al 2005) and promoted innovative working by SLTs (NESS, 2005, Fuller, 2010).

Melhuish et al (2008) in a National Evaluation of Sure Start (NESS), examined outcomes from 150 SSCC; found language outcomes did not improve compared to children who did not receive input via an SSCC. Language and cognitive development were not differentiated, therefore language outcomes in their own right are difficult to discern. In a later evaluation, Melhuish et al (2010) found positive language outcomes measured on British Ability Scales – Naming Vocabulary and foundation stage profile. They attributed these results to high quality preschool care. Related outcomes of SSCC are likely to influence language development including: earlier referrals (Fuller, 2010); increased awareness and an improved home learning environment (NESS, 2008; Camps and Long, 2011).

SSCC demonstrates a model for interprofessional, preventative intervention for late talkers. Additional investigation into the effectiveness of language outcomes is necessary. It does however illustrate how interprofessional working can support outcomes relating to language delay.

### ***Outcome Measures:***

The quality drive and pressure placed upon SLT services to provide economic measure tools. They identified TOMs, Therapy Outcome Measures, to be the 'best fit' tool (Enderby and mic and effective intervention means identifying an effective tool of outcome measures is crucial. In 2014 the RCLT carried out an appraisal of outcome John, 2015; Powell, Ward and Lowenthal, 2015). It can be used in relation to current diagnostic tools and frameworks of practice; it is quick to administer and applicable across clinical areas; valid and reliable (Enderby, John and Petheram, 2006; Enderby and John, 2015).

TOMs was developed to measure clinical outcomes during intervention (Enderby, John and Petheram, 2006). It reflects and measures clinical, social and functional abilities related to an individual's needs, in order to represent a holistic view (Enderby, John and Petheram, 2006). The four main domains cover impairment, activity, participation and wellbeing, in line with the International Classification of Functioning, Disability and Health model (appendix 4) (WHO, 2001). It provides a clear baseline prior to, during and at the end of intervention, reflecting the impact of an impairment clinically and upon a person's day to day functioning (Enderby and Johnson, 2015).

In a RCT, Roulstone (2004) evaluated the application of TOMs to preschool children with primary speech and language impairments. Due to the nature of a RCT, an entirely valid evaluation could not be applied, as the same clinician administered assessments and TOMs; this however reflects clinical practice. An identified limitation is that TOMs considers only the core impairment such as language delay, but does not necessarily reflect additional areas of need such as phonology or receptive language. The main conclusion of the investigation found TOMs to be a valid and viable outcome measure which could be applied to late talkers. As the only study, results must be considered cautiously until further investigations have been completed.

There is no discussion or indication into how TOMs should be applied if input is indirectly provided. As there is a shift to indirect intervention, the application of outcome measures to this needs to be considered.



## **Discussion:**

In the literature analysed above concurrent themes were identified and will be discussed in the next section.

### ***Receptive language***

Research indicates that children identified as having both receptive and expressive language delay are more likely to have persistent difficulties (Paul and Roth, 2011. Henrichs et al, 2011).

Most studies analysed above incorporate receptive delay in inclusion criteria (Law et al, 2010; Law et al, 2014; Broomfield and Dodd, 2011; Baxendale and Hesketh, 2003; Gibbard et al, 2004; van Bakolm et al, 2010); yet there is little emphasis in discussion of results. In all four studies, which examine PBI and clinic, assessments used examine receptive language and results are displayed in tables (appendix 5), however only two of the studies discuss the implications. Baxendale and Hesketh (2003) and van Bakolm et al (2010) suggest findings provide some evidence that Hanen and parent video based intervention could be effective to support receptive language. Both studies attribute this to child orientated strategies targeted at levels appropriate for the child's language and attention.

Results from Gibbard et al (1994) and Gibbard (2004), show a positive gain on scores of receptive language for both PBI and clinic; with PBI obtaining more significant results. However, when statistical analysis was applied no significant differences were found. Despite minimal discussion or analysis of results, initial examination suggests PBI could be effective to support receptive delay.

Research analysing language impairment does consider receptive language. Analysis of these papers may provide an indication of how to intervene effectively with receptive delay. Further research needs to be conducted to identify a potential evidence base for this.

### ***Disorder versus delay?***

Further discussion is needed in relation to severity and criteria of the children in the studies analysed above. In Gibbard et al (2004) the inclusion criteria was children who scored 2SD below the norm for receptive language. In the DSM-IV diagnosis criteria for SLI is 2SD below the mean on language measures (Gallagher and Chiat, 2009). Therefore a clearer distinction between delay and disorder criteria may be required to provide clarity in studies.

Rescorla (2005) argues that in earlier years a distinction between SLI and late talkers is inappropriate, advocating late talkers as a milder form of SLI; with the proposal of language impairment as a spectrum rather than distinct deficits. Research needs to consider those most at risk of persistence or impairment, and therefore who is important to target. In addition severity of need may influence the effectiveness of intervention; some studies indicate that PBI may not be as effective for children with severe delays (Gallagher and Chiat, 2009; Baxendale and Hesketh, 2003).

## Dynamic assessment

Statistics-based formal assessments measure specific skills such as vocabulary. They do not analyse the functional and pragmatic use of language which inform our understanding of children's language development. Hence the need for dynamic assessment; this differentiates between late talkers as a result of a poor learning environment and those whose language is delayed regardless (Broomfield and Dodd, 2011). Hassen and Joffe (2007) advocate the need for SLT to incorporate dynamic assessments, to enable a distinction for those whose language delay will persist. Dale et al (2003) advocate the need for a screening method which identifies those most at risk of persistent difficulties, to improve the effectiveness of SLT for preschool children rather than the emphasis placed upon intervention. Dynamic assessments may be an effective means to identify those most at risk, although additional research is required to support this hypothesis.

## Findings in relation to research questions:

In this review a consultative model has been defined as; intervention provided by another, under the guidance of an SLT, in a natural environment. The findings are;

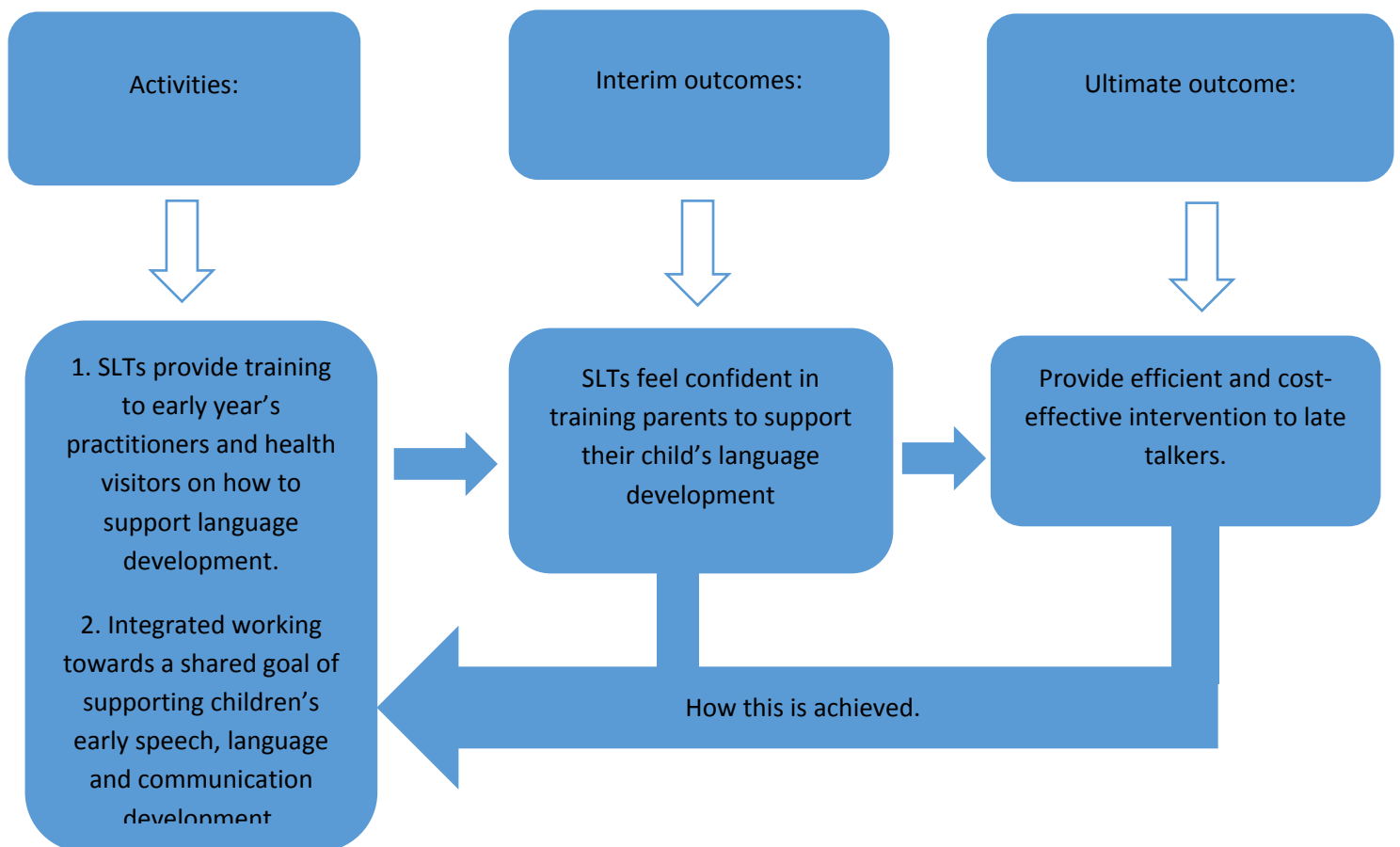
- 1) Research indicates that intervention is appropriate for late talkers. Outcomes include improved expressive language and reduced secondary impairments in phonology, social and pragmatic skills.
- 2) In a comparison of PBI, when parents are the agents of change, and clinic based, led by an SLT, outcomes are equivalent. Highlighted advantages of PBI include increased generalisation resulting from intervention in a natural environment. There is some indication that this approach may also support receptive language, although more research is required. Points raised above highlight the effective aspects of intervention are; focused stimulation and a natural environment. Parents offer an economic means of providing high intensity intervention meeting these aspects. More research needs to be built upon this finding. In relation to the NHS, PBI could offer an economic means of providing high intensity preventative intervention.
- 3) The evidence collected to answer the initial two aims and the discussed case studies, indicate that a consultative model could be an effective means of administering intervention. In addition this approach should enhance the efficacy of support provided to facilitate language development. This reflects the agenda of the NHS five year forward view to provide preventative, integrated, effective and economic intervention for an at risk client group. The findings of this review begin to provide a clear evidence base for a consultative model for late talkers.

## Implications:

### ***Theory of Change:***

The RCSLT use the theory of change to develop a strong evidence base to achieve desired outcomes. Lowenthal's (2013) definition is: to provide an example of how change could elicit desired outcomes (appendix 6). The findings of this review have been mapped on to a model of theory of change (Lowenthal, pg. 6. 2013) (figure 6), to illustrate how they could be applied to practice.

**Figure 6: results applied to theory of change model:**



The overarching aim, in relation to this review, is whether intervention provided indirectly could be equally, if not more, effective than a direct model. This review has found evidence that to support children's speech, language and communication an increase in awareness and confidence is necessary. To achieve this SLTs need to train other professionals and parents. This supports Gascoigne's (2006) request for research to identify how and whether a shared skill mix could be effective. Elklan provides an established and effective model of providing training to support children with SLCN. This review proposes that this could be effective for an at risk client group. In addition, integrated working through health visitors initially screening, and teachers becoming

involved in intervention will mean that there is a clear shared goal towards supporting children's speech, language and communication development. SSCC illustrate that shared outcomes can be achieved through an integrated approach. This model demonstrates this review's findings, and begins to propose how it could be implemented in practice.

### ***Limitations of this review:***

This review is limited by university word limit restrictions, affecting the depth of discussion.

A narrow and specific definition of consultative model was used, inhibiting generalised interpretation. However it does reflect the recommendation to define a consultative model for SLT (Gascoigne, 2006).

Narrow inclusion criteria means not all relevant literature may have been analysed. This review discussed late talkers, however additional variables may have transpired if studies looking at language impairment were considered.

This review did not discuss environmental factors. Whilst justified in the introduction, this is a component that should be considered to respond to effectiveness of indirect intervention.

Cost effective analysis was not examined in relation to each intervention.

### ***Recommendations for future research:***

Research needs to analyse effective intervention for receptive and severe language delay (Law et al, 2004). It also needs to include participants from socially deprived areas as these are most at risk of delay. Any studies will need to incorporate and validate dynamic assessment, to examine language holistically rather than specific individual skills.

Longitudinal studies are needed to increase validity of findings and establish PBI as an economic and effective intervention. Future studies need to control how often parents employ strategies to reduce the impact of confounding variables. The framework of Elklan suggests that nursery based intervention could be effective, however more research needs to be conducted to validate this hypothesis.

Research into how outcomes measures can be incorporated into indirect intervention is necessary. The provision for intervention is predominantly dictated by political and financial factors rather than the evidence found in literature (Gallagher and Chiat, 2009). Therefore there is a pressing need to establish an evidence base for SLTs role in indirect intervention.

## Conclusions

In relation to Gascoigne's (2006) recommendation this review has defined a consultative model, and found that SLTs training parents and professionals to support late talkers could be economic and effective.

This review has found that PBI is an effective means of providing intervention and has evidenced that PBI is effective at a population and an individual level, within the parameters of the samples used. This review has begun to find evidence that PBI could be effective for receptive delay, however further research needs to be conducted to identify the efficacy of this. In addition, research needs to consider outcome measures, how to ensure parents consistently carry out strategies and develop screening to identify children at risk of persistence.

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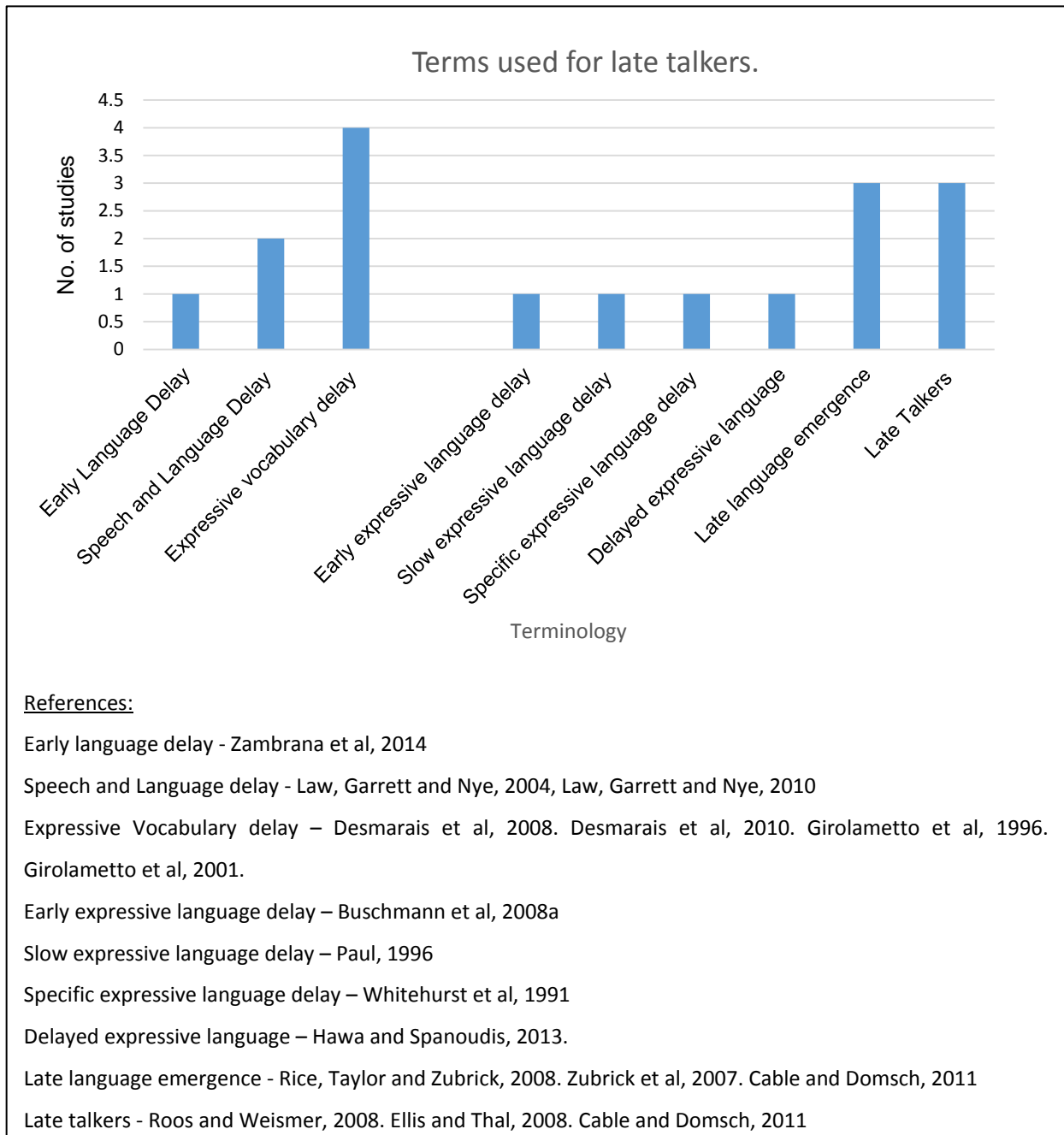
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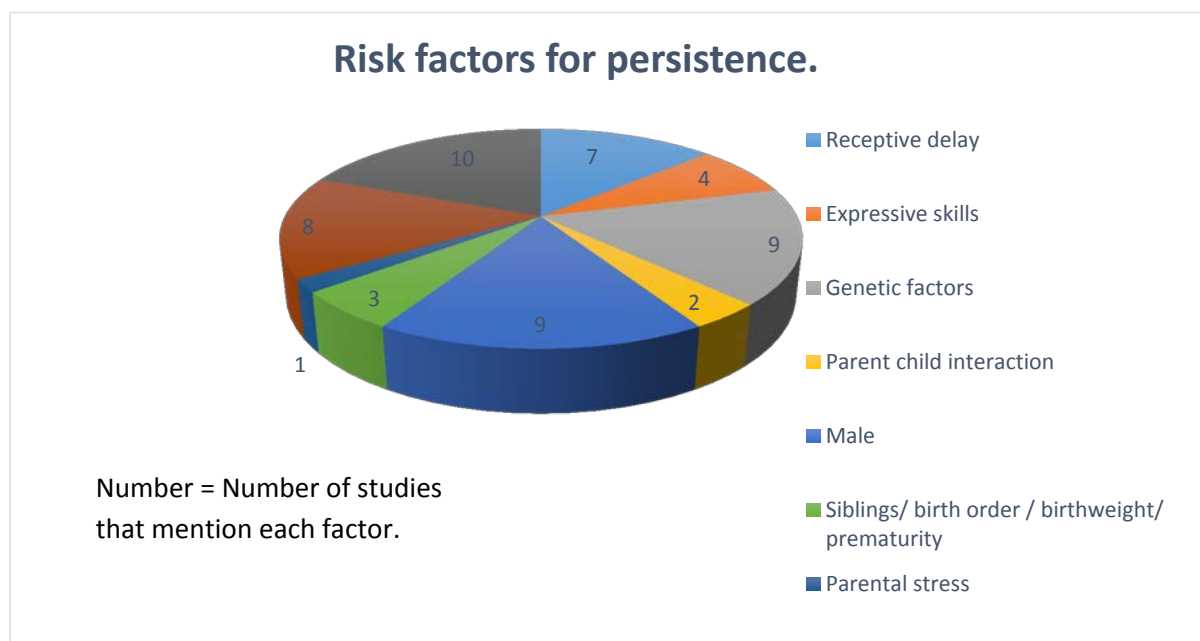
## Appendices:

### Appendix 1: Terminology used synonymously with late talkers.





## Appendix 2: Proportion of risk factors:



**Receptive language** - Paul and Roth, (2011). Rescorla, (2011). Desmarais et al, (2008). Henrichs et al, (2011). Zamabrana et al (2014). Kelly's (1998) Zambrana et al (2014)– doubles the likelihood of persistence.

**Early expressive skills** - Henrichs et al, (2011). Rescorla, (2011). Everitt et al (2013). Bishop and Edmundson (1987). Reilly et al (2009) Bishop and Edmundson (1987) - hypothesis persistence is more likely for children who have impairments across language.

**Genetic Factors** - Zubrick et al, 2007. Rescorla, 2011. Paul et al, 1991. Reilly et al, 2009. Ellis and Thal, 2008. Whitehurst and Fischel, 1994. Rice et al, 2008. Zambrana et al, 2014. Bishop et al, 2003.

Zambrana et al (2014) identify this tripled the likelihood of persistent language delay.

**Male gender** - Rescorla, 2011. Rescorla et al, 2009. Zambrana et al, 2014. Ellis and Thal, 2008. Whitehurst and Fischel. 1994. Zambrana et al, 2014. Rice et al, 2008. Dales et al, 2003

Rice et al; (2008) found that gender was a predictor at 24months, but there was no evidence it continued to be so for older children.

**Parent-child interaction** - Vigil et al, 2005. D'Odorico and Jacob, 2006.

**Siblings/ birth order/ birthweight/ prematurity** - Zubrick et al, 2007, Ellis and Thal, 2008. Whitehurst and Fischel, 1994

**Parental stress** - Rescorla, 2011

**Social disadvantage** - Locke et al, 2002, Locke, 2006 Ginsborg, 2006, Hoff, 2003, Spencer et al, 2012. Law et al 2011, Law et al, 2000. Whitehurst and Fischel, 1994. Letts et al, 2013. Desmarais, 2008. Hart and Risley, 2003.

**Maternal education** - Desmarais, 2008. Letts et al, 2013. Hoff, 2003. Hart and Risley, 2003. Law et al, 2011. Locke et al, 2002. Spencer et al, 2012

Hoff (2003) identified that mothers with low educational attainment used a decreased range of vocabulary, more direct and brief utterances and less frequently continued topics related to what their child had said.

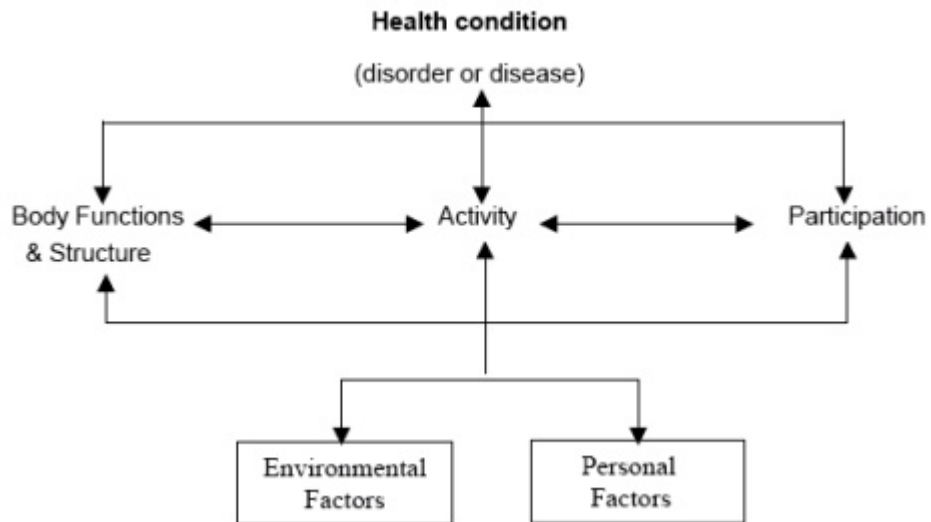
**Appendix 3: Assessments used and scores to identify language delay:**Assessments:

MacArthur Communication Development Inventory (Paul, 2004. Rescorla, 1991. Fenson et al, 1993). – below 10<sup>th</sup> percentile.

Language Development Survey (LDS) (Rescorla, 1989. Rescorla, 1991) - fewer than fifty words

Ages and Stages Questionnaire (ASQ) (Bricker et al, 1995. Zubrick et al, 2007) - -1.0 SD

Appendix 4: WHO ICF model (2001, pg.2).



**Appendix 5: PBI versus clinic – assessments and results referring to receptive language.**

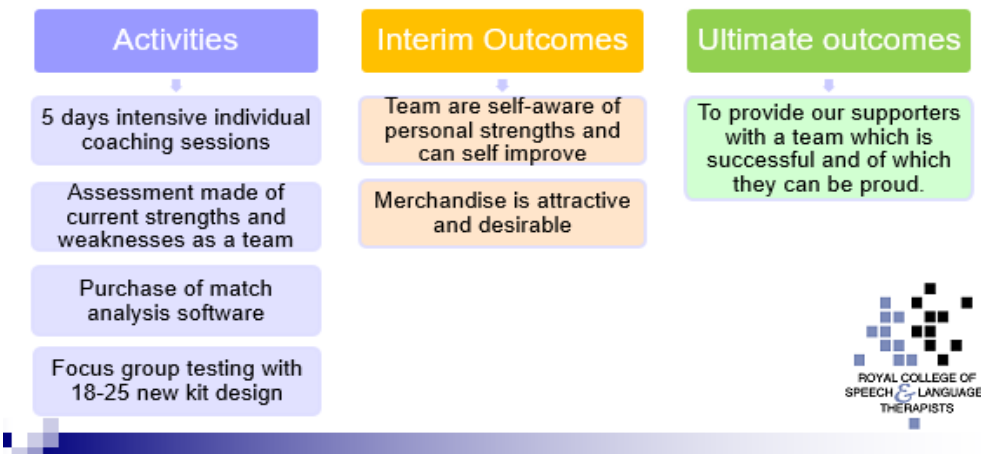
| <p><b>PBI versus Clinic. See table 2 for more information.</b></p> <p><b>Author:</b></p> | <p><b>Assessment procedures used</b></p>   | <p><b>Results reported about receptive language:</b></p>   |
|--|--|--|
| <p><b>Gibbard, 1994.</b></p>   | <p><b>Case history</b><br/> Mother's 'subjective word list' estimate number of single, two and three word utterances.</p> <p><b>Reynell's developmental language scales.</b></p> <p><b>Language sample</b> – of vocalisations during play with mother and independent play</p> <p><b>Renfrew picture test</b> – awareness of content and grammatical elements.</p> <p><b>Language scheme picture test</b> – vocabulary assessment.</p> | <p>Both expressive and receptive language reviewed through RDLS.</p> <p><b>Receptive language:</b></p> <p><b>Clinic</b><br/> pre = 16.9 Post = 30.4</p> <p><b>Parent lang. group</b><br/> Pre = 20.2 post = 38.0</p> <p><b>Parent control group</b><br/> Pre = 21.7 post = 32.5</p> <p>ANCOVA analysis of variability of results showed no significant difference.</p> <p>However when additional covariance analysis was applied, receptive language was not discussed.</p> |
| <p><b>Gibbard et al, 2004</b></p>  | <p><b>Parent survey</b> – reported estimated vocabulary and estimated phrase length.</p> <p><b>RDLS</b> – to assess receptive language</p> <p><b>Pre-school language scale – 3 (PLS)</b> – assess expressive and receptive</p> <p>MLU measured via language</p>  | <p>Receptive and expressive language assessed at pre-test phase:</p> <p><b>PLS – 3 receptive language scores:</b></p> <p><b>Mean gain:</b><br/> PBI 7.36<br/> Clinic 3.30</p> <p>Receptive language was not discussed in results.</p>  |

|                                     |   |  |
|-------------------------------------|---|--|
|                                     | sample taken during play with parents   |  |
| <b>Baxendale and Hesketh (2003)</b> | <p><b>PLS-3</b> - Receptive and expressive language assessed.</p> <p><b>Parent child interaction</b> – audio tape session of parent-child interaction<br/>MLU<br/>Intelligible spontaneous utterances were used to identified MLU</p> | <p><b>Results: from PLS – 3:</b></p> <p><b>PBI:</b><br/>Receptive (receptive/expressive) language – 7/14<br/>Expressive - 1/5</p> <p><b>Clinic:</b><br/>Receptive/expressive - 7/13<br/>Expressive - 4/5</p> <p>Do discuss receptive language in discussion.</p>   |
| <b>van Balkom et al, 2010.</b>      | <p><b>GRAMAT</b> (dutch version of LARSP) was used to identify scores of grammaticality and MLU</p> <p>Receptive language was assessed on Dutch version of <b>RLDS</b></p> <p>Mother-child interactions were analysed via video.</p>  | <p><b>1. Pre-treatment</b> (receptive score via dutch RDLS):<br/>PVHT = 7.8(mean) SD = 2.2<br/>DCI = 8.6 (mean) SD = 1.44</p> <p><b>2. Post-treatment</b><br/>PVHT = 7.7 SD = 2.3<br/>DCI = 7.8 SD.98</p> <p><b>3. Follow up</b><br/>PVHT = 9.2 SD = 3.5<br/>DCI = 8.0 SD 1.3</p> <p><b>Difference between 2 and 1</b><br/>PVHT p = .92<br/>DCI p = .08</p> <p><b>Difference between 3 and 2</b><br/>PVHT p = .09<br/>DCI p = .74</p> <p>Some discussion of receptive language.<br/>No significant difference was found between DCI and PVHT.<br/>But identify that PVHT may be helpful to support receptive language as maternal language is at an appropriate level for the child.</p> |

## Appendix 6: RCSLT theory of change model (Lowenthal, pg. 6. 2013).

### Example theory of change

Acme Football Club have not been performing very well over the last two seasons. The club and players want to make some changes to see some improvements.



## The role of the speech and language therapist in the management of selective mutism: a review of the literature

Saffron Meluish, Supervisor Pip Cornelius

### *Abstract*

**Introduction/background:** Selective mutism (SM) is a relatively rare disorder usually onset in childhood, characterized by a lack of speech in select settings. Despite being first identified over 100 years ago it remains a poorly understood and under researched disorder. This has resulted in high levels of misdiagnosis and dissatisfaction with care. Despite a multidisciplinary team (MDT) approach recognised as producing positive outcomes, there appears a lack of clearly defined roles and responsibilities amongst the wide range of professionals involved. Moreover, as well as impacting on social skills, high levels of additional speech, language and communication needs (SLCN) have been identified amongst the SM population. It therefore appears that speech and language therapists (SLTs) have a key role to play in the management of SM.

**Aims:** The review aims to discuss the current SM literature, identifying the outcomes of studies involving SLTs to explore their role in SM management.

**Methods and procedures:** A thorough search of the database CINHAL identified studies involving SLTs in all stages of the management of SM.

**Contribution/findings:** At present there is a lack of large scale, systematic research into SM management, particularly within SLT literature, suggesting children with SM are a vulnerable client group. There is a need for the development of an established care pathway that is used consistently across services. Only 15 studies involved SLT input, with 13 of these producing successful results. Key themes identified for positive outcomes included a strong MDT approach and a lengthy duration of input.

**Conclusion/clinical implications:** Despite further research being needed, tentative conclusions can be made that SLTs have a key role to play in the management of SM.

### **Introduction**

Selective mutism (SM) is a relatively rare condition, defined as ‘persistent lack of speech in at least one social situation, despite the ability to speak in other social situations’ (Royal College of Speech and Language Therapy (RCSLT), 2006). Typically, more girls than boys are affected (Smith and Sluckin, 2015) and onset usually co-occurs with school admission (Keen, Fonseca and Wintgens, 2007), the setting where most children remain mute, although traits of shyness and social phobia are commonly identified prior to this. Reported prevalence levels vary greatly within published literature, with SM considered to affect approximately one percent of the UK population (Smith and Sluckin, 2015), however many researchers deem this an underestimate.

First identified in 1877 by German physician Adolf Kussmaul, the term ‘aphasia voluntaria’ was coined to describe a number of cases of children who remained silent in certain situations. The term ‘elective mutism’ was later adopted by Moritz Tramer (1934) to label a child who would only speak in specific situations. This term remains in use by the International Classification of Mental and Behavioural Disorders (ICD-10, World Health Organisation, 2016), the diagnostic manual mainly utilised in Europe. It classifies the disorder as one ‘of social functioning with onset specific to childhood and adolescence’, and applies the following diagnostic criteria:

- Language expression and comprehension, as assessed on individually administered standardised tests within the 2 standard deviation limit for the child’s age
- Demonstrable evidence of a consistent failure to speak in specific social situations in which there is an expectation that the child would speak (e.g. in school), despite speaking in other situations
- Duration of selective mutism that exceeds four weeks
- Absence of a pervasive developmental disorder, or a specific speech or language disorder and absence of a lack of fluency in the language that is expected in the situation

Comparatively, the Diagnostic and Statistical Manual of Mental Disorders-VI (DSM-VI, American Psychiatric Association, 2013) is used more commonly in the US and Australia. The differing criteria presents one of the key debates surrounding SM, regarding the disorders aetiology and classification. Many believe the term ‘elective mutism’ implies a voluntary aspect to the child’s silence, whether at a conscious or unconscious level, bringing connotations of manipulative and oppositional behaviour. To remove these negative assumptions, the DSM-VI makes use of the term ‘selective mutism’, which is felt to simply reflect the nature of the silence.

A number of differences exist between the two criteria, for example the DSM-VI states ‘the disturbance interferes with educational or occupational achievement or social communication’, but is less specific regarding levels of language knowledge and development. Furthermore, the DSM-VI recently changed its categorisation of SM from ‘disorders usually first diagnosed in infancy, childhood or adolescence’ to an anxiety disorder, despite the nature of this disorder remaining largely debated. These differences have led to discrepancies in the children who are eligible for different types of care across different countries.

### ***SM Categorisation***

One body of researchers agree SM is best categorised as an anxiety disorder, whereby muteness occurs due to heightened levels of social anxiety. This has been supported by numerous studies identifying common anxious personality traits amongst the SM population. (Black and Uhde, 1992; Kristensen, 2001; Cunnigham, McHolm and Boyle, 2006). Some researchers go as far as to suggest SM should not be considered its own disorder, but rather a subtype or symptom of the disorder ‘Social Phobia’ or as a specific phobia of expressive speech (Omdal and Galloway, 2008).

Conversely, some believe although anxiety plays a role in SM, it is too complex and multifactorial in nature to be classified solely in this way. As stated by Cross (2004, p. 45) ‘as yet it has not been possible to untangle the emotional, behavioural and linguistic factors which lead to selective



mutism'. A growing body of research exploring co-morbidities associated with SM has identified a large proportion present with some level of additional speech, language or communication need (SLCN) (Giddan et al, 1997; Wong, 2010) despite significant SLCNs being an exclusion for an official diagnosis. One of the most recent and large scale studies (Klein, 2012) found 25% of their sample of 146 SM children presented with language disorders, referring to deficits with decontextualized language, compound and complex sentences, mean length of utterance, narrative language and the ability to verbally express thoughts. A further 12% presented with speech articulation disorder, 3% with stuttering, 1% with voice disorders and many with combined difficulties. In fact, only 19% of their sample had no level of additional SLCN. It was considered this may have even been an underestimate because of difficulties assessing language due to muteness and the incidence of subtle, higher level language difficulties likely to go unidentified by parents. It has been suggested children may develop SM as an avoidance method due to fear of being teased for mispronouncing a word, therefore a treatment method should be implemented in which the child's underlying language deficits are the focus of intervention, 'considered ahead of selective mutism' (Wong, 2010, p.25). In addition, there is some evidence of voice disorders amongst the SM population, with Dummit et al (1997) reporting cases of high-pitched, tense sounding voices amongst their study cohort.

Aside from language and speech skills, SM impacts on communication in the domain of pragmatics and social skills. SM will inevitably decrease opportunities for social interaction, reducing practice and refinement of the social skills required for successful and competent communication, perpetuating a cycle of social withdrawal and isolation. Teachers and parents have been found to rate SM children as significantly less competent in both verbal and non-verbal social skills (Cunningham, McHolm and Boyle, 2006). However, interestingly, children's self-rated results on the Perceived Competence Scale (Harter, 1982) identified no difference between SM children and controls, suggesting SM children still feel accepted by their peers. Studies of narrative ability have also suggested reduced pragmatic competence in SM children (McInnes et al, 2004). Moreover, Nowakowski et al (2011) found SM children are less likely to engage in early joint attention with parents. However, despite this clear link, it is currently an under-researched area with very few studies focusing on social skills, resulting in a lack of any strong evidence base.

Furthermore, SM is likely to have an impact on academic achievement. Studies have produced varying results, with some suggesting children perform at lower than average levels (Kumpulainen et al, 1998), and others suggesting children achieve well academically (Cline and Baldwin, 1994; Cunningham et al, 2004). However, with the National Curriculum placing increasing focus on the importance of spoken communication, it is clear further difficulties will be created for SM children in the school environment.

### ***Care Pathway***

Despite being defined over 100 years ago, SM remains a poorly understood disorder, resulting in numerous cases of late referral and misdiagnosis. One study (Schwartz, Freedy and Sheridan, 2006) identified 70% of their cohort had been misdiagnosed or never referred by primary care physicians, with it taking on average one year for an accurate diagnosis to be made following initial concerns

being expressed to a doctor. Common misdiagnoses include autism, language delay, defiance or learning disability, or an assumption being made the child will grow out of the mutism. There is much debate amongst both professionals and academics under whose remit care should lie and very few research papers have considered the influence of the professionals involved in management, resulting in no determined 'gold standard' of care. Consequently, at an anecdotal level, there appears high levels of dissatisfaction both from the viewpoint of parents and professionals.

Speech and Language Therapists (SLTs) role of supporting wider communication skills, alongside the co-occurrence of SLCN, suggest SLTs have their place in SM management. In 2006 the RCSLT followed the lead of the American Speech-Language-Hearing Association (ASHA) and included SM within the professional remit of SLTs, however it remains on a local level in the UK a number of paediatric services policies still state they do not cover the care of these children. An attempt to develop a comprehensive care pathway was carried out by Keen, Fonseca and Wintgens (2007), who used a two-round Delphi process with a number of internationally recognised professionals. Even amongst this panel of experts, debates remained surrounding which professional should take the lead management role, with SLTs and educational psychologists both feeling they were best suited. An agreement was however reached that all professionals required extra training regarding SM. Despite being developed over 7 years ago, no published evidence of this care pathway being implemented, or of its outcomes, exists. It appears a decision needs to be made as to which professional is most suited to take the key management role to ensure consistent high quality care is provided.

This literature review aims to explore the current literature surrounding the SLT's role in assessment and treatment of SM, in order to reach a conclusion as to what extent management is within the professional remit of an SLT.

### **Search Strategy**

A thorough search of the existing literature was carried out to identify all research deemed relevant to this review. Due to a distinct lack of extensive, systematic research into SM, initial search criteria remained very open. The database CINAHL was searched to identify studies including the following search terms anywhere within the text: 'selective mutism', 'elective mutism' and 'aphasia voluntaria'.

This yielded 235 results published between the dates 1978 to 2015. Although appearing a reasonable amount of data, a brief search using the terms 'autism' and 'children', a disorder with a similar prevalence (Carlson, Mitchell, and Segool, 2008), produced over 12,000 results, clearly highlighting the dearth of research in SM.

Studies identified with SM as a study exclusion criteria were immediately excluded from the present literature review.

Further exclusion criteria were as follows:

- Studies with a strong focus on bilingualism due to disagreements over diagnostic criteria

- Complex medical cases including ASD, schizophrenia, Fragile X and Pervasive Developmental Disorders (PDD)
- Studies where SM was mentioned but was not the main focus of research
- Studies with a strong focus on medical treatments – although these appear a promising treatment option for SM, it is recognised this is a treatment option outside the remit of an SLT
- Studies not published in English

SM usually presents within the paediatric population, but on rare occasions is found in adult clients. In these cases, SM usually presents alongside complex psychiatric disorders, such as schizophrenia, or cerebellar diseases. Cases of conversion mutism, a severe form of conversion voice disorder, have also been documented. The literature search resulted in only 5 studies exploring selective mutism in adults, all at case study level (Babikian et al, 2007; Bell and Espie, 2003; Hollifield et al, 2003; Jacobsen, 1995; Thorpe, Keegan and Veeman, 1985). Of these cases, four occurred as the result of trauma alongside additional psychiatric disorders, including schizophrenia and dissociative identity disorder, and one occurred in the presence of severe learning difficulties. In addition, the ICD-10 criteria classifies SM as a disorder ‘with onset specific to childhood and adolescence’. Therefore, all studies involving adult cases were excluded from this literature review.

A number of previous literature reviews discussing treatment options will be considered but not discussed in detail to minimise the inclusion of secondary sources, thus increasing the authenticity of this review.

The remaining papers were searched to identify those involving SLTs or speech and language pathologists (SLPs). The references included in these studies were scanned to identify further relevant literature.

The final inclusion criteria applied:

- Studies including the role of a SLT or SLP
- Studies involving participants with a diagnosis of SM
- Studies with a focus on SM assessment, management or treatment
- Studies published from outside the UK – although recognised different health care systems utilise different diagnostic criteria and have differing professional roles and responsibilities, this was deemed necessary due to the lack of British research.

This resulted in 15 studies fitting the inclusion criteria to be included in the following review (see table 1)

Table 1. Studies meeting inclusion criteria

| Author                           | Year | Article  | Journal  |
|----------------------------------|------|--|--|
| Klein, Armstrong and Shipon Blum | 2013 | Assessing spoken language competence in children with selective mutism: using parents as test presenters               | Communication Disorders Quarterly                                  |
| Roe                              | 2011 | Silent voices: listening to young people with selective mutism   | British Educational Research Association Annual Conference.        |
| Manassis and Tannock             | 2008 | Comparing interventions for selective mutism: a pilot study  | Canadian Journal of Psychiatry                                     |
| Sharkey et al                    | 2008 | Group therapy for selective mutism: a parents and children's treatment group   | Journal of Behavior Therapy and Experimental Psychiatry            |
| Borger                           | 2007 | The importance of a team approach in working effectively with selective mutism: a case study                           | Teaching Exceptional Children Plus                                 |
| Dunway                           | 2005 | Using a counselling approach when working with children with selective mutism  | California Speech-Language Hearing Association Magazine            |
| McInnes                          | 2004 | Narrative skills in children with selective mutism: an exploratory study   | American Journal of Speech-Language Pathology                      |
| Cleator and Hand                 | 2001 | Selective mutism: how a successful speech and language assessment is really possible                                   | International Journal of Language and Communication Disorder       |
| Hungerford, Edwards and Iantosca | 2003 | A socio-communication intervention model for selective mutism  | American Speech-Language-Hearing Association Convention            |
| Amari et al                      | 1999 | Treating selective mutism in a paediatric rehabilitation patient by altering environmental reinforcement contingencies | Paediatric Rehabilitation  |
| Giddan et al                     | 1997 | Selective mutism in elementary school multidisciplinary interventions  | Language, Speech and Hearing Services in Schools                   |
| Davies and Winter                | 1996 | Mute in mainstream   | Bulletin of the Royal College of Speech and Language Therapists    |
| Watson                           | 1995 | Successful treatment of selective mutism: collaborative work in a secondary school                                     | Child Language Teaching and Therapy                                |
| Harris                           | 1993 | Elective mutism with accompanying phonological disorder: a case report   | National Student Speech Language Hearing Association Journal       |
| Khron, Weckstein and Wright      | 1992 | A study of the effectiveness for a specific treatment of elective mutism   | Journal of the American Academy of Child and Adolescent Psychiatry |

It is recognised it would have been useful to discuss research into management not inclusive of a SLT and compare outcomes, however this was not in the scope of this review. This is an area for further research.

## **Discussion**

The role of the SLT and other professionals in the included studies will be discussed. The studies have been grouped into those that relate to the assessment of SM and those which relate to the intervention of SM.

## **Assessment**

It is strongly agreed SM children should have their SLCNs assessed, whether to rule out SM, or identify comorbid difficulties. SLT's have the necessary skills to carry out such assessments, and typically have experience in assessing SLCNs in children presenting with a wide range of needs. However, clearly language assessment for a mute child is challenging, particularly assessment of expressive language. Although assessments requiring no verbal output can be utilised, such as the Peabody Picture Vocabulary Test (PPVT) (Dunn and Dunn, 1981), which assesses receptive vocabulary at single word level through a finger pointing response, these fail to provide a comprehensive language profile. Furthermore, some SM children have been identified as reluctant to engage in non-verbal communication. A strong reliance is therefore placed on parental reported information. More recently, SLTs have been researching innovative methods in which to better assess the language of these children. However, research remains sparse, and only three studies relating to speech and language assessment in SM were identified.

Cleator and Hand (2001) carried out a study to identify a method in which the speech and language skills of SM children can be successfully assessed. They made use of situations in which the child feels most comfortable by videotaping five SM children during conversations with family members in the home environment, then analysed these using the Language Assessment, Remediation and Screening Procedure (LARSP) (Crystal, Fletcher and Garman, 1989) and social conversational analysis. Further formal language assessments were implemented, including the PPVT, Test of Auditory Comprehension of Language (TAACL) (Carrow-Woolfolk, 1985), Reynell Developmental Language Scales-Revised (Reynell, 1982), and Smit-Hand Articulation and Phonology Evaluation (SHAPE) (Smit and Hand, 1997). Results indicated varying communication difficulties in 4 of the 5 children, a higher level than earlier research suggests, including difficulties with syntax, semantics, speech, prosody, fluency and speech acts, with no one identifiable pattern. However, results must be taken tentatively, as assessment results were not published within the paper and, due to the nature of the study, DSM-VI diagnostic criteria (e) was not applied in this study, making it unsurprising results indicated higher prevalence of communication difficulty. Despite this study identifying videotapes as a promising method of assessment, they failed to successfully carry out all the formal assessments with all the children.

Klein, Armstrong and Shipon-Blum (2013) illustrated a more successful attempt at administering formal assessments by utilising parents as test presenters. Despite heavy

parental involvement being routinely mentioned throughout SM literature, this appears the first study to focus solely on its efficacy. The study, one of the largest SM studies to date, compared results of formal assessments of 33 SM children when carried out by SLPs and parents following SLP training. Order of assessment was randomised, eliminating familiarity with assessments impacting outcomes. Parental sessions were found to be highly successful, with 96% adherence to test procedures when a randomised third were rated. A number of standardised norm-referenced measures, all with high levels of reliability and concurrent validity, were used to measure language ability, including the PPVT, the Expressive Vocabulary Test-2 (EVT-2) (Williams, 2007), a test of expressive vocabulary at single word level, and the Test of Narrative Language (TNL) (Gillam and Pearson, 2004), which is divided into two subtests; comprehension (TNL-C), requiring verbal responses to orally presented pictures, and oral narration (TNL-O). Narratives were assessed as they are deemed as important to everyday communication as well as a clinically useful indicator of pragmatic competence, higher level discourse skills, such as complex sentences and cohesion, and a strong indicator of linguistic maturity.

13 of the children, whose results were excluded from analysis, would not engage in verbal assessment, and one child in any assessment, with the therapist, meaning if parents had not been utilised, no standardised measures of language would have been gathered. As hypothesised by the authors, assessment scores were significantly higher when carried out with parents, illustrating professionally administered tests are likely to underestimate language capabilities with this client group. When assessed by parents, no statistical differences were found between measures of receptive and expressive language at single word level. Narrative comprehension results were significantly lower than single word measures, albeit within 1 standard deviation of the population, and oral narrative results were the poorest of all measures, often at 1 standard deviation lower than narrative comprehension. Although narrative comprehension required verbal responses, the fact scores did not drop significantly below average range until oral narrative production means it can be deduced difficulties lie not within spoken language per se, but rather with narrative telling and decontextualized language tasks, with 42% exhibiting expressive narrative deficits at or below the 5<sup>th</sup> percentile. The study concludes with a suggestion for a pathway of care, stating SM children performing within normal range for all language measures should receive specific SM therapy, whereas children who do not perform within normal range on the TNL should also receive support from an SLP.

Despite the focus of their study being language abilities in SM and not methods of assessment, McInnes (2004) further demonstrated the efficacy of utilising parents as test presenters to implement formal language assessments. The narrative abilities of 7 SM children were compared to a group with social phobia matched for receptive language abilities. The Strong Narrative Assessment Procedure (SNAP) (Strong, 1998), a formal assessment which requires the participant to listen to, retell, and answer questions about a story, was implemented by parents in both the home and clinic environment. Assessment results showed discrepancies between clinic and home environments, with the length of answers in clinic being shorter at a statistically significant level, indicating language abilities

can be much more accurately assessed in the home environment. Results were supportive of the significant levels of higher level language difficulties identified in the previous study. Large effect sizes for the use of subordinate clauses, internal character responses and initiating events were evident, with SM children performing more poorly than children with social phobia, highlighting the need for detailed language assessment even when surface level language skills appear normal.

It appears clear SM children require a thorough assessment of their SLCN, and the clinical knowledge of SLTs makes them the best placed professional to identify language difficulties that may go unnoticed by untrained individuals. It also appears assessment is most effective when SLTs adopt a different approach that includes parents in formal assessment. However, the dearth of research and failure to implement assessments with a number of the study subjects means assessment is an area that evidently needs further research in order to identify successful and standardised procedures to be implemented amongst the SM population.

### ***Intervention***

A range of different intervention methods have been described in the literature, including pharmacological methods (Copur, Gorker and Demir, 2010), behavioural approaches (Bergman et al, 2013; Hung, Spencer and Dronamraju, 2012; Casey, 2011; Vecchio and Kearney, 2009; Beare, Torgerson and Creviston, 2008; Facon, Sahiri and Riviere, 2008; Lescano, 2008; Amari et al, 1991; Reid et al, 1967), cognitive-behaviour therapy (Oerbeck et al, 2014; Reuther, Davis and Matsom, 2011; Watson, 1995), psychodynamic psychotherapy (Omdal and Galloway, 2007), family therapy (Afnan and Carr, 1989) and creative based therapies, including drama, art and play (Fernandez, Serrano and Tongson, 2014; Oon, 2010), as well as some more specific approaches, including social problem solving (O'Riley et al, 2008), counselling (Dunway, 2005), language training (Pecukonis and Pecukonsis, 1991) and social-pragmatic based approaches (Hungerford et al, 2003), and multimodal treatments consisting of a combination of two or more of the above approaches (Stegbauer, 2002; Mitchell and Kratochwill, 2013; Sharkey et al, 2008; Giddan et al, 1997; Borger et al, 2007; Steinhausen et al, 2006). The most successful appear to be behavioural approaches, which make use of techniques such as shaping, stimulus fading, desensitisation and reinforcement. A recent trend appears to be the movement toward a more pragmatic approach to treatment, where SM is considered as a global deficit in communication rather than a specific deficit in speech.

It is beyond the scope of this review to analyse all the intervention literature surrounding SM treatment. Rather a focus will be taken on interventions including SLTs, and analyse their level of involvement. Of the treatment focused studies identified, twelve of these include an SLT to some extent. However, this varied greatly, indicating the lack of consensus over the SLTs role.

In two studies, SLTs had limited involvement in the intervention process. Khron, Weckstein and Wright (1992) used a multimodal treatment approach known as the Hawthorn Approach

with twenty SM children. One child was referred via an SLT, but SLTs were not involved any further in the process. This was despite three of the children presenting with an articulation disorder, and one presenting with combined articulation disorder and delayed speech. Although all 17 of the 20 children had 'excellent' outcomes, defined as 'complete resolution of all speech difficulties' with 'no signs of maladjustment in other areas of functioning' (p.714), it can be argued that involvement of a SLT to target comorbid speech needs would have further improved results. There was however no correlation between comorbid speech difficulties and treatment outcomes.

Borger et al (2007) also highlighted SLTs are often the first professionals involved with SM children. However, in this case study, which used the detailed viewpoints of different professionals to explore the outcomes of multidisciplinary team (MDT) working, once identified to have no additional SLCNs, the SLP passed the case on to a psychologist to carry out intervention. Despite the SLP having no further involvement, this case still highlights the need for SLTs to be well trained in the identification and assessment of SM, providing them with the skills to make appropriate and timely referrals. It would have been useful to include the SLP further in the study, to explore their views of their role in SM management, and to justify the reasons why they felt no further involvement was deemed necessary.

In comparison, in a number of cases, both involving children with and without additional SLCNs, SLTs have been considered an integral part of the MDT. Seven studies report SLTs having a positive impact on the outcomes of SM.

In four identified studies producing positive outcomes SLTs have taken the lead role in management. The earliest of these (Watson, 1995) involved a CBT approach written by an SLP and carried out in close partnership with school staff in the case of a 10-year-old SM female, presenting with significantly delayed developmental milestones, including speech and language. An integral aspect of the approach was education of staff, as it is reported 'teachers often feel distressed when working with selectively mute pupils' (p. 168). This aimed to change expectations of teachers who had grown to accept mute behaviour. A hierarchal, stimulus fading approach was utilised, with a low key reaction to speech to avoid drawing unwanted attention to the child, and a key focus on desensitisation to communicating thoughts, feelings and being heard during twice weekly sessions. A holistic approach, commonly emphasised by SLTs, was taken through close involvement of the child's social network. The final stage of intervention applied the Social Use of Language Program (SULP) (Rinaldi, 1993), often used by SLTs, in group sessions. Despite the lack of quantitative, objective outcome measures, the rich qualitative results are promising, with the child speaking appropriately to school staff as well as individuals beyond the school environment post treatment, and the child herself reporting satisfaction and appreciation for the techniques implemented. However, it is noted the child still only spoke when necessary and did not freely initiate conversation. Moreover, the process was time consuming and lengthy, with intervention spanning 13 school terms, limiting the practicality of this method. A final note is the therapist in the study concludes although SLTs should be an integral part of the MDT, sole treatment is beyond their professional remit, and close liaison with other professionals is key.



The lengthy treatment duration appears common to many SM treatments. This is again illustrated by Davies and Winter (1996), who used 'Breaking Down the Barriers' (Johnson and Glassberg (1999) cited by Davies and Winter (1996)), a well-established but unpublished SM treatment manual developed by East Kent community SLT department in consultation with a group of SM children. The program, which uses behavioural techniques, was implemented in the case of a 2;4 SM male with a comorbid phonological disorder and mild language delay by a learning support assistant in consultation with a SLT. Despite fairly positive final results, with the child speaking in class with four other children and four adults present, this took 33 weeks of daily sessions. Moreover, it took 60 sessions before the child produced their first word. It can therefore be questioned how practical this is in real life clinical situations.

A paper presented at the American Speech-Language-Hearing Convention (ASHA) described a social-pragmatic approach to intervention (Hungerford, Edwards and Iantosca, 2003), which stems from the belief 'SM is a profound pragmatic communication disorder and is within the scope of practice of SLPs'. This model, which is perhaps more familiar to SLTs, stems not from a psychiatric or operant conditioning theoretical viewpoint, but rather from social communicative and pragmatic development, incorporating speech and situation variables as well as verbal and non-verbal social engagement through activities emphasising turn-taking, social reciprocity, shared focus and joint attention. Rather than focusing on one root cause of SM, this approach addresses SM as a multimodal disorder, believing it is a psychological, psychiatric, learning and communication disorder and a family problem, therefore requires a strong MDT to carry out intervention. Illustrated through the case of a SM child presenting with an absence of nonverbal behaviour, eye contact and engagement in joint activity, sessions were primarily carried out by an SLP in consultation with other professionals. Despite being ongoing at the time of publication, reference is made to significant functional gains, with the child engaging in normal interaction in a range of settings. The preliminary positive results are indicative this may be an intervention worth further research.

Dunway (2005) discussed how SLPs are the best placed professional to lead management, due to 'expertise in language facilitation' and understanding of 'the complex psychological and behavioural dynamic required to change how individuals communicate' (p.10). She stresses subtle counselling strategies, in which SLPs are highly skilled, should be adopted, alongside behavioural strategies implemented during play activities in conjunction with classroom staff, which is illustrated in a brief case study. However, written by an SLP, a strong professional bias appears to exist in this article, and the lack of methodologically sound research and peer review means the conclusions of this paper are low in validity.

Other studies have placed a stronger focus on MDT working. Another key professional in the management of SM across both research and clinical practice is educational psychologists, with two papers yielding highly positive results through joint SLT and psychologist working. Giddan et al (1997) highlighted the need for SLPs and psychologists to work closely together, and made note of the psycholinguistic expertise an SLP can bring. An MDT involving an SLP, psychologist, psychiatrist and the class teacher implemented behavioural and psychotherapy interventions with a child enlisted in a behavioural difficulties special educational needs (SEN) program, with numerous comorbid SLCNs, including phonological and syntactic errors

patterns and pragmatic deficits. The psychologist implemented a one-day intensive session to commence treatment, whereby the child was required to speak to the therapist before returning home. Although the ethics of this method can be questioned, it was effective in eliciting speech in the child. Following this, an intervention program was implemented, consisting of twice weekly group sessions with the SLP and class teacher, weekly individual psychotherapy sessions, and twice weekly individual SLT sessions. Methods included psychoeducation, stimulus fading with positive reinforcement, and SLT work on articulation and syntax.

Although outcome measures are only reported in the qualitative subjective manner of the professional's observations, this appeared an effective, albeit lengthy and intensive, technique, establishing full voice within one and a half years of commencing intervention. However, no note is made of the child's speech or language abilities post-treatment, the aspect of treatment in which with SLP played the largest role. This study has clinical applications, again concluding with SLP guidelines, suggesting they are best suited for initial assessment and intervention in close connection with teachers and parents. It recognises cases may be beyond the professional remit of an SLP, and following two months of unsuccessful SLP treatment, referral to mental health professionals is necessary.

Sharkey et al (2008) again made use of conjoint psychologist and SLT working using behavioural and psychoeducational approaches. This study builds on that previously discussed by recruiting a larger, albeit still small, cohort of 5 families of SM children to partake in separate parental and child group sessions run by three psychologists and an SLT. It is key to note, unlike the previous studies utilising SLTs, none of the participants had comorbid SLCNs. This study further strengthens previous research by making use of multiple quantitative outcome measures, improving the reliability and validity of results, and appears a highly promising treatment method. Scores on the Children's Global Assessment Scale (CGAS) (Shaffer et al, 1983), a rating scale of a child's level of functioning, increased post therapy, as well as clinical observation identifying decreased measures of anxiety and an increase in both verbal and non-verbal behaviours, all at statistically significant levels ( $p < 0.05$ ). Therapy gains were maintained at a six-month follow-up, and two children no longer met SM diagnostic criteria. Positive outcomes were evident after just 8 once weekly sessions, a much shorter duration than needed in many studies. In addition, a holistic approach, often advocated by SLTs, was taken by targeting both children and their parents. Group therapy appears a highly practical way of working for many SLTs with already stretched caseloads, and provides both children and parents with a support network. The positive outcomes are suggestive SLTs and psychologists make an effective MDT in the treatment of SM, however it is difficult to determine whether results would have differed if treatment was implemented by a single professional body. Unlike the previous study, teachers were not included in the intervention process and no work was carried out on generalisation to the classroom setting. Although inferred, no direct measures of improvement beyond the clinical setting are mentioned, so teacher reported outcome measures would have been useful in strengthening the study results.

Amari et al (1999) emphasised the need for a wider MDT in a case control study which utilised a multiple baseline across settings design to investigate a behavioural treatment in a 7-year-old SM female in a rehab setting following orthopaedic surgery. In conjunction with a medical team, a SLT developed a program consisting of graduated reinforcement and stimulus fading which was implemented by all individuals in contact with the child. Following differential praise for verbal behaviours, positive results were produced, with the child producing an average of 110.7 words during half hour therapy sessions, compared to no vocalisations produced during baseline measures. Generalisation effects also occurred, with an average of 88.4 words produced in half hour classroom observations at a 13 week follow up.

However, not all studies involving SLT input have produced positive outcomes. Harris (1993), an SLT, was the sole professional involved in the treatment of a 5;4 SM male with an accompanying moderate-severe phonological disorder. The therapist utilised the Cycles Approach (Hodson and Paden, 1983) and auditory bombardment to target a range of sounds, closely involving the mother to elicit speech on video and later analysing these during therapy sessions. Despite evidence of considerable phonological improvement, little progress was made with the child's SM following four weeks of therapy, challenging studies which suggest children may benefit from approaches focusing on speech and language targets instead of a direct focus on SM (McInnes and Manassis, 2005). Conclusions may be drawn SLTs are therefore not the best placed professionals for SM intervention, but it must be noted intervention focused solely on speech sounds and made no attempt to address the SM. It may therefore be the approach as opposed to the professional that resulted in less than favourable outcomes. Furthermore, the duration of input was much shorter than many other studies which are suggestive intensive and lengthy treatment is needed. Follow up beyond this study indicated more positive SLT input, with the school based SLT reporting improvement in SM following enrolment in group speech therapy sessions, with the belief these allowed the child to 'see first-hand that other children have speech problems' (p. 82). This is in line with theories suggesting children may develop SM as an avoidance method due to heightened sensitivity around speech difficulties and fear of being teased by peers (Wong, 2010).

Moreover, this study illustrates a way in which SLTs are able to adapt their approaches to work with SM children, through training and close involvement of parents, showing SLT is possible even in cases where the child will not communicate verbally. The SLT involved in this study did however identify the role may have been fully outside of their professional remit, noting the involvement of a psychologist would have been highly beneficial. However, the parents were unable to pay for this input due to financial issues. This situation is unlikely to occur in the UK due to NHS healthcare, leaving more scope for MDT working to ensure best outcomes. It does however suggest parents deem SLT input as valuable.

The positive parental views of SLTs in SM intervention are further illustrated in a retrospective study by Manassis and Tannock (2008), who compared outcomes of medical versus non-medical based treatments in 17 SM children, who were recruited via a larger study. Despite SLT or psychotherapy not being offered due to resource constraints, 5 families

chose to obtain speech therapy privately, suggesting parents deem speech therapy as value for money. However, the results of the study illustrate a trend towards a greater, albeit non-significant, CGAS improvements in the absence of additional therapy, indicative SLT can actually have a negative impact on SM outcomes. The results however are difficult to analyse, as no differentiation is made between the outcomes of psychotherapy and SLT. Moreover, the study fails to describe whether the children had additional SLCN, or the focus of the SLT input.

Although few studies have included the child's view of therapy input, one such study (Roe, 2011), which aimed to do so through the use of questionnaires, found children also view SLTs as positive in helping to deal with their SM. Participants were recruited through the Selective Mutism Information and Research Association (SMIRA), allowing a nationwide sample to be targeted. Of the 30 families who returned completed questionnaires, 4 children received specific SLT input. A number of other children received behavioural therapy delivered by SLTs, however the exact figure is not specified. Despite outcomes of specific SLT input being defined only through vague descriptors, two participants reported 'positive' outcomes and two reported 'mixed' outcomes. More importantly, three out the four children reported SLTs were helpful in dealing with their SM. SLTs also received the highest total number of positive comments of all professionals, with a total of 15. Despite being highly subjective in nature, this study presents the unique insight of clients. However, it would have been useful for treatment methods to be discussed in more detail, allowing replication and further exploration of treatments deemed as successful by clients.

Despite not meeting the inclusion criteria for this review, as it is not inclusive of an SLT, research by Pecukonis and Pecukonis (1991) adds an interesting point to this discussion. They utilised a language training model (Gray, 1968), one previously implemented successfully by SLTs in cases of childhood aphasia, autism, echolalia and intellectual handicaps, with a 7-year-old SM male. The model, which usually progresses through four steps; attention training, non-verbal imitation, verbal training and functional language training, was adapted to treat a child whose SM was characterised by extreme response latencies, tense monosyllabic utterances and impaired non-verbal attending, alongside comorbid developmental delay, intellectual limitation and depression. Outcomes appeared highly effective, with the set criterion for functional language abilities reached in 22 days and spontaneous generalisation occurring. As this is an approach already familiar by many SLTs little additional training would be required before its implementation. However, as in many other studies, the treatment was intensive, with 5 weekly sessions carried out over a period of 6 weeks, so the practicality of this treatment can be brought into question.

## **Conclusion**

Despite a dearth of research and inconclusive results, these studies are suggestive SLTs do have a role to play in the management of SM. As a number of studies mention, SLTs already possess the necessary skills and theory, such as knowledge of communication development

and counselling skills, needed to work with this client group, and are able to adapt a range of familiar approaches to implement them successfully. In many cases SLTs are likely to be the first professionals to come into contact with SM children, as, despite debates surrounding classification, SM initially presents as a disorder of communication. In addition, 10 of the 15 studies discussed included participants with some level of SLCN, an incidence level higher than previous research has indicated, suggesting SLT input is desirable in many SM cases. However, it is recognised the incidence of SLCN across these studies is likely not to be reflective of the SM population as a whole, as studies exclusive of SLTs were not included in the present review. High levels of SLCN in SM children are however fairly well established across the literature.

Studies into assessment indicate all SM children require a thorough assessment of their SCLN, regardless of whether a SLT is involved any further in the intervention process. Not only is this a crucial aspect in developing a differential diagnosis, SLTs possess valuable clinical knowledge of language abilities and higher level language deficits that may go unidentified by untrained individuals. Therefore, even if not the lead professional in management, SLTs require a good understanding of SM, allowing them to administer thorough assessment and make timely and appropriate referrals.

The role into intervention appears less clear cut. The majority of studies utilising SLTs produced positive outcomes, with only 2 negative results. It is difficult to determine the reasons for negative outcomes, and these were not explored in detail in the studies. The focus of intervention in Harris' study was the child's speech sound difficulties as opposed to the SM suggesting, unlike some research suggests, an approach which fails to place focus on the SM may not be effective. The reasons for negative outcomes in Mannis and Tannock's study (2008) when an SLT was involved are more difficult to determine as little detail is provided of the actual therapy received or the knowledge of the professionals implementing the therapy.

Most positive outcomes occur in studies making use of an MDT, which closely involves parents and school staff, alongside a range of professionals. It is difficult to determine which outcomes were specifically produced by SLTs, therefore a suggested area for further research is the comparison of studies including and excluding SLTs to identify trends in outcomes. This does however help provide the guideline that a strong MDT model, one in which SLTs commonly work, is successful. SLTs are often already placed in the classroom environment where SM most frequently presents, therefore appear in the best placed position to work closely with school staff to implement an effective program that can be reviewed and updated regularly. A further important aspect appears to be the education of others, particularly school staff and parents, which can be easily implemented if a MDT approach is adopted.

A final common theme across the literature is the lengthy and intensive input required for positive outcomes. This may limit the practicality of SLTs being the lead professional in management in the UK, where healthcare budgets are limited and many caseloads are already stretched. It must be noted the majority of studies have been conducted outside of

the UK, where private healthcare means SLTs possibly have more of a scope to be involved in intensive treatment. The influence of differing professional roles and cultural views must be taken into consideration when interpreting the literature. This lengthy duration again highlights the importance of strong MDT working, as school staff and parents are able to implement techniques on a daily basis and help with generalisation across settings.

A currently under researched but seemingly promising intervention model for SM appears to be group work, which helps manage issues of limited therapy funding. Despite only one study focusing on group work (Sharkey et al, 2008), this study produced positive results in the shortest duration. Group work is common for SLTs, and allows treatment of several children to be carried out at once. As SM is a relatively rare disorder, groups consisting of several SM children may be difficult to set up. However, the participant in Harris' study (1993) made improvements in SM following group sessions focusing on speech sound disorders with non SM children, suggesting the group would not need to be made solely of SM children.

A further promising area appears to be pharmacological treatments. Most commonly antidepressant medication is prescribed in the form of serotonin reuptake inhibitors (SSRI's) which work to decrease anxiety levels. These have not been discussed within this review, as this is a treatment outside the professional remit of SLTs. In most cases medical treatments have been prescribed alongside other forms of therapy, such as behavioural treatments, and tend to be a last resort if other therapy is unsuccessful. If future research demonstrates pharmacological approaches should be the main treatment modality, further questions will be raised about SLT involvement in SM management. Although still able to play a role in diagnosis and within the MDT if a multimodal approach is implemented, SLTs would clearly be unable to take the lead professional role.

## **Limitations of Review**

Despite some conclusions about the role of the SLT being reached, these must remain tentative as the current SM literature presents with a number of methodological flaws, particularly regarding the lack of large scale studies utilising objective, standardised outcome measures. Of the papers discussed, 9 explored single cases, with the largest study recruiting only 33 participants. Despite SM being a relatively rare disorder, this remains a small sample size, making it difficult to generalise findings across the general SM population. Furthermore, the majority of outcomes are reported in a highly subjective manner, and a lack of standardised outcome measures for SM makes comparison of research results difficult. There also fails to be any substantial follow up to evaluate long term impacts of interventions, with only four of the studies discussed carrying out any formal long term outcome measures, the longest of which was 6 months. More recently, a number of more methodologically rigorous studies into SM treatment have been carried out, helping build on research flaws, such as a randomised control trial (RCT) by Oerbeck et al (2014), which randomly assigned 24 SM children to treatment versus control groups to explore defocused communication and behavioural treatments, then conducted a one year follow up, and a RCT by Bergman et al (2013) which investigated integrated behaviour therapy in a group of 21 SM children.

However, neither of these RCTs included an SLT in the intervention process, so were not within the inclusion criteria of this review.

A further limitation making comparison of results problematic is the differing use and rigour of diagnostic criteria and individual characteristics of participants. 10 of the studies fail to mention the use of a formal diagnostic criteria. Even amongst the studies utilising formal criteria, the rigour with which these are applied vary and individual SM symptomology greatly differs, for example the participant in Hungerford, Edward and Iantosca's study (2003) failed to engage in any verbal communication or joint attention activities at baseline, whereas the participant in Borger et al's study (2007) engaged in appropriate verbal and non-verbal behaviours during play with peers, such as gestures and laughing. Moreover, some studies use bilingualism as an exclusion criterion due to disagreements around SM diagnosis in bilingual children, whereas four studies include bilingual participants. Similarly, some studies exclude children with learning difficulties and SLCNs, whereas a number are inclusive of these children. A final key difference appears to be the age range, with the youngest participant aged 2;4 and the oldest 14 years. It is well established SM is easier to treat in younger children, where behaviours are not so entrenched. Surprisingly, however, there appears little correlation between individual characteristics and therapy outcomes.

In conclusion, SLTs appear to have a role to play in SM management, but further research is needed to determine the extent of their role. Large scale quantitative studies using rigorous methodologies, such as randomised control trials, are needed to determine the most effective approaches to SM management to ensure these children receive consistent high quality of care that provides the most positive outcomes and prevents these children from slipping through the net.

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## **The role of oral hygiene in prevention of aspiration pneumonia in the elderly population living in nursing homes: a review of the evidence.**

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### *Abstract*

**Introduction** Incidence and mortality rates of aspiration pneumonia (AP) are particularly high in the elderly population living in nursing homes. Numerous risk factors exist that increase the likelihood of developing AP. Poor oral hygiene is one risk factor that unlike others, has the potential to be eliminated through oral health care (OHC) methods. Unfortunately, various barriers in the health care system mean that OHC is regularly administered to insufficient standards and for this reason the oral hygiene of elderly residents is often poor.

**Aims** The aim of this literature review is to establish whether good oral hygiene is important in preventing AP in the elderly population living in nursing homes.

**Methods** A systematic review of literature was completed to identify empirical studies that investigated the relationship between oral hygiene/oral health care and aspiration pneumonia. Using electronic databases and reference lists of found papers, 10 final articles met the inclusion criteria and have been used in this review.

**Findings** In spite of various methodological limitations and inconsistencies, findings highlight that there is a significant association between poor oral hygiene/lack of additional OHC and AP.

**Conclusion** This review is suggestive that good oral hygiene is important in preventing AP in the elderly population living in nursing homes. As a preventable risk factor it is important to explore practical ways in which poor oral hygiene can be reduced. This paper accentuates the need for increased commissioning, care staff training, multidisciplinary working and a set of national guidelines. More robust empirical evidence is needed in order to make accurate clinical recommendations for the delivery of OHC.

**Impact statement** This review synthesises existing research on the relationships between poor oral hygiene/ lack of OHC and AP, providing grounds for OHC policies and further research.

### **Introduction**

Aspiration pneumonia (AP) occurs when bacteria from the oropharyngeal flora are misdirected into the trachea instead of the oesophagus. Subsequently, this bacterium is then directed into the lungs, where if not eradicated by the immune system, AP occurs. The incidence rate of AP ranges across populations however, is particularly high in the elderly population living in nursing homes (Medina-Walpole and Katz, 1999) with mortality rates ranging from 12 to 21% (El-Solh, Akinnusi and Alfarah, 2009). Elderly individuals living in nursing homes are more likely to die from AP than any other infection (Engelhart et al, 2005). As a result of advancements in medicine and disease detection the number of elderly individuals living in nursing homes in the United Kingdom is increasing. The population of

those over 65 years has increased by 30 million from 1984 to 2014 (National Statistics, 2015) and as AP is most commonly associated with this elderly age group, it is likely that the incidence of AP is also increasing.

Various risk factors such as increased age (Langmore, 1998; Bassim et al 2008), dependence on others (Langmore et al., 1998; Bassim et al., 2008), dysphagia (Langmore, 1998; Quagliarella et al 2005; Kikutani et al, 2015), being dentate (Scannapieco, 1999) and reduced activities of daily living (Kikutani et al, 2015) increase the likelihood that an individual will develop AP. A gender imbalance has also been noted, suggesting that men are more susceptible to onset of the disease (Hibberd et al, 2013).

Poor oral hygiene is one risk factor that, unlike others, has the potential to be eliminated. This risk factor has been investigated in numerous studies (Langmore et al., 1998; Adachi et al., 2002; Yoneyama et al., 2002 ;Abe et al., 2005; Quagliarella et al., 2005; Abe et al., 2007; Adachi et al., 2007; Bassim et al., 2008; Ishikawa. et al., 2008; Kikutani et al., 2015). Oral hygiene can be defined as the 'scientific care of the teeth and mouth' (Xavier, 2000, p49). Indicators of good oral hygiene include: moist mucosa, clean teeth, pink tongue, absence of ulcers, well fitting dentures and healthy gingiva (Adams, 1996). When oral hygiene is poor, bacteria colonisation increases, making AP more likely due to the increased likelihood of aspiration of harmful pathogenic units (Illsley, 2012).

Good oral hygiene can be achieved through oral health care (OHC) procedures, which aim to prevent the build up of bacterial units (Chalmers and Pearson, 2005). It has been identified by Macentee, Throne and Kazanjuan, (1999) that OHC should be provided daily in order to ensure good oral hygiene. OHC should involve achieving and maintaining oral cleanliness, keeping the oral mucosa moist and removing debris and plaque from teeth (Mallett and Dougherty, 2000). Specific OHC procedures range in different settings, however, it is expected that individuals have their teeth brushed for two minutes twice a day with a toothbrush and fluoride toothpaste (Curzio and McCowan, 2000; National Health Service (NHS), 2013).

Achieving good oral hygiene through OHC measures is associated with a reduction in AP Incidence (Mojon, 2002; Sarin et al., 2008) and mortality (Sjogren, 2008), which highlights the importance of OHC methods and oral hygiene. OHC and good oral hygiene are not only associated with a reduction in AP incidence and mortality but also an improved quality of life (Ueda, 2005), as they allow individuals to eat, drink and talk with confidence and comfort (Chalmers, Carter and Spencer 2003).

Individuals in nursing homes often rely on care staff to provide OHC, however, various barriers in the health care system mean that OHC is not always performed to a sufficient standard. Funding limitations mean that staff may not be trained to adequate standards and therefore may not understand the implications of poor oral hygiene. This, alongside low staffing levels, means that staff are often unable to provide OHC to satisfactory standards due to time constraints and large caseloads. These barriers often result in poor oral hygiene among many elderly individuals and therefore an increased risk of developing AP.

The high incidence and mortality rates of AP combined with the modifiable nature of poor oral hygiene indicates a need to investigate the relationship between oral hygiene and AP. The purpose of this review is to evaluate existing empirical research in order to determine the effectiveness of oral hygiene in preventing AP in the elderly population in nursing homes, and to provide a coherent synthesis of this research in order to guide future clinical recommendations.

## Review Of Literature

### Method

#### *Search methods*

In order to see if good oral hygiene is important in preventing aspiration pneumonia in the elderly population in nursing homes, a systematic search of literature was completed between May 2015 and October 2015 using the search terms and Boolean operators in table 1.

**Table 1: Search terms**

| Search term number | Words and Boolean operators used in search                               |
|--------------------|--|
| 1                  | Oral hygiene OR oral care OR oral health                                 |
| 2                  | Aspiration pneumonia   |
| 3                  | Elderly OR older OR geriatric  |
| 4                  | Nursing home OR care home OR residential care OR long term care facility |

These search terms were then combined in numerous ways in order to identify relevant articles (see appendix A), which were then screened to identify papers that met the inclusion criteria. A narrative search and backwards/forwards citation searches also identified papers which were relevant to the topic but which did not meet the criteria for inclusion. These papers contribute to the discussion but are not included in the review. Overall, search terms were entered into five online databases: CINAHL plus full text, Scopus, Cochrane Library, AgeInfo and Medline (PubMed).

A flow chart representing the process of the systematic search is included in appendix B. Three of the five databases searched yielded the 10 final studies (CINAHL, Scopus and Medline). Initial searches led to 757 articles being identified. Title scanning for relevance reduced the number significantly to 185 papers. The abstracts of these papers were then

scanned for relevance and all duplicates and review articles were removed, leaving 21 journal articles. Application of the inclusion criteria yielded a final cohort of nine papers. One additional paper was identified through scanning reference lists of the nine papers; thus 10 papers are included in this review and critique.

### ***Inclusion criteria***

Studies that met the following criteria were included in this review:

- Empirical study that investigates the relationship between oral hygiene/OHC and AP.
- Study that is published during or after 1998.
- Study with a population of over 65 years or considered to be 'elderly'.
- Study population that live in a nursing home.
- Peer reviewed journal.
- Paper written in English.

In order to meet the inclusion criteria all papers must detail empirical studies, either interventional or observational, which investigate the relationship between oral hygiene/OHC and AP. Langmore et al's seminal paper, published in 1998, was pivotal in the research of oral hygiene and is thought to have greatly influenced subsequent research in this area. For this reason, only papers published during or after 1998 have been included in this review. All papers feature a study population of 65 years and above, which the World Health Organization (2011) consider to be 'elderly'. Some papers do not specify age range, but consider their population to be 'elderly' and therefore these papers have been accepted. All papers include a population sample that live in nursing homes. Some papers include a population from outpatient environments and hospitals as well as nursing homes. These papers have been accepted, however, only the nursing home population has been examined and discussed. Participants of both male and female genders, dentate and edentate and those with co-morbidities have been accepted in this review. Japan and the United States of America have a larger cohort of studies that investigate oral hygiene and OHC, as compared to the United Kingdom. For this reason, and the lack of research in the United Kingdom, papers from Japan and the United States of America have been accepted.

### ***Summary and quality appraisal of studies***

Once a systematic search had been completed and each study had been critically analysed, tables were developed to summarise each study and to synthesise the data (see appendix C), separating studies according to whether they included an OHC intervention or not (observational studies). During critical analysis, the quality of each study's methodology was evaluated and rated using a 13-category system (see appendix D). The rated sections were developed from Bislick et al (2012), with each paper given a point for each category it had

achieved. Then each paper was given an overall high, intermediate or low rating dependent on the total score (see appendix E). The category 'description of retention' was removed from the table as it was considered irrelevant as none of the studies included in this review looked at the effect of intervention outside of the studies' durations, and some (observational studies) had no set intervention.

## **Findings**

### ***Summary of studies***

Out of the 10 papers that met the inclusion criteria, five were intervention studies (Adachi et al., 2002; Yoneyama et al., 2002; Adachi et al., 2007; Bassim et al., 2008; Ishikawa et al., 2008) that monitored the effects of OHC and its relationship with AP diagnosis and/ or AP mortality. Eight hundred and seven participants across 18 different nursing homes participated in these five intervention studies. All studies apart from Ishikawa et al's (2008) study had two set intervention groups- an 'OHC group and a 'no OHC group'. It must be noted that those in the 'no OHC' groups still continued with their typical OHC routines but did not get any additional OHC intervention. Ishikawa et al (2008) had three OHC groups: group A had weekly OHC for the entire five months, group B had weekly OHC from 2 months and group C gargled iodine daily for the entire five months and had weekly OHC from month two. OHC ranged in type and frequency across these five studies and those providing the OHC also differed across the studies (nursing home staff/dental professionals).

The remaining five studies were observational studies (Langmore et al., 1998; Abe et al., 2005; Quagliarella et al., 2005; Abe et al., 2007; Kikutani et al., 2015) that identified certain risk factors in their sample population and then monitored these factors in order to examine the relationship with AP diagnosis. Overall there were 1,489 participants across 23 different nursing homes in these observational studies. Risk factors that were identified and monitored in these studies included poor oral hygiene, inadequate OHC, dysphagia, co-morbidities and dependency on others for feeding/OHC. According to the rating scale (appendix E), 9 out of the ten papers in this review yielded a 'high' quality rating score, suggesting that as a whole the reviewed papers are likely to be reliable and valid for interpretation.

### ***The relationship between OHC and AP diagnosis***

Two of the intervention studies examined the relationship between 'no OHC' and AP diagnosis (Yoneyama et al., 2002; Ishikawa et al., 2008). Yoneyama et al. (2002) found 'no OHC' to be significantly associated with AP diagnosis ( $p < 0.01$ ). With a large sample size of 366 participants across 11 different nursing homes, this appears to demonstrate high ecological validity, however it is difficult to generalise results to either gender due to the uneven sample sizes (293 female and 73 male). Ishikawa et al. (2008) found that OHC significantly reduced oral bacteria count ( $p < 0.01$ ) however, they did not find OHC to be significant in reducing AP



diagnoses. Group A<sup>15</sup> was the only group to receive AP diagnoses (eight individuals); the other groups did not have any AP diagnoses during the study. As group A was the only group to have consistent OHC across the length of the study, results are suggestive that OHC does not decrease chances of developing AP, and perhaps the inverse is true. This staggered design approach, along with relatively even group sizes (24,24,19) increases the chance of generalisation of findings. However, participants were not matched for mobility across groups, with group A containing the largest proportion of immobile individuals. This may account for the higher rate of AP in the consistent OHC group, as being immobile is a risk factor associated with AP (Loeb et al., 1999). This consequently lowers the external validity of the data.

### ***The relationship between OHC and AP mortality***

Four of the five intervention studies examined the relationship between 'no OHC' and death from AP (Adachi et al., 2002; Yoneyama et al., 2002; Adachi et al., 2007; Bassim et al., 2008). All studies found a positive correlation between 'no OHC' and AP mortality, however, statistical significance of this varies. Adachi et al. (2002) found 'no OHC' to be significantly associated with AP mortality ( $p < 0.01$ ) and with increased numbers of candida albicans ( $p < 0.01$ ). A reasonable sample size (143) increases the chances of the findings being generalisable. Sampling for bacteria count was taken at the same time each day (before OHC) suggesting results show longer-term effects of OHC rather than immediate effects. In support of this, Yoneyama et al. (2002) also found 'no OHC' was significantly associated with AP mortality ( $p < 0.01$ ). However, Bassim et al. (2008) found no significant difference between the number of deaths and the 'no OHC' and OHC groups. This study consists primarily of male participants (only one female) meaning it is largely generalisable to the male population. As the study's duration was one and a half years, there is a question as to whether this is long enough to detect AP mortality. It may be the case that many participants developed AP during the study and perhaps died after the study was terminated. This study included data from those resistant to OHC; researchers encouraged and adapted OHC measures to best suit their participants. Based on the intention to treat principles (Hertier, Gebski and Keech, 2003), this increases the ecological validity, as it is more representative of a typical clinical context. The final study that examined mortality from AP was Adachi et al. (2007). Findings suggest that 'no OHC' is significantly associated with AP mortality ( $p < 0.05$ ). However, a relatively small sample size (88), may limit the generalisability of the study.

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<sup>15</sup> Summary of groups A, B and C (Ishikawa et al., 2008)

Group A: weekly OHC for the entire five months

Group B: weekly OHC from 2 months

Group C: gargled iodine daily for entire five months and had weekly OHC from month two

### ***The relationship between oral hygiene and AP diagnosis***

All observational studies analysed poor oral hygiene as a risk factor for AP. Langmore et al. (1998) found that decayed teeth was significantly associated with AP diagnosis ( $p < 0.01$ ), those with AP had on average 4.6 decayed teeth, compared to 2.5 in the group without AP. This study used a small sample size (41), which means statistical tests may lack power, potentially leading to a type II error. Only male participants were used in this study, suggesting that results may be generalisable to the male but not the female gender. Abe et al. (2005) found that increased tongue plaque index (TPI) and dental plaque index (DPI) scores were significantly associated with increased bacterial units ( $p < 0.01$ ), and that high DPI score was significantly associated with AP diagnosis ( $p < 0.01$ ). A sample size of 145 participants means that findings are likely to be representative of other elderly individuals in nursing homes.

Quagliarella et al. (2005) suggested that inadequate oral hygiene was significantly associated with AP diagnosis ( $p < 0.024$ ). However, in this study oral cavities were not assessed; inadequate OHC was determined by 'no documentation of oral care' and therefore this may represent how reliably OHC was documented, rather than how reliably it was performed. In spite of this, this study has a large sample of 613 participants across five different nursing homes and therefore results have an increased likelihood that they can be generalised to other elderly individuals living in nursing homes. Additionally, inter-rater agreement of two radiologist's pneumonia diagnosis was calculated using Cohen's kappa coefficient in a blinded pilot assessment, yielding a  $k$  value of 0.57. This represents the strength of agreement as moderate (Altman, 1991), which suggests that AP diagnosis may not always be accurately diagnosed. Abe et al. (2007) also found high TPI and presence of increased oral bacteria to be significantly associated with AP diagnosis ( $p < 0.05$ ). This study has a small sample size of 71 participants from one nursing home so generalisability is reduced. However, sampling of oral bacteria and rating of TPI was done at the same time each day, which increases external validity of the results. Lastly, Kikutani et al. (2015) found that a bacteria count of  $10^{8.5}$  or above was significantly associated with AP diagnosis. This large sample size of 619 participants over 16 nursing homes means findings are more likely to be representative of the wider cohort of nursing homes.

### ***Influence of dentition***

Developments in dentistry practice mean more elderly individuals are dentate in their later years. As compared to being edentate, dentate individuals are more likely to have increased numbers of oral bacteria and are more likely to develop periodontal disease and AP (Scannapieco, 1999). Two out of the five observational studies included in this review identified and monitored dentate/edentate individuals (Yoneyama et al., 2002; Bassim et al., 2008). Yoneyama et al (2002) found that more dentate individuals were diagnosed with and

died from AP than edentate individuals, though this difference was not found to be significant. This non-significant finding must however, be interpreted with caution, due to the smaller sample of edentulous participants (158 were edentate, 208 were dentate). Furthermore, Bassim et al (2008) monitored edentate individuals, and results suggest that being edentulous was not associated with AP mortality. As being dentate was not monitored, it is difficult to suggest these results support wider findings that being edentulous may reduce the likelihood of developing AP (Scannapieco, 1999).

### ***Method of OHC delivery***

Both mechanical and chemical OHC procedures have been found to be effective in maintaining good oral hygiene; however, there are differences in opinion about which method is most effective. Costerton et al. (1999) suggest that mechanical OHC is more effective; as a toothbrush is able to penetrate the tooth's surface meaning a larger number of bacterial units can be destroyed. In comparison to mechanical methods, Hayes et al. (2014) found that use of chlorhexidine 0.2% mouthwash reduces amounts of bacteria in the mouth, which consequently aids good oral hygiene. Out of the five intervention studies, three included both mechanical and chemical OHC variations within their intervention (Yoneyama et al, 2002; Bassim et al, 2008; Ishikawa et al, 2008). Both Bassim et al (2008) and Yoneyama et al (2002) combined mechanical and chemical OHC throughout their entire intervention. Both studies found that OHC significantly reduced AP incidence and mortality. As both chemical and mechanical are combined it is not possible to state whether one type of intervention is more effective than the other. However, this does imply that a combination of both methods is effective in preventing AP incidence and mortality. Ishikawa et al (2008) separated the mechanical and chemical methods to some extent- group C gargled iodine for entire 5 months and started OHC from week two. They found that those that gargled iodine did have a reduction in bacterial units, however, this reduction was not as significant as when the mechanical intervention began. This suggests that both methods of OHC are effective in reducing bacterial levels in the oral cavity, but mechanical methods are likely to be most effective. In this study, no significant associations were found between poor oral hygiene and AP diagnosis. However, findings must be viewed with caution due to individual differences between the groups. Both groups A and B had more dentate individuals in them than Group C, and as previously mentioned being dentate can increase the amount of oral bacteria and likelihood of AP diagnosis.

### ***Frequency and duration of OHC***

It has been suggested by Macentee, Throne and Kazanjuan (1999) that OHC should be performed on a daily basis. This is also supported by NHS (2013) and Curzio and McCowan (2000), who suggest that OHC should be performed for two minutes, twice a day. Out of the five intervention studies, OHC ranged in frequency from both daily and weekly (Yoneyama et

al., 2002), to every three days (Bassim et al., 2008) to weekly (Adachi et al., 2002; Ishikawa et al., 2008). The study that included daily OHC intervention (Yoneyama et al., 2002) found OHC to be significant in reducing AP incidence. One study performed OHC every three days (Bassim et al., 2008) and their OHC was not found to be significantly associated with AP mortality. These results should however, be viewed with caution, as only mortality rates were included in the statistical analysis. Therefore participants may have had AP, and been at risk of subsequent AP-related mortality, however, this would not have been captured.

Out of the two studies that included weekly OHC, Adachi et al (2002) found that their OHC was significantly associated with a reduction in AP diagnosis, however, Ishikawa et al. (2008) found no significant association between OHC and AP diagnosis. The results of the study with the shortest duration (Ishikawa et al., 2008) should be interpreted with caution, as any individuals that developed AP after the five-month time span would not have been identified. As a result of the differences in OHC methods and the combination of daily and weekly OHC it is difficult to confirm that daily OHC is more effective than weekly intervention.

### ***Influence of professional OHC delivery***

Out of the five studies that had set intervention, three used professional dental staff to perform their OHC (Adachi et al., 2002; Adachi et al., 2007; Ishikawa et al., 2008), one study used only care staff (Bassim et al., 2008) and one used both dental professionals and care staff (Yoneyama et al., 2002). All studies that used dental professionals found OHC to be significantly associated with a reduction in AP. The study that used both dental hygienists and care staff also found that their OHC was significantly associated with a reduction in AP. The only study that used only care staff found that OHC was not significantly associated with AP mortality. These results may suggest that OHC provided by dental professionals is more effective, however, this cannot be assumed due to differences in OHC methods, duration and outcomes measures (AP mortality vs. incidence).

### ***Associated risk factors***

Age has been identified as a significant risk factor associated with diagnosis of AP (Langmore, 1998; Bassim et al 2008). It appears that other associated risk factors such as poor oral hygiene, dysphagia, reduced activities of daily living and dependency on others are not only associated with AP, but also age itself. Those over the age of 65 years are more vulnerable to poor oral hygiene because of increased susceptibility to plaque accumulation (Hayes et al. 2014). Elderly individuals have a reduction in the number of secretory leukocyte protease inhibitors in the saliva, which means their oral cavity is less efficiently protected from bacterial units (Shugars, Watkins and Cowen, 2001). As individuals age, they are also more likely to acquire dysphagia due to an increased incidence of stroke and other progressive neurological diseases such as dementia, as well as general age-related deconditioning which can result in decreased safety of the swallow (Sura et al., 2012). Out of the five observational studies, three monitored dysphagia, and all found it to be a significant risk factor (Langmore, 1998; Quagliarella et al 2005; Kikutani et al, 2015). Each of these studies had strict criteria for

dysphagia diagnosis that included both observational features, directly observed by researchers, and/or documented dysphagia recorded by a health care professional. This strict inclusion criteria that is distinct to dysphagia suggests that dysphagia diagnosis is unlikely to be misdiagnosed.

Increased age is also associated with other risk factors such as reduced activities of daily living (Kikutani et al, 2015), dependency on others for OHC (Bassim et al., 2008) and feeding (Langmore et al.,1998; Bassim et al., 2008). Langmore et al (1998) suggest that risk factors may work synergistically with one another in increasing the risk of AP in elderly individuals. They suggest that a single risk factor in isolation is unlikely to cause harm, however, stress that individuals are typically exposed to more than one of these risk factors, due to their close inter-dependence and co-occurrence in the elderly population.

## **Discussion**

The existing evidence base shows that administration of additional OHC methods and good oral hygiene are likely to reduce the incidence of AP. Despite various methodological limitations, the papers in this review demonstrate how additional OHC and good oral hygiene can help prevent AP incidence and mortality, potentially reducing associated hospital admission and treatment costs. Certain barriers exist within the health care service, which make providing effective OHC challenging. Some of these barriers will be discussed below, alongside ways in which they could be addressed or reduced.

### ***Optimisation of OHC delivery***

Who should be responsible for OHC?

In order to become a dental professional an individual must complete extensive training on OHC and the importance of good oral hygiene. As a result of this it is likely that dental staff have more in depth knowledge of OHC methods than nursing home staff. They are also trained in areas of OHC such as plaque control and are therefore likely to be able to provide more thorough OHC than the care staff. Of the intervention studies included in this review, the only paper that solely used care staff to provide OHC found that OHC was not significant in preventing AP mortality. In all other papers dental professionals provided all or part of the OHC. Findings from these papers showed that OHC administered by dental professionals was significant in preventing AP incidence and mortality; and it can therefore be hypothesised that dental professionals provide higher quality OHC than care staff. However, due to noted methodological limitations throughout a small sample of 10 studies, where only one paper had solely care staff administering OHC, no robust assumptions can be made.

Although the evidence base appears to point to dental professionals as the most effective agent for delivering OHC, certain barriers exist that make the feasibility of dental

professionals administering regular OHC difficult. Dentists and dental hygienists are not typically situated in care homes and therefore employment of dental staff to take on responsibility of regular OHC would incur additional costs. Two studies (Ueda, Toyosato and Nomura, 2003; Peltola, Vehkalahti and Simoila, 2007) indicated that even when weekly professional OHC was administered, care staff were still required to oversee daily tooth brushing to guarantee good oral hygiene. This implies that regardless of who administers OHC, it should be performed on a daily basis. This is further supported by the National Institute of Dental and Craniofacial Research (2012), who state OHC should be administered daily. The role of the care staff in nursing homes requires them to wash and dress the majority of their residents, and because of this it would seem more practicable for care staff to administer OHC as part of their daily care routine. This would save time in the workplace and reduce any additional expenses required to employ dental staff. There is however, 'strong evidence' that those individuals in regular contact with their dentist have better oral hygiene than those that do not (National Institute for Health and Care Excellence (NICE), 2014). For this reason and limitations in the practicality of regular (e.g. weekly) dental professional OHC, it may be more realistic for residents to have regular dental check ups several times a year, with daily OHC delivered by care staff. This less frequent, but regular professional involvement, would allow dentists to administer more thorough OHC, as well as assess the residents' oral hygiene status and give advice to carers. In order to confirm who should administer OHC, further comparative studies are needed, for example with between-groups analysis of dental professional versus care staff administration of OHC, with consistent protocols for method and frequency of OHC.

#### Care staff awareness of OHC importance

Maintaining good oral hygiene through OHC methods should be a vital part of care in nursing homes (Grap et al, 2003). In spite of this, OHC procedures in nursing homes are often considered to be substandard, even when protocols exist (Macentee, 2005). OHC is not seen to be a high priority for nursing staff across the country (Chalmers et al., 1996) and is typically associated with resident comfort rather than associated health difficulties. OHC has been found to vary significantly across nursing homes as many employees lack the knowledge required to perform adequate OHC and are also unwilling to provide this care (British Dental Association, 2012). Staff members tend to have a poor understanding of the risk factors associated with poor oral hygiene (NICE, 2014a), which may contribute to why OHC is often overlooked by carers. An ethnographic study (Coleman and Watson, 2006) identified that only 16% of residents received OHC and that staff would often document OHC had been administered, when it had not been. A self-report study (Monaghan and Morgan, 2010) showed how 56% of managers thought their staff were not sufficiently trained to provide adequate OHC. Training staff about OHC and oral hygiene has been found to be significantly effective in improving oral hygiene across nursing home residents (Kullberg et al., 2010). These findings accentuate the need to promote staff knowledge of oral hygiene importance and OHC methods.

### Lack of funding

Nursing homes are often subject to financial strain and strict budgets (Financial Times, 2015). This limited funding often results in reduced employee numbers, meaning staff struggle to provide residents with the high quality care that is expected. This reduced staff to resident ratio means that care staff have less time to carry out each individual's care needs. A survey of 584 nursing staff found that almost 2/5 of employees thought that there were not enough staff to meet resident's needs (Royal College of Nursing, 2012). Subsequently, these time restraints mean nursing staff only have time to carry out basic care needs such as washing and dressing. Oral hygiene parameters are therefore overlooked due to the prioritisation of other needs that are considered to be more important. Furthermore, reduced staff numbers also leads to high demands on staff, leading to stress, difficulty managing workload and low staff morale (Royal College of Nursing, 2012). This reduction in mood can lead to a high staff turnover rate, creating additional challenges with staff training and competence in delivery of OHC. In addition to this, low morale has been found to negatively effect job performance and productivity (Jex, 1998; Chin-Chin, 2006). These staffing challenges give reason for how OHC can be overlooked and highlight the requirement for increased commissioning of care staff in residential settings.

### Optimum method of OHC

Both mechanical and chemical methods of OHC have been found to significantly reduce AP incidence and mortality. High DPI has been found to significantly increase the incidence of AP (Abe et al., 2005), which highlights the need for mechanical methods such as teeth cleaning. NICE (2014) guidelines highlight that mechanical methods (tooth brushing) should be part of daily OHC. For adults it is recommended that toothpaste with a fluoride concentration of 1350 ppm and above is used (NICE, 2014). However, increasing a toothpaste's concentration of fluoride to between 2800 and 5000 ppm has been found to be more effective in reducing harmful bacteria (Baysan et al., 2001; Biesbrock, 2001). This highly concentrated fluoride toothpaste can be easily incorporated into daily life, however, does need to be prescribed by a doctor. The need for a prescription in order to access this toothpaste may reduce the availability to residents, as doctors may be more likely to prescribe this toothpaste when oral hygiene is poor, rather than prescribing it as a preventative method. Similarly to high DPI, high TPI has been found to significantly increase the incidence of AP (Abe et al. 2007), which stresses the importance of tongue cleaning in mechanical OHC methods. As part of one of the reviewed studies, (Yoneyama et al, 2002) the resident's oropharynx was scrubbed with iodine. This was only done 'if necessary' and therefore is likely this was not consistently used across all participants. This makes generalisation of results and comparison between manual and chemical methods difficult. This invasive method of OHC may also be deemed inappropriate, and violate guidance from the General Medical Council (GMC) (GMC, 2006)

which highlight the importance of protecting patients from harm, particularly where individuals are very elderly, unwell or have dementia, for example.

In comparison to mechanical methods, NICE (2014) also make recommendations for chemical means of OHC. It has been suggested that those more at risk of poor oral hygiene should use a fluoride mouthwash with a concentration of 0.05%, at separate times to brushing. The use of chlorhexidine (0.2%) mouthwash is considered the most effective chemical medium in reducing plaque and gingivitis (Najafi et al., 2012) and has been found to promote good oral hygiene by reducing bacteria count in the oral cavity (Hayes et al., 2014).

It is clear that both mechanical and chemical means are effective in reducing bacteria count in the oral cavity, suggesting that a combination of both mechanical and chemical methods may result in more effective OHC. In order to make an assured conclusion, more empirical research is needed. These studies should include randomisation of patients to comparative groups of mechanical, chemical and combined methods, with all other variables (for example the intensity and the professional providing the OHC) remaining constant. Alternatively, a staggered design may help to address this research question.

#### Intensity and duration of OHC

Both weekly and daily OHC have been seen to be effective in preventing AP incidence and mortality. Across the five interventional studies, there was no clear relationship between the intensity of OHC and AP diagnosis or mortality. For this reason, and the inconsistency in OHC methods and persons delivering the care across the studies, it is difficult to make any inferences as to the optimum intensity of OHC. The recommendations that teeth should be brushed for two minutes twice a day (Curzio and McCowan, 2000; NHS, 2013; NICE, 2014) and suggestion that daily OHC should be provided in order to establish and maintain good oral hygiene (Macentee, Throne and Kazanjuan, 1999) implies OHC should be administered daily as opposed to weekly. Although the exact frequency of optimum intensity and duration can not be established, research is suggestive that OHC should be performed several times a day for approximately two minutes per care episode.

#### Timing of OHC

The optimal time for teeth brushing varies depending on the reason for cleaning teeth, whether brushing is to prevent plaque build up or to remove food particles. Dentists recommend that teeth should be brushed prior to meal times, as when fermentable carbohydrates combine with bacteria in the oral cavity, acid is produced (O'Hehir, 2013). This acid then has the potential to wear away tooth enamel resulting in cavities and tooth decay (O'Hehir, 2013). In contrast, there is reason to suggest that OHC should be administered post mealtimes. For those at risk of pocketing food in the oral sulci, OHC after meal times can aid removal of food residue, subsequently reducing aspiration risk post swallow. Research suggests that OHC after meal times is significant in reducing AP incidence (Yoneyama et al.,



2002). It is clear that there are discrepancies between opinions of when best to perform OHC. For this reason alongside the limited number of studies stating their exact timing of OHC, no definitive conclusions can be made about the optimum timing of OHC. It has been stated that exact timing of OHC is less relevant than the method of OHC (Bartlett, 2007), although further research is required to investigate the impact of timing on OHC effectiveness.

### ***Risk factors and complications***

#### Dementia

Individuals living in nursing homes have a range of health needs, which often make OHC difficult. Approximately 80% of those living in nursing homes in the UK are said to have dementia (Alzheimer's society, 2015). Difficulties associated with dementia such as impaired memory and cognition mean many residents are resistant to health care procedures (Morrison, 2003). For this reason many individuals with dementia have poor oral hygiene (Preston, 2006). Often those with dementia become dependent on others for OHC, which in itself is a risk factor associated with AP mortality (Bassim et al., 2008). Furthermore, a variety of medications can reduce saliva production, causing a xerostomia. In the elderly population having a dry mouth is common (Loesche et al., 1995), primarily as a result of multiple drug use (Narhi et al., 1999). Individuals with dementia are often prescribed certain antipsychotic drugs, which have been found to reduce saliva production (Swager and Morgan, 2011). Those with dementia also tend to have a preference towards sweet foods. This high sugar diet combined with xerostomia and reduced OHC makes accumulation of plaque and oral bacteria common (Rogers, 2011).

#### Dependency on others

As a result of decreased mobility and cognition, many elderly individuals living in nursing homes are dependent on others for OHC and feeding. Being dependent on others for feeding is significantly associated with AP incidence (Langmore et al., 1998) and mortality (Bassim et al., 2008). Feeding someone reduces the oral preparatory stage of the swallow, meaning that an individual's sensory feedback for feeding is reduced. This can result in a reduction in efficiency of the swallow, meaning that aspiration is more common. As well as reduced upper limb dexterity and co-ordination, individuals are often fed when they fatigue too quickly to feed themselves and this fatigue can further increase the individual's risk of aspirating. Bassim et al (2008) found that being dependent on others for OHC is also significantly associated with AP mortality. This may reflect the insufficient OHC provided by care staff due to the issues discussed above, such as limited knowledge and high workloads. Nevertheless, the evidence base highlights the importance of encouraging individuals to self-feed through prompting and encouragement, to promote self-feeding where possible.

## Dysphagia

In addition to oral hygiene, the presence of dysphagia has also been significantly associated with AP incidence (Langmore et al., 1998; Quagliarella et al., 2005; Kikutani et al., 2015). All of the studies within this review that identified dysphagia as a risk factor found that it was significantly associated with AP incidence. A combination of poor oral hygiene and dysphagia mean that an individual is more likely to develop AP. For those with dysphagia it may not be possible to eliminate the chances of aspiration; however, professional assessment and management strategies can reduce the likelihood of this. Appropriate involvement of a Speech and Language Therapist to assess and manage an individual's swallowing difficulty is of paramount importance. Management techniques such as dietary modification and postural changes can help to reduce the likelihood of aspiration (Sura et al., 2012). Through OHC, bacterial units are decreased in the oral cavity, meaning that if a person with dysphagia aspirates on their own saliva or on a food or fluid bolus, it is less likely to cause AP. This shows that although dysphagia is a risk factor that cannot necessarily be eliminated, aspiration and therefore AP can be reduced through appropriate management techniques.

## Dentistry advancements and dentition

Recent advances in the field of dentistry have led to increased effectiveness of dental interventions. This, alongside an increased awareness of dental health care means that more elderly individuals are dentate in their later years (Murray, 2011). Although this may be viewed as a positive development in health care, being dentate has been found to increase the levels of bacterial units in the oral cavity, as well as increasing the chances of periodontal disease (Loesche et al., 2000). As a consequence of this, being dentate is positively associated with the development of AP (Scannapieco, 1999). This link between poor oral hygiene and dentition means that an increased number of individuals are at risk of developing AP, highlighting the importance of developing effective OHC methods.

## Commissioning implications in the workforce

Hospital admission for elderly residents who develop AP is common (Mylotte, 2002) and the cost of diagnosis and treatment of AP is particularly high when individuals are admitted to hospital (Barnes, 2014). OHC has been found to reduce health care expenses through reduced hospital admission and treatment costs (Kullberg et al., 2010). As previously discussed, there is a need for training amongst care staff to promote their knowledge of OHC methods. Although this training process would potentially be costly in the short term, the long-term effects could decrease AP incidence, which has the potential to save millions of pounds annually (Grap, 2003). In order to promote commissioning, increased awareness is needed through research to prove how small funding investments in the short term can be cost saving in the long term. Involvement of suitable professionals to work as part of an MDT can also aid cost savings. Dental and care staff collaboration can aid oral hygiene by improving

OHC measures, which can consequently prevent AP, reducing expenditure in the long-term. Additionally, appropriate referral to a Speech and Language Therapist for dysphagia assessment and management has been found to reduce hospital admissions and treatments costs, saving £13.3 million annually (Harulow, 2011).

### ***Summary of limitations in existing research***

It is difficult to draw strong conclusions from this review, due to various limitations in the evidence base as a whole. There is variability between all of the studies in this review with regards to the person delivering OHC, the method of OHC, intensity of OHC and timing of OHC, meaning it is difficult to directly compare the empirical research. The small number of studies and methodological limitations discussed previously also make it difficult to draw firm conclusions and recommendations about the optimum frequency, method, timing and professional delivery of OHC. The presence of other co-morbid risk factors such as dysphagia, dementia and being dependent on others adds to this difficulty, although this is representative of the context in which these challenges exist in the real world.

Moreover, the diagnosis of AP is difficult to reliably diagnose; one study identified a moderate inter-rater agreement between two radiologists (k-value 0.57; Quagliarella et al., 2005), suggesting that AP is difficult to diagnose accurately in a clinical setting. There is no objective test to identify AP and diagnosis is solely based on a professional's subjective view of the presenting symptoms in assessment and on chest x-rays. This is further complicated by co-morbidities such as chronic obstructive pulmonary disease (COPD). For this reason AP diagnosis and AP as a cause of mortality may not always be reliable and should be cautiously viewed.

Within the observational studies, different risk factors were identified and monitored throughout, although as discussed, these risk factors are often difficult to reliably diagnose or quantify. The intervention studies all had a control group entitled 'no OHC' or similar. As previously noted, due to ethical considerations and the fact that best alternative intervention is of even greater interest clinically than comparison with no intervention, the individuals within the 'no OHC' groups still continued with standard care for OHC. This means that studies investigate only how effective *additional* OHC practices are, as opposed to comparing them with no OHC. As an outcome measure, four of the five intervention studies monitored AP mortality, however, there is question as to whether some studies were conducted for long enough to detect this mortality. Overall, these factors demonstrate the need for additional more consistent research.

### **Conclusion**

Regardless of this review's limitations, it can be concluded that poor oral hygiene and standard OHC procedures (as compared to enhanced OHC methods) are associated with AP incidence and mortality. Thus suggesting that good oral hygiene is important in preventing AP

in the elderly population living in nursing homes. As a modifiable risk factor that is mostly preventable through OHC measures (Levine and Stillman-Lowe, 2009), this review demonstrates the importance of proactive practices to prevent poor oral hygiene and its associated complications. Uncertainties remain regarding the optimum timing, frequency, method and professional to deliver OHC, which is reflected in the absence of a current protocol for OHC delivery. Existing variation in practice between nursing homes arguably indicates a need for national guidelines and professional standards, which should be built on both the existing research, and on further robust research in this area. The need for OHC training and increased funding in nursing homes is evident. An increase in education and commissioning in care homes can improve the efficiency of OHC, which consequently has the potential to decrease AP incidence and mortality. Moreover, interdisciplinary collaboration between care staff and dental professionals is necessary if oral hygiene is to improve in nursing homes. With their specialist knowledge, dental professionals need to become more involved in the OHC of residents in nursing homes. Through regular oral assessment, dental professionals can give advice to care staff to improve the efficiency of the resident's daily OHC. In order to make accurate suggestions for future policies and guidelines for practice, further, more robust empirical research is needed in this area.

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## Appendices

### ***Appendix A: Combining search terms***

Combined: CINAHL

S1+S2= 51

S2+S4=44

S1+S2+S3+S4=14

Combined: SCOPUS

S1+S2= 152

S2+S4=216

S1+S2+S3+S4=38

Combined: MEDLINE

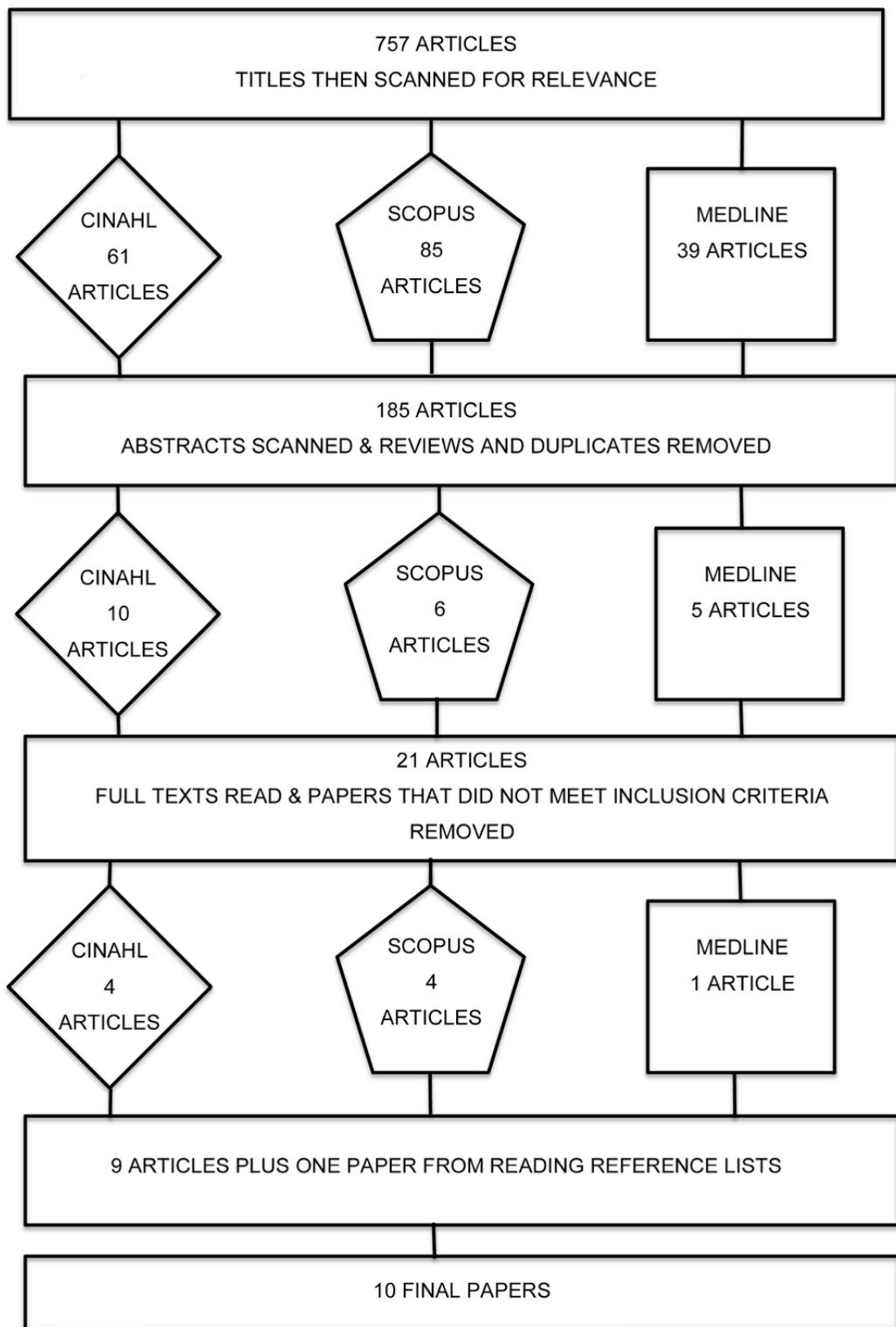
S1+S2= 127

S2+S4=93

S1+S2+S3+S4=22



**Appendix B: Flow chart to show systematic breakdown of searches**



### Appendix C: Tables of summaries

Table to summarise intervention studies

| Article and topic   | Duration of study | Participants   | Description of intervention/OHC   | Who performed OHC               | How often was OHC performed | Findings   |
|---|-------------------|--|---|---------------------------------|-----------------------------|--|
| 1) Adachi et al. (2002)<br><br>Effect of professional oral health care on the elderly living in nursing homes | 2 years           | - 143 residents from 2 nursing homes.<br>-Mean age 84 years<br>-74% women, 36% men   | -2 groups- OHC/ no OHC<br>-Brushing with electric toothbrush, interdental brush, sponge brush, buccal mucosa, tongue and dentures cleaned | Dental hygienists               | Weekly                      | The OHC group had a significantly lower number of individuals that died from AP ; 2 (5%) compared to the OHC group; 8 (17%); Fishers exact test= p<0.05.   |
| 2) Bassim et al. (2008)<br><br>Modification of the risk of mortality from pneumonia with oral hygiene care    | 1.5 years         | -143 residents from one nursing home.<br>-Mean age 71 years<br>-All male, but one<br><br>Includes those that refused (made adaptations & encouraged) | -2 groups- OHC/no OHC<br>-Tooth brushing, antiseptic mouthwash, oral and denture cleaning   | Care staff                      | Every three days            | The OHC group had a lower number of individuals that died from AP ;12 (15%) than the no OHC group ;13) (20%). Using Multivariable logistic regression, this was not statistically significant (p=0.51) |
| 3) Yoneyama et al. (2002)   | 2 years           | - 366 residents from 11 nursing homes  | -2 groups- OHC/ no OHC<br>-Teeth cleaning after each meal, brushing palatal and   | Dentists (weekly)<br>Care staff | Daily /weekly               | OHC group had significantly less individuals with AP ;21 (11%) compared to the no OHC group ;34 (19%); two way analysis of variance  |

|  |          |  |   |                   |                               |  |
|--|----------|--|---|-------------------|-------------------------------|--|
| Oral care reduces pneumonia in older patients in nursing homes.  |          | -Mean age 82 years<br>-293 female, 73 male | mandibular mucosa & tongue dorsum, oropharynx scrubbed with iodine applicator.<br>-Plaque and calculus control x1/pw  | (daily)           |                               | (p<0.05)<br><br>Two way analysis of variance showed that 'no OHC' was significantly associated with AP mortality (p<0.1)   |
| 4)_Adachi et al. (2007)<br><br>Professional oral health care by dental hygienists reduced respiratory infections in elderly persons requiring nursing care | 4 years  | -88 residents                              | -2 groups –OHC/no OHC<br>-Teeth brushed with electric toothbrush<br>-Oral cavity cleaned  | Dental hygienists | Not Specified                 | The OHC group had significantly less individuals that died from AP (5%) compared to the no OHC group (16.7%); Fishers exact test- p<0.05.  |
| 10) Ishikawa. et al (2008)<br><br>Professional oral health care reduces the number of oropharyngeal bacteria   | 5 months | -67 residents from three nursing homes     | -3 groups<br>- A- OHC for entire 5 months<br>-B- OHC from 2 months<br>-C- gargled iodine daily for 5 months & OHC from 2 months<br><br>OHC- brushing teeth/cleaning dentures, ultrasonic irrigation | Dental hygienists | Daily (iodine)<br>Weekly -OHC | Data analysed using repeated measures ANOVA, Bonferroni test-<br>Group A- Total bacteria significantly decreased by month 3 (p<0.05) and month 5 (p<0.01). Numbers of staphylococci, candida pseudomonas, black pigmented bacterioides species all significantly decreased by month 5 (p<0.05).<br><br>Group B- During first 2 months (no OHC) no change in total number of bacteria. After OHC began- total bacteria count decreased significantly from months 3-5 (p<0.01) |

|  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|
|  |  |  |  |  |  | <p>Staphylococci, candida, black pigmented bacterioides species all significantly decreased in number by month 5 (<math>p&lt;0.01</math>). Pseudomonas not found to be significant.</p> <p>Group C- Gargling period (first 2 months) significant change in total number of bacteria (<math>p&lt;0.01</math>) but no significant change in streptococci number. From months two –five (OHC period) a further significant drop in total number of bacteria was noted (<math>p&lt;0.01</math>) and decrease in numbers of staphylococci (<math>p&lt;0.01</math>), candida (<math>p&lt;0.05</math>), black pigmented bacterioides species (<math>p&lt;0.01</math>). Pseudomonas not monitored.</p> <p>No significance noted in any group when examining correlation between groups and AP incidence.</p> |
|--|--|--|--|--|--|--|

Table to summarise observational studies

| Article  | Duration | Participants   | Initial oral hygiene ax                                    | Monitored risk factors   | Findings  |
|--|----------|--|--|--|---|
| 5) Quagliarella et al. (2005)<br><br>Modifiable risk factors for nursing home acquired | 1 year   | -613 residents from 5 nursing homes<br>-Mean age 85 years<br>-460 females, 153 males | Looking in notes- inadequate OHC= no documentation of care | OHC, dysphagia, lack of influenza vaccination, depression, feeding position <90, smoking | Using cox proportional hazards models adjusting for covariates, inadequate OHC ( $p=0.024$ ) and dysphagia ( $p=0.033$ ) were significantly associated with AP<br><br>When these factors were evaluated |

|  |          |  |  |  |   |
|--|----------|--|--|--|---|
| pneumonia  |          |  |  |  | simultaneously in the same Cox proportional hazards model inadequate OHC ( $p=0.03$ ) and dysphagia ( $p=0.043$ ) remained independently associated with pneumonia.   |
| 6) Abe et al. (2005)<br><br>Oral hygiene evaluation for effective oral care in preventing pneumonia in dentate elderly | 1 year   | -145 residents<br>- Mean age 85 years                                  | Oral evaluation, TPI, DPI, saliva samples  | Measure of activities of daily living (ADL), bacteria count, dental plaque index (DPI) and tongue plaque index (TPI) | Individuals with high DPI and TPI had significantly higher oral bacteria count; Sheffe multiple comparisons test ( $p<0.01$ , $p<0.05$ )<br>High DPI (DPI-1) score significantly associated with AP; $\chi^2$ test ( $p<0.01$ ) |
| 7) Langmore et al. (1998)<br><br>Predictors of Aspiration Pneumonia: How Important Is Dysphagia?                       | 4 years  | -41 residents from one nursing home<br>-Mean age 72 years<br>-All male | Thorough oral cavity ax, saliva samples, throat cultures, interview-medical and dental history | Age, comorbidities, smoking, dysphagia activity level, dependency for care/OHC                                       | Following Bivariate analyses- Using Multiple logistic regression analyses; increased age ( $p<0.05$ ), COPD ( $p<0.01$ ), dysphagia ( $p<0.05$ ) and dependency for feeding ( $p<0.05$ )  |
| 8) Abe et al. (2007)<br><br>Tongue-coating as risk indicator for aspiration pneumonia in edentate elderly              | 1 year   | -71 residents from one nursing home                                    | Oral cavity evaluation, TPI, bacteria saliva samples   | TPI, bacteria levels   | High TPI (TPI-1) significantly associated with increased bacteria levels; student's t-test ( $p<0.05$ ).<br>High TPI scores significantly associated with AP; $\chi^2$ test ( $p<0.005$ )                                       |
| 9) Kikutani et al.   | 6 months | - 691 residents  | Oral bacteria count  | Bacteria levels, comorbidities,  | Using $\chi^2$ test; reduced ADL ( $p=0.007$ ),   |

|   |  |   |  |  |  |
|---|--|---|--|--|--|
| <p>(2015)</p> <p>Relationship between oral bacteria count and pneumonia onset in elderly nursing home residents</p> |  | <p>from 16 nursing homes</p> <p>-Mean age 86 years</p> <p>-554 female, 137 male</p> |  | <p>dysphagia, nutritional status, xerostema, ADL</p> | <p>dysphagia (p=0.04) and bacteria count of that equal to or more than <math>10^{8.5}</math> (p=0.029) were significantly associated with AP.</p> <p>Using logistic regression analyses, bacteria count of that equal to or more than <math>10^{8.5}</math> was an independent explanatory factor for pneumonia onset (p=0.012).</p> |
|---|--|---|--|--|--|

**Appendix D: Rating Scale based on Bislick et al (2012)**

| Category  | Points  |
|---|---|
| Longitudinal cohort design                        |   |
| Control group                                     |   |
| Detailed participant profile                      |   |
| Factors either measurable or observable           |   |
| Clear description of intervention/<br>observation |   |
| Panel attrition                                   |   |
| Clear findings description                        |   |
| Statistics used and described                     |   |
| Identification of reliability limitations         |   |
| Identification of validity limitations            |   |
| Clear conclusion drawn from results               |   |
| Blinding of assessors                             |   |
| Blinding of participants                          |   |
|   | <b>Total score possible: 13</b>   |
| <b>Quality Rating Score:</b>                      |   |
| <b>9-13= High</b>                                 | Study likely to demonstrate appropriate design and use of experimental controls: results are more likely reliable and valid for interpretation. |
| <b>5-8= Intermediate:</b>                         | Study likely to demonstrate flaws in design and experimental control: results may or may not be reliable and valid for interpretation.          |
|   | Study Likely to have flawed design, and ineffective use of experimental control:  |

|                |                                |
|----------------|--------------------------------|
| <b>0-4=Low</b> | Interpret results with caution |
|----------------|--------------------------------|

### **Appendix E: Final rated scores for found papers**

| Article  | Overall rating score based on Bislick et al (2012) |
|--|--|
| 1) Adachi et al. (2002)<br>Effect of professional oral health care on the elderly living in nursing homes  | 10 (High)  |
| 2) Bassim et al. (2008)<br>Modification of the risk of mortality from pneumonia with oral hygiene care   | 10 (High)  |
| 3) Yoneyama et al. (2002)<br>Oral care reduces pneumonia in older patients in nursing homes.   | 10 (High)  |
| 4) Adachi et al. (2007)<br>Professional oral health care by dental hygienists reduced respiratory infections in elderly persons requiring nursing care | 8 (Intermediate)                                   |
| 5) Quagliarella et al. (2005)<br>Modifiable risk factors for nursing home acquired pneumonia   | 10 (High)  |
| 6) Abe et al. (2005)<br>Oral hygiene evaluation for effective oral care in preventing pneumonia in dentate elderly                                     | 10 (High)  |
| 7) Langmore et al. (1998)<br>Predictors of Aspiration Pneumonia: How Important Is Dysphagia?   | 9 (High)   |
| 8) Abe et al. (2007)<br>Tongue-coating as risk indicator for aspiration pneumonia in edentate elderly  | 10 (High)  |
| 9) Kikutani et al. (2015)<br>Relationship between oral bacteria count and pneumonia onset in elderly nursing home residents                            | 9 (High)   |
| 10) Ishikawa. et al (2008)<br>Professional oral health care reduces the number of oropharyngeal bacteria   | 10 (High)  |



## **Gender differences in communication skills in males and females with autism: a review of the current evidence.**

Jo White, supervisor Adam Brown

### *Abstract*

**Background.** It has historically been widely accepted that there are more males with autism than there are females. However, some professionals in the field of Autism Spectrum Disorder (ASD) have queried whether males and females display a different phenotypic presentation of ASD.

There have been a number of studies that investigate gender differences within ASD as a whole, or within specific traits. However, to date, there have not been studies specifically regarding communication skills of males and females with ASD. In order for Speech and Language Therapists, who take a lead role in assessing and diagnosing the social and communication skills associated with ASD (Royal College Speech Language Therapists, 2015) to confidently identify ASD in females, they must have a clear picture of the presentation of ASD in both genders.

**Aim.** The aim of this literature review was to collate information from published studies regarding the skills of males and females with ASD and use it to establish whether there is a gender difference in communication, what further investigation may be needed, and any potential implications for diagnosis and intervention.

**Method.** Relevant literature was found through a systematic search of two large academic databases, and then filtered by hand. Only studies which contained numerical data on communication skills of both males and females were included for review.

**Outcome.** This review has been unable to conclude whether there are communication differences between males and females with ASD, as the data found was conflicting. It has demonstrated the need for further investigation, and been able to highlight a possible trend in relation to communication skills, gender and age. The only known clinical implication to the original question is that the lack of clarity makes diagnosis and intervention planning difficult. However, this review does discuss hypothetical implications for individuals on the autistic spectrum.

## **Introduction**

There is an abundance of literature concerning various aspects of Autism Spectrum Disorder (ASD) since the 1940's, when cases of children showing similar social and communication difficulties were described by Kanner (1943), and Asperger (1944). Both authors independently used the term "autistic" to describe the display of behaviours (Lyons and Fitzgerald, 2007). Some more recent literature has discussed differences in gender, such as the study regarding sex differences into timing of diagnosis by Begeer et al., (2013). However, the literature has not typically focused on the effect of gender on language and communication, but on emotional, behavioural or cognitive aspects (May, Cornish and Rinehart, 2014). However, some of these studies have measured language or communication as part of the wider study of ASD, but have not fully explained or drawn conclusions

from those measurements (Bolte et al., 2011, Zwaigenbaum et al., 2012). It is the aim of this project to do just that.

### ***ASD – What is it?***

A full description of ASD is beyond the scope of this study, which will concentrate on communicative aspects of ASD presentation. See Appendix A for further information.

### ***ASD – Problems of Terminology***

A complication of studying the literature on ASD is the lack of agreed and consistent terminology.

Firstly, a number of terms are used interchangeably, such as “Autism Spectrum Difference”, “Autism Spectrum Condition” and “Pervasive Developmental Disorder” (PDD). Other examples of inconsistent terminology can be seen in the inconsistent use of ‘sex’ and ‘gender’ to mean the same thing, and the terms ‘typically developing’ and ‘neurotypical’.

Secondly, even where the terminology is settled there can be inconsistencies because of changes to the accepted meaning. Having previously been classed as a discrete disorder, Asperger’s Syndrome has, since 1999, (Jolliffe and Baron-Cohen, 1999) been accepted to be a part of the ASD continuum. Further, since the publication of the updated Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association (APA), 2013), diagnosis criteria have changed so that previously separate subcategories of the autism spectrum have been eliminated. ASD is now the overarching term used to refer to a group of social development disorders.

The implications for this review are that when considering research which has been conducted prior to or shortly after the release of the DSM-5, the studies are more likely to distinguish between the subtypes of ASD. Thus complicating searching of the literature using ‘target terminology’.

### ***ASD and Communication***

Communication is one of the key areas of impairment for individuals on the autistic spectrum (APA, 2013). People with autism have persistent difficulties with social communication and interaction which the DSM-5 breaks down into ‘deficits in social-emotional reciprocity’, ‘deficits in nonverbal communicative behaviours used for social interaction’ and ‘deficits in developing, maintaining, and understanding relationships’ (APA, 2013, cited by the Royal College of Speech and Language Therapists, (RCSLT) 2015). As autism is a spectrum, the range and level of impairment can differ dramatically (APA, 2013). Some individuals with ASD are non-verbal or may only say a few words, whereas others may appear to have good expressive language and vocabulary but difficulty putting the language to social use. Many individuals will have difficulties understanding and using both verbal and non-verbal social cues such as body language, eye contact and intonation (Bishop, 2013). Some of the social communication difficulties displayed by individuals on the autistic spectrum

include difficulties with empathy, turn taking, choosing a topic, holding a socially appropriate conversation and understanding and identifying emotions (American Speech and Hearing Association, n.d). Language difficulties can include; reading for meaning, understanding and telling narratives.

### ***ASD and Gender***

Past and current diagnosis data suggests that ASD is more common in males than females, although the exact ratio differs between studies. The Centre for Disease Control and Prevention (CDC, 2015) state that ASD is almost 5 times more common among boys than girls, based on data from a report by Baio, and the Autism and Developmental Disabilities Monitoring Network (2010) which focused on children. Brugha (2009) found that of adults within the population 1.8% of males but only 0.2% of females had ASD. Wing (1981) suggests that the ratio of males to females in early childhood differs depending on cognitive ability, finding that within individuals with high-functioning autism there were fifteen times more males than females, but in individuals with learning disabilities, it was closer to double.

The reason for this gender discrepancy is as yet unexplained and there are multiple theories which could account for the trend. Baron-Cohen (2010) hypothesises that autism is an exaggerated display of a normal masculine brain. He suggests that people are either “systemising” or “empathising” to differing degrees, and that males tend to be predominantly systemising and females tend to be empathising. He then goes on to state that autistic individuals are systemising to an inflated level and therefore displaying an ‘extreme male brain’. This theory, suggests males are predisposed to having autism, and builds upon an early observation by Hans Asperger (1944), that the male pattern of behaviour is exaggerated to ‘the extreme’ within autistic individuals.

Over the last ten years, literature which discusses gender differences in autism has varied in its findings and conclusions.

Van Wijngaarden-Cremers et al. (2014) who carried out a review of gender differences in ASD, found that males and females did not differ in the domains of social behaviour or communication, but that above the age of six, males showed more restricted and repetitive behaviours. They concluded that the autism phenotype was likely to differ between the genders. Kirkovski, Enticott and Fitzgerald (2013), who carried out a similar review found that 78.8% of the reports they looked at supported an altered phenotypic presentation in females.

Both of these reviews raised diagnosis in relation to this altered presentation of symptoms as an issue. Van Wijngaarden-Cremers et al. (2014, page 627) suggested that ASD is “defined according to the male phenotype” and that therefore, tools of assessment may have a diagnostic bias towards males.

Some non-peer-reviewed literature, (Attwood and Grandin 2006, Nichols et al.2009, Hendrickx, 2015, Nye, 2000) which is based on anecdotal evidence and personal experiences of clinicians in the field, people with ASD and their caregivers, suggests that there are important differences in the presentation of and impact of ASD across gender. Attwood, (2009) describes his experiences of

females with Asperger's Syndrome and notes that they appear more able to display appropriate social actions by delayed imitation and that their restricted and repetitive behaviours are not as conspicuous as their male counterparts, which matches the findings of Wijngaarden-Cremers et al. (2013).

Some of the literature highlights gender specific difficulties which are emphasised by differences in the social behaviours and communication of typical boys and girls, such as the "relational aggression" that adolescent females display (Crick and Grotpeter, 1995). Ehlers and Gillberg, (1993) propose that females with ASD are under-diagnosed due to presentation differences not detected by diagnostic tests. The National Autistic Society's Lorna Wing Centre for Autism has seen a steady increase in the number of females being diagnosed, which they suggest is indicative of a historic bias towards males in the diagnostic criteria for autism (National Autistic Society(NAS), 'Gender and Autism', n.d).

However, as yet there is insufficient evidence for the theory that females present differently from their male counterparts or that the current assessment materials available may be less appropriate for females. Nevertheless, the possibility of the verity of this theory should be considered by clinicians when involved in the diagnosis of ASD.

## **Aims**

With a view to providing useful information to Speech and Language Therapists taking a lead role in assessing and diagnosing the social and communication skills associated with ASD (RCSLT, 2015), the following literature review aims to:

- Consider information on gender difference in the skills of males and females with ASD in all areas of communication.
- Use the available information to draw tentative conclusions as to:
  - What knowledge we can assume based on current data.
  - What may need further investigation.
  - The implications for diagnosis and intervention.

## **Method**

The initial literature search for this project collated peer reviewed research from two medical databases, PubMed (MedLine) and Cinahl Plus, as they contain large numbers of social and health related journals and should therefore be suitable for collating literature on this subject.

A systematic search was carried out using different combinations of the following relevant terms (Table 1), which relate to concepts of Autism and differences in gender.

| <u>Concept of Autism:</u> |     | <u>Concept of Gender:</u> |
|---------------------------|-----|---------------------------|
| ASD                       |     | Sex Differences           |
| OR                        |     | OR                        |
| Autism                    | AND | Gender Differences        |
| OR                        |     | OR                        |
| Asperger*                 |     | Women                     |
| OR                        |     | OR                        |
| ASC                       |     | Girl*                     |
|                           |     | OR                        |
|                           |     | Female                    |

**Table 1: Search Term Combinations**

Initially, in order to assess the volume of literature on the topic, a third set of terms relating to “communication” were included. This was too restrictive, resulting in very little relevant literature being found. Therefore, despite communication being the focus of this study, it was decided that this term should be removed from the search, and to proceed with the wider search on autism, with the intention of sifting the information for the communication element.

The databases were restricted to searching within the titles and abstracts of papers, based on the assumption that the relevant literature would discuss both of the concepts of autism and gender (using terminology in table 1) within the abstract, but that communication may not be a focus of the study, and therefore only noted within the body of the papers.

In order to ensure that any studies collated and used were up-to-date, linguistically accessible to the researcher and of a good academic and reliable standard, the filters on the databases were set to:

- Written after 2005
- Available to read in English
- Peer reviewed

So that results would not be further restricted, the search included studies:

- from all economically developed countries
- which used participants of any ages

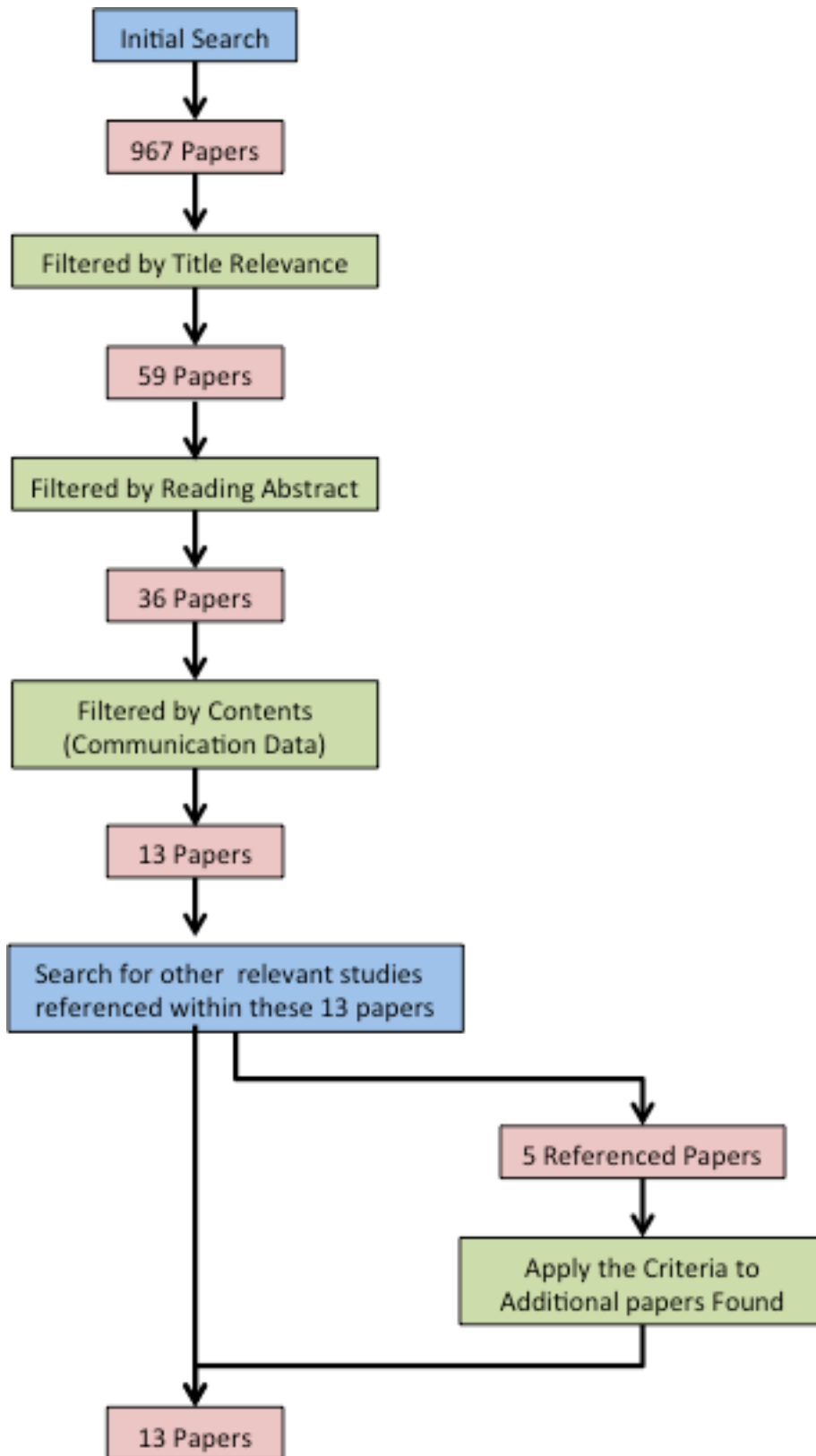
- which used participants diagnosed with ASD both prior to and during the research.

These were included because the concept and diagnosis in the majority of developed countries is unlikely to differ greatly as guidelines set by the World Health Organisation and American Psychiatric Association are used as a basis. It was felt that if a study appeared to have a significantly different process and definition of ASD diagnosis, that it could be excluded at the researcher's discretion. Literature containing different aged participants, with diagnosis occurring at different stages was included so as not to be overly restrictive and ensure that the possibility of gender differences could be considered at a range of ages which more fully represent the ASD population.

The initial search identified a high number of papers (nine hundred and sixty-seven). These were then filtered by the researcher judging the relevance of the studies, firstly based on the title (which left fifty-nine) and then the abstract. However, this included other literature reviews of general gender differences in autistic individuals and empirical studies which were related, but not necessarily the focus, of the project being undertaken. The remaining thirty-six papers were read and filtered for numerical data related to communication in both males and females with ASD, which was needed for the comparison of males and females communication.

Some of the empirical studies in the reviewed literature either banded male and female communication results together, or did not report the results of any communication subtests. Thirteen papers contained relevant and accessible data comparing the communication of males and females with ASD.

The introductions and discussions within each of these 13 papers were read for potentially relevant references. From this, 5 further relevant studies were identified, but then later discarded, as none contained any numerical communication data. This process is demonstrated in Figure1.



**Figure 1: Flowchart of Search Strategy**

## Results of the Research

### *Results*

During the initial systematic search for literature it became apparent that there are a lack of empirical studies which focus on investigating communication in males and females with ASD, although, there are studies and literature reviews which focus on gender differences in other aspects or in ASD as a whole. These found conflicting results.

Comparing communication information from the thirteen studies was not straightforward. Each study had different methods of carrying out research on demographically different participants and used different tests to assess a range of aspects of ASD.

The focus of the research varied between studies. (see Appendix B). Some papers looked broadly for any differences between the genders within a specific age group of the ASD population (Reinhardt et al., 2015), whereas some focused on gender differences within specific traits (Lai et al., 2012 focused on cognition and Solomon et al., 2012 on internalizing psychopathy). Communication differences between genders may not have been explicitly analysed or discussed. It was unclear whether this was due to insignificant results, or whether communication was overlooked as an important trait to investigate.

In order to find information relevant to this research project, it was necessary to sift through assessments and discussions, and then, rather than analysing results from full assessments, to filter out and use the results of the individual subtests related to communication.

### *Findings:*

The results were not in agreement on whether males and females with ASD display differences in their communication skills. Seven of the thirteen studies found a significant difference on one or more of the assessments they carried out, but six found no gender difference.

Findings were inconsistent both within individual studies, and within the same assessment tool when used across different studies, as seen in Table 2. For example, Carter et al., (2007) used four different tools to assess the same participants, only two of which found a significant difference in communication. It is important to consider reasons for the inconsistency, and to explore whether there might be any trends in relation to factors other than solely gender, such as the age of the participants, the type of communication being assessed, the assessment or the ways in which the data was collected by the studies.



| Study No. | Author and Date:                          | Age Group:  | Test used:<br>*** | Type of Communication Assessed: | Findings:     | Significance Level:              |
|-----------|---|-------------|-------------------|---------------------------------|---------------|----------------------------------|
| 1.        | Zwaigenbaum et al., 2012                  | <5          | ADI-R             | Social                          | F>M           | P<0.001                          |
|           |   |             | MSEL              | Exp. & Rec. Language**          | No difference | Exp. p=0.47<br>Rec. p=0.21<br>** |
| 2.        | Mandy et al. 2012                         | 5-13        | ADOS-G            | Social                          | No difference | P=0.34                           |
|           |   |             | 3Di               | Social                          | No difference | P=0.62                           |
| 3.        | Hartley and Sikora., 2009                 | <5          | ADOS-G            | Social                          | M>F           | P=0.03                           |
|           |   |             | MSEL              | Exp. & Rec. Language            | No difference | P=0.26                           |
| 4.        | Reinhardt et al., 2015                    | <5          | CSBS              | Social                          | No difference | P=0.92                           |
|           |   |             | MSEL              | Exp. & Rec. Language            | No difference | Not stated.                      |
|           |   |             | VABS              | Exp. & Rec. Language            | No difference | P=0.192                          |
| 5.        | Lai et al., 2012                          | Adult       | ADOS-G            | Social                          | F>M           | P<0.001                          |
|           |   |             | ADI-R             | Social                          | No difference | Not stated                       |
| 6.        | Andersson, Gillberg and Miniscalco., 2013 | <5          | GDS               | Rec. Language                   | No difference | P=0.66                           |
|           |   |             | VABS              | Exp. & Rec. Language            | No difference | P=0.10                           |
|           |   |             | RDLS3             | Exp. & Rec. Language            | No difference | P=0.66                           |
| 7.        | Solomon et al., 2012                      | Adolescent* | SRS               | Social                          | No difference | P=0.07                           |
|           |   |             | CCC2              | All areas.                      | No difference | Not stated                       |
| 8.        | Holtmann, Bolte and Poustka., 2007        | Adolescent* | ADOS (German)     | Social                          | No difference | P=0.64                           |
|           |   |             | ADI-R (German)    | Social                          | No difference | P=0.28                           |
| 9.        | Harrop et al., 2015                       | <5          | ESCS              | Social                          | No difference | Not stated                       |
|           |   |             | MSEL              | Exp. & Rec. Language            | No difference | Exp. P=0.88<br>Rec. P=0.75<br>** |
| 10.       | Carter et al., 2007                       | <5          | VABS              | Exp. & Rec. Language            | M>F           | P<0.05                           |
|           |   |             | MSEL              | Exp. & Rec. Language            | No difference | Not stated                       |
|           |   |             | ADOS-G            | Social                          | M>F           | P<0.05                           |
|           |   |             | ADI-R             | Social                          | No difference | Not stated                       |
| 11.       | Lai et al., 2011                          | Adult       | ADOS-G-G          | Social                          | F>M           | P<0.001                          |
|           |   |             | ADI-R             | Social                          | No difference | P=0.1                            |
| 12.       | Goddard, Dritschel and Howlin., 2014      | Adolescent* | BPVS2             | Rec. Language                   | No difference | Not stated                       |
|           |   |             | SCQ               | Social                          | F>M           | P=0.01                           |
|           |   |             | VF                | Exp. Language                   | F>M           | Not stated                       |
| 13.       | Bolte et al., 2011                        | Adolescent* | ADOS-G            | Social                          | No difference | P=0.81                           |
|           |   |             | ADI-R             | Social                          | No difference | P=0.89                           |

**Table 2 . Summary of Results for each assessment and study**

**Notes to table 2:**

- \* Adolescent – studies where the majority of participants were between 13 and 18years. At times they also included participants outside of this age range.
- \*\* "Exp." and "Rec." used to mean "Expressive Language" and "Receptive Language"
- \*\*\* Tests Used by Studies which Included Communication Data:

Autism Diagnostic Assessment- Generic (ADOS-G) - (Lord et al. 2000)

ADOS in German – (Rühl et al., 2004)

Autism Diagnostic Interview – Revised (ADI-R) – (Lord et al. 1994)

ADI-R in German– (Bölte et al., 2006)

Mullen Scales of Early Learning (MSEL) – (Mullen, 1995)

Vineland Adaptive Behaviour Scales (VABS) – (Sparrow et al. 1984)

The Developmental, Dimensional and Diagnostic Interview (3Di) – (Skuse et al., 2004)

Communication and Symbolic Behaviour Scales (CSBS) – (Wetherby and Prizant. 2002)

Griffiths' Developmental Scales I and II (GDS) – (Alin-Akerman and Nordberg. 1991)

Reynell Developmental Language Scales III (RDLS-3) – (Edwards et al., 1997)

Social Responsiveness Scales (SRS)- (Constantino, 2002)

Children's Communication Checklist (CCC2) -(Bishop, 2003)

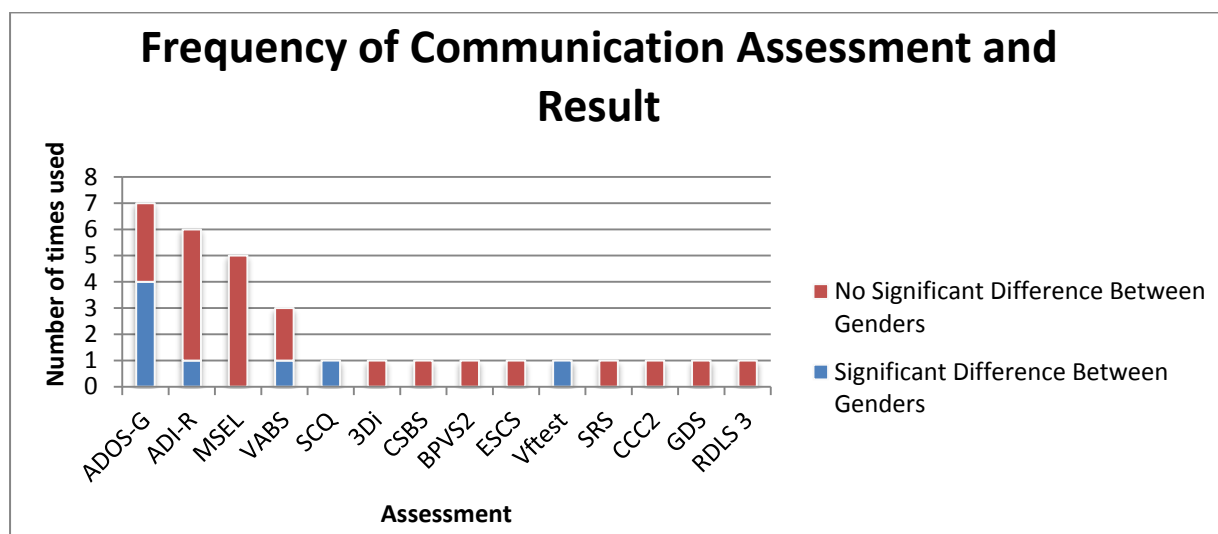
British Picture Vocabulary Scale II (BPVS2) – (Dunn et al. 1997)

Social Communication Questionnaire (SCQ) – (Rutter, Bailey and Lord, 2003)

Early Social Communication Skills (ESCS) – (Mundy et al., 2003)

Verbal Fluency test (VF) – (Goddard, Dritchel and Howlin, 2014)

### Assessments used:



**Figure 2. Graph demonstrating frequency of assessment and communication result**

A total of fourteen different assessment tools assessing some aspect of communication, were used across the thirteen studies reviewed. However, of these fourteen assessment tools, only four (ADOS-G, ADI-R, MSEL, VABS) were used by more than one study (see Figure 2). Therefore, only results from the studies using these assessment tools could be directly compared. This reduced the data-pool available and therefore conclusions drawn are less reliable.

Some consideration must be given to the attributes of the different assessment tools and how their individual focuses may impact results.

For example, the functionality of the assessment of verbal fluency used by Goddard, Dritschel and Howlin (2014), should be taken into account when considering the weighting of the results. Testing verbal fluency is not necessarily important as it is only considering word-finding ability, which is not a primary difficulty within ASD.

Five studies (Zwaigenbaum et al., 2012 Hartley and Sikora., 2009, Reinhardt et al., 2015, Harrop et al., 2015 and Carter et al., 2007) used the MSEL in conjunction with at least one other assessment. Across these, the MSEL did not highlight any significant difference between communication of males and females with ASD, although other assessments used within three of these same studies did. The reason for this is unclear.

The ADI-R only once showed a significant result (out of the six times it was used) even when the MSEL on same group did not (Zwaigenbaum et al. 2012). For example, in the studies by Lai et al. (2011 and 2012), and Reinhardt et al. (2015), the ADI-R showed no significant gender difference in communication skills, whereas other assessments on the same participants did, even when used in conjunction with assessments such as the ADOS-G, which have a similar focus on more social aspects of communication.

## ***Impact of Age***

Because this research project has included data from studies which use participants of all ages, it is important to consider age as a factor influencing the results.

The studies have been grouped into four categories based on the age ranges of the participants included: under-five, five to thirteen, adolescents, adults. The results of each group were then analysed separately to determine if there was a consistent pattern based on age of participants.

In the six studies which used participants aged under-five, three showed no significant difference between genders (Reinhardt et al., 2015 and Andersson, Gillberg and Miniscalco, 2013 and Harrop et al., 2015). Two found that females were more impaired (Hartley and Sikora., 2009 and Carter et al., 2007) using the ADOS-G and VABS. However, Zwaigenbaum et al., (2012) shows the opposite, finding males to be more impaired, when assessed using the ADI-R. Of these six, the studies which found no significant difference did not use either of the two most commonly used assessments, ADOS-G or ADI-R. The reason for this discrepancy is unclear, and later in this review, results will be analysed for trends based on assessments used.

The only study which focuses on older children (Mandy et al. 2012), found no significant difference between the genders.

Three out of the four studies which included adolescents (Solomon et al., 2012, Holtmann, Bolte and Poustka., 2007 and Bolte et al., 2011) show no significant difference between the communication skills of the genders. However, the study by Goddard, Dritschel and Howlin, (2014), found males to be more impaired than their female counterparts through the use of two assessments which no other study used (SCQ and informal test of Verbal Fluency). The SCQ is a checklist for parents, which claims to be in-line with the ADI-R (WPS, Online Catalogue, n.d). However, studies which used the ADI-R on the same age group, by Solomon et al. (2012) and Bolte et al. (2011), do not support evidence of difference.

Studies by Lai et al. (2011 and 2012) were conducted on an adult population. When using the ADOS-G, both studies found that males displayed significantly more impaired communication skills than the female participants. However on the communication section of the ADI-R no significant difference was demonstrated.

It should be pointed out, however, that in the study by Lai et al. (2011), the ADI-R results which were insignificant, were based on information about the participants childhood gathered from their primary caregiver, whereas the ADOS-G results which found males to be more impaired, were obtained as adults and carried out by a trained professional. The question as to why the same group of participants showed no difference in communication on one test based on their childhood, but that on a different test based on their skills as adults, they did show a difference needs to be considered.

The different results obtained from the two studies could be a consequence of the participant's skills changing over time, or due to the different assessments used. In addition, although using caregiver information (within the ADI-R) allows for the possibility that a participant behaves differently at home to in clinic, this was done in-hindsight and is therefore potentially less reliable. Further

consideration is needed regarding the expectations of the questioner in assessing communication skills across gender at different ages, how the assessments ask the questions and how the assessor scores responses in order to reduce the possibility of assessment and assessor bias.

In the only two studies which used ADOS-G on participants aged under-five, (Hartley and Sikora, 2009 and Carter et al., 2007), females were found to be significantly more impaired, but in the only two studies which use the ADOS-G on adults, males were found to be significantly more impaired. However, in the small sample of studies which were carried out on participants aged over four years but before adulthood, the ADOS-G did not highlight any significant differences in male and female communication. This prompts questions as to not only whether age affects gender differences and communication skills in those with ASD but also as to whether the test used in combination with age impacts results.

### ***Types of assessment***

The four most common assessments used in these thirteen studies, ADOS-G, ADI-R, MSEL and VABS can be divided into two groups based on the aspects of communication they are focused on assessing. MSEL and VABS assess both receptive and expressive language (VABS includes written language). The ADOS-G and the ADI-R focus on social communication – e.g. use of language, pragmatics and non-verbal skills. Although there is a difference in the focus of these assessments, no clear pattern can be seen in the results as to whether that focus impacts upon detection of any gender difference in communication. MSEL consistently found no difference between the communication skills of males and female across all four of the studies which used it. Due to the nature of the assessment, it was only used with participants aged under-five, and thus it could be considered that there is no difference in the expressive and receptive language of very young children, but that there are differences in social communication. However, Carter et al. (2007), who used participants of under-five, found a difference using VABS, which also measures expressive and receptive language.

In four out of seven incidences of the ADOS-G being used, a significant difference in communication skills of the different genders was found. However, even within these four there was a discrepancy between which gender was more impaired. Studies by Lai et al., (2011 and 2012), which found males to be more impaired, were conducted on adults, whereas studies by Carter et al., (2007) and Hartley and Sikora, (2009), which found females to be more impaired, were conducted on infants under the age of four. Goddard, Dritschel and Howlin, (2014) found males to be more impaired when using participants aged 8-16 years. This again raises questions as to whether the communication skills of the genders change with age.

## **Critical analysis and Limitations of the Literature**

### ***Size of Study***

The size of the studies included for analysis in this research project varied greatly. The number of participants used ranged from 325 participants with ASD in the study by Mandy et al. (2012) to as few as 24 participants with ASD in the study by Goddard, Dritschel and Howlin., (2014). Of the studies considered in this review, ten used fewer than 100 participants with ASD, and four of these used less than 50. When a sample size is too small, results cannot be assumed to be representative of the population studied (Kadam and Bhalerao, 2010). None of the studies made it clear whether they had statistically calculated the necessary number of participants needed to reliably generalise their results. When attempting to make comparisons between and draw conclusions from the results in these studies, it is important to consider these differences. Biases of the assessors cannot necessarily be measured or known and therefore conclusions should be made cautiously and not generalised for the whole ASD population. The study using 325 participants (Mandy et al. 2012) is likely to have a more representative view of ASD in its defined demographic than smaller studies, assuming, that all other aspects of the study are carried out in an unbiased and consistent manner.

A sample of only 24 is too small to assume results can be generalised to the rest of that population. Goddard, Dritschel and Howlin, (2014) acknowledge this within their study, and suggest that the study needs to be replicated in a larger and more diverse sample of participants to increase reliability.

### ***ASD Group***

Some studies matched males and females based on age or another factor; others did not. Three studies state that they intentionally matched males and females with ASD for age and IQ. Instead of this, Andersson, Gillberg and Miniscalco (2013) chose to match participants based on chronological and developmental age, and Harrop et al (2015) matched participants based on their severity of ASD. Mandy et al. (2012) and Hartley and Sikora (2009) do not state that they intentionally matched males and females based on any factor, but both included information that there was no significant difference in age between the genders. Although Reinhardt et al. (2015) did not match the participants, they carried out the assessments at approximately the same age on each child.

In order to compare results of a male group with ASD to those of a female group with ASD, all variables other than gender should be kept the same between the groups, so that any difference in results can be confidently presumed to be down to gender and not any other contributing factor. Therefore the results of studies which did match the male and female participants will more reliably represent true similarities and differences as the variables within the study have been controlled and we can assume that a difference in variables such as age or IQ have not caused either males or females to perform better/worse.

When reviewing these thirteen studies, a number of concerns were noted, such as the method of recruitment of the ASD participants in some of the studies. For example, Zwaigenbaum et al. (2012)

purposefully recruited “high-risk” participants as this was the focus of their study. They recruited infant siblings of children with ASD from four diagnostic and treatment centres in Canada. It is possible that due to being high-risk participants, the presentation of symptoms are not representative of the wider ASD population. This is because the participants are genetically predisposed to ASD and may be more likely to display a stronger autism phenotype and are environmentally pre-disposed to showing learned and copied behaviours of an older sibling (Piven et al. 1997) and therefore, results can be less reliably generalised. Mandy et al. (2012) recruited all of their participants from one specialist clinic which means that they will not be demographically varied and therefore, again, potentially not representative of the ASD population as a whole. Only recruiting from one clinic also means it’s possible the diagnosis of the participants is relying on diagnostic judgements of one team who could be diagnosing differently to other teams. Therefore this could impact upon the impairment profile of individuals included.

It should be noted that some studies did not include participants with varying titled ASD diagnosis, whereas others were more inclusive. Especially where restrictions were imposed as to high and low functioning forms of ASD, such as the study by Lai et al. (2011), this could impact upon results.

### ***Ratio Males to Females***

The ratio of males to females with a diagnosis of ASD differs between studies and between autism sub-types and IQ. As discussed, the unequal numbers of males and females may be due to preconceived views of male and female typical behaviours and a diagnostic bias. In the studies considered in this review, ratios of male to female participants ranged from 5:1 to equal numbers of each gender. This could be problematic because the ratio difference is perpetuated and multiplied further if the ratio is not equal at the outset of the research study.

### ***Age of participants***

There was a wide range of ages represented across the studies and the limitations of the data provided make it difficult to map any developmental sequence from communication impairments in relation to the question of gender differentiation. Only Holtmann, Bolte and Poustka, (2007) looked at children and adults, however they did not break their results down by age.

### ***Use of Control Group***

Six of the included studies made use of a non-ASD control group during their research (Zwaigenbaum et al. 2012, Reinhardt et al. 2015, Lai et al. 2012, Solomon et al. 2012, Goddard, Dritschel and Howlin 2014 and Bolte et al. 2011). Whether this was necessary depended on the focus of the study being conducted.

When looking into gender differences in ASD, it is most appropriate to use a control group of typically developing individuals which demographically matches the ASD participants. This allows for

the patterns found in the presentation of the ASD group to be compared with what is expected within the typical population. A factor which is pertinent to the significance of any findings.

If there are differences between the interaction and communication skills of typical males and females, but no differences between the genders in ASD, then although this is unlikely to impact on the diagnosis rates, it would have a social impact for the individuals with ASD when interacting with their peers. For example, if typical females display significantly stronger social skills than their male peers, but males and females with ASD (who are already impaired in this area due to the nature of the disorder) show no gender difference, then the skill-gap between typical and ASD females is greater than that between typical and ASD males.

At times, the recruitment method of the control participants appears to be carried out in a way which means the participants are not necessarily representative of the typical population and therefore the results cannot be relied upon to display as such. For example, the study by Bolte et al. (2011) which looked at gender differences in cognitive domains, first recruited participants with ASD, and then as a control sample, used the siblings of the ASD participants. It cannot be assumed that this is a representative control group as it is likely that siblings are predisposed to show traits of a broader autism phenotype (Piven et al. 1997). Although Bolte et al do acknowledge this. In the study by Reinhardt et al. (2015) the recruitment method of the “Typically Developing (TD)” group of participants is not clearly outlined.

Ideally, the TD control group should be recruited from the typical population, matched with the ASD group for age, gender, IQ and demographic background as closely as possible; so that a baseline expectation which is age and gender appropriate can be formed and results of the ASD and typical groups directly compared. Of the six studies which used a control group, only two age and gender matched them to the ASD participants (Solomon et al., 2012 and Goddard, Dritschel and Howlin, 2014). Lai et al., 2012 pooled both ASD and TD participants from within another study, but did not detail how this was done.

### ***Assessments Used***

A total of fourteen different tools which assessed some aspect of communication were used across the thirteen studies collated here. The studies had differing focuses and aims and therefore the use of different tools and methods of data collection was appropriate. Although this makes comparing results from different studies difficult, it highlights that there are a range of ways of looking at communication.

The four most common assessments used were the ADOS-G, ADI-R, MSEL and VABS. The ADOS-G and the ADI-R are used as a basis for diagnosis. They build a picture of an individual’s abilities and difficulties in relation to the triad of impairment, which although is outdated for diagnosis, is a useful tool to map ASD related impairments. The ADOS-G is a semi-structured assessment, which uses a series of standard activities to elicit behaviours, which a trained professional then rates in relation to the triad of impairment. The ADI-R gathers information regarding the subject’s behaviours through an interview with their care-giver. Both assessments are very detailed, and put an emphasis on social



communication and use of language, which when assessing for ASD is important. On one hand the ADOS-G can be argued to collect information in a more reliable manner, as the ADI-R relies on carer responses and descriptions, which may not be entirely accurate. Carers may interpret their child's behaviours in a different manner to a trained professional and may give more emotive and less objective descriptions. However the ADI-R builds a picture of a child's behaviour and functioning within their day-to-day life, unlike the ADOS-G which makes assumptions based on the participant's performance in one particular incidence in an unnatural situation.

MSEL and VABS assess expressive and receptive language level rather than social aspects of communication, which are a key impairment in ASD (Attwood and Grandin, 2006). Therefore, these assessments may not have picked up some of the key impairments, or more subtle differences between the genders. In the five studies using it, the MSEL did not find a significant difference however, its ability to do this cannot be reliably commented on based on the five studies mentioned here, it would need to be assessed on a larger population where the presence or absence of differences was already confirmed.

Goddard, Dritschel and Howlin (2014) made use of an informal assessment of verbal fluency where participants were required to name objects in a given category (e.g. animals) within sixty seconds. The relevance and functionality of this assessment is questionable as it is not a standardised assessment so results cannot be compared to what is typical.

The CCC2 is the only assessment used which looks at all aspects of communication. However, it is only designed for use with children aged 4-16 and so was not viable in many of the studies looked at in this project, and was only used once, by Solomon et al., 2012.

### ***Issues using the literature for this project***

To collate the data relevant to this literature review, which has its main focus on communication, it was necessary to identify and use the results of individual subtests which had a communication element broken down by gender. This created difficulties during this review because results of individual subtests were often disregarded and not analysed.

Within the individual studies, a lack of analysis or comment upon communication skills is not in itself an issue, as it was not necessary or conducive to their individual aims. However, it caused difficulties for this research project. It also holds significance in regards to a lack of knowledge base and therefore could impact on the diagnosis and care of individuals with ASD.

## **Discussion and Conclusion**

### ***Findings in Relation to Aims***

Overall, the data collated within this project has not enabled a definitive answer to the question of whether there are communication differences between males and females with ASD. The evidence

was conflicting both between and within the thirteen studies reviewed, with some individual assessment data finding that in the area of communication skills, males were more impaired, some showing females were more impaired, and some showing no significant difference.

The wide range of communication measures used made comparing results and coming to a conclusion difficult. So far investigations have not shown much difference between males and females with ASD, but, it is important to note that a lack of difference between genders may be just as pertinent as finding one, when considering the impact upon individuals.

The preliminary research, which was made up of a relatively small and incomplete data set, suggested that there may be trends in relation to communication of males and females with ASD at different ages.

If comparing only the results from the ADOS-G assessment, it can be seen that in adults, males demonstrated a greater impairment in their communication skills, but in participants age under-five, females were more impaired. Attwood (2007) suggested that females develop coping strategies during their childhood which mask their difficulties, such as learned interactions and imitating their peers. If this is true, it could explain this apparent discrepancy between children and adults with ASD. When including results from other assessments, this pattern is contradicted by one result on age under-five, where, on the ADI-R, males showed more impaired communication.

### ***Other Potential Findings***

This project did not set out to investigate males and females with ASD in relation to their typically developing (TD) peers, however, during researching and collating the data, it became apparent that comparing the scores of the ASD participants to those of the TD control groups raised important questions. For example, Reinhardt et al. (2015), found no significant difference between males and females with ASD, however when comparing their CSBS scores to TD males and females there was a significant difference. While both TD groups showed better communication skills than participants with ASD (as would be expected), the gap between ASD and TD females was found to be significantly larger (effect size of -0.03) than the gap between ASD and TD males. In the study by Solomon et al., 2012, carried out on adolescents there was no significant difference displayed on the SRS between the genders within the ASD group, nor between ASD and TD males. There was, however, a significant difference ( $p < 0.001$ ) between TD females and females with ASD, who presented as significantly more impaired.

Although this would not have an impact upon diagnostic bias of males and females, this could have an impact upon the lives of females with ASD. If, as these results suggest, males with and without ASD are communicatively not that different, but females are, then females with ASD will find it more difficult to fit in with their typical peers. Society will have a greater expectation of female social skills, and therefore they may appear more impaired than males due to difficulty adapting to the level of communicative skill and social understanding needed to fit in with typical female social groups. Females with ASD would be likely to need even more social support than males in-order to function within society.

Lai et al (2011), found no gender difference in clinically significant levels of coexisting psychopathy, and males and females did not differ in self-reported anxiety, depression, and obsessive-compulsive traits. However, it is pertinent to acknowledge that females self-reported having more severe symptoms of ASD, but that on clinician rated assessments they were not significantly different to the males. It is not clear whether this discrepancy was because females believed themselves to be more impaired than they were or whether the male participants rated themselves less impaired than they actually were. Holtmann, Bolte and Poustka, (2007) found that females with ASD displayed more social withdrawal and social problems than their male peers, when assessed using the Child Behaviour Checklist subscales (Achenbach, 1991). This raises the question of the impact of self-perception and whether females may be more socially self-aware. It directly links to societal expectations and the fact that females with ASD may be comparing themselves to their significantly more socially advanced typical peers.

### ***Implications Of Findings***

#### For Practitioners

The current lack of conclusive evidence as to whether males and females with ASD present with differences in their communication skills leaves practitioners in the field with an unclear path of progression. It is not known whether current diagnostic assessment tools are sensitive enough to communication differences to distinguish gendered communication behaviour.

If there are significant differences in the presentation of males and females with ASD in other areas of core symptomatology then females may not meet diagnostic criteria in those domains. Therefore, diagnostic assessment of females may be heavily weighted upon the communication and interaction domain. There is therefore a need for the development of more sensitive assessment tools and accurate descriptions of the presentation of female ASD, to reduce the possibility that some females may go undiagnosed.

The possibility of adult females with ASD being more communicatively impaired than their male counterparts may suggest need for a review of the services available to females with ASD, in order to ensure that support is available during periods of time when the individual most needs it.

#### For Individuals

If there is a difference in the presentation of males and females with ASD, which the diagnostic assessments are not identifying, and which clinicians are unaware of or have no evidence of and therefore not looking out for, the individual has the potential to go undiagnosed or to receive the wrong diagnosis. Lack of correct diagnosis may lead to higher rates of mental health issues in this population.

## **What Next?**

In conclusion, this is an area in which there has been a lack of research, and what research there is has not been focussed on communication. Further investigation is needed in-order to clarify the facts so that clinicians can base diagnosis and intervention on up to date information.

This review suggests that that a large study into the potential communication differences of males and females with ASD needs to occur. It should include participants of a range of ages, and contain scores broken down and analysed by age group so as to identify any consistent patterns in that variable. The male and female participants should be from a range of demographic backgrounds and the study should include all forms of ASD. The male and female participants should be matched for age, IQ and demographic background.

It would be pertinent to use a control group of typically developing participants who were also matched with the ASD group for age, IQ and demographic status, to allow a reliable comparison to the typical population.

Ideally a range of assessment tools should be used with each individual, so as to gain a full picture of all aspects of their communication. All of the participants should undertake age/developmentally appropriate versions of the same assessments where possible. It would be recommended that the assessments used look at social communication, use of language and expressive and receptive language level. Using a mixture of professional observation, structured assessment, carer interview and self-rating scales would allow for a thorough assessment of an individual's communicative functioning, and may allow for trends in the kinds of assessments and results to emerge. This may give some guidance as to the most appropriate future assessment tools. The use of a self-rating scale would allow for monitoring of the participants self-awareness and potentially indicate any other related areas that need addressing, such as mental health issues. The possibility that females skills improve and overtake the skills of their male peers at puberty should be considered as a potential hypothesis for future study.

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## **Appendix A.**

Autism is a disorder which affects a person's ability to relate to and communicate with others and the world around them (National Autistic Society (NAS). (n.d). "What is Autism?"). In the past, the difficulties associated with Autism were described using the "Triad of Impairment": 'language and communication' difficulties, 'social and emotional interaction' difficulties and 'imagination & flexibility of thought' difficulties (National Autistic Society (NAS). (n.d). "What is Autism?"). The categories used for diagnosis of ASD are now: "social communication impairment" and "restricted interests and repetitive behaviours" (American Psychiatric Association, 2013).



## Appendix B.

| <u>STUDY NO.</u> | <u>Citation</u>                           | <u>Title of Study</u>   | <u>No. ASD Participants with Comm. Data</u> | <u>M:F Ratio</u> | <u>Age of Participants</u>           | <u>Age Category</u> | <u>Control Group Used?</u> |
|------------------|---|---|---|------------------|--------------------------------------|---------------------|----------------------------|
| 1                | Zwaigenbaum et al., 2012                  | Sex Differences in Children with Autism Spectrum Disorder Identified within a High-Risk Infant cohort   | 80  | 1.7:01           | Assessed at 3 years                  | <5                  | Y                          |
| 2                | Mandy et al. 2012                         | Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents   | 325   | 5.3:01           | Mean Female: 10.2<br>Male: 9.7 years | 5 to 13             | N                          |
| 3                | Hartley and Sikora., 2009                 | Sex Differences in Autism Spectrum Disorder: An Examination of Developmental Functioning, Autistic Symptoms and Coexisting Behaviour Problems in Toddlers | 199   | 3.7:01           | Range 1.5-3.9 years                  | <5                  | N                          |
| 4                | Reinhardt et al., 2015                    | Examination of Sex Differences in a Large Sample of Young Children with Autism Spectrum Disorder and Typical Development                                  | 288   | 5.3:01           | Mean 28months                        | <5                  | Y                          |
| 5                | Lai et al., 2012                          | Cognition in Males and Females with Autism: Similarities and Differences.   | 64  | ~Equal           | Range 18-49 years                    | adult               | Y                          |
| 6                | Andersson, Gillberg and Miniscalco., 2013 | Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles?   | 40  | Equal            | Range 1.8-3.9 years                  | <5                  | N                          |

|    |                                      |   |    |        |                                       |                       |   |
|----|--------------------------------------|---|----|--------|---------------------------------------|-----------------------|---|
| 7  | Solomon et al., 2012                 | Autism Symptoms and Internalizing Psychopathy in Girls and Boys with Autism Spectrum Disorders                              | 40 | Equal  | Range 8-18 years                      | Including adolescents | Y |
| 8  | Holtmann, Bolte and Poustka., 2007   | Autism Spectrum disorders: Sex differences in autistic behaviour domains and coexisting psychopathology                     | 46 | Equal  | Range 5-20.2 years                    | Including adolescents | N |
| 9  | Harrop et al., 2015                  | Does Gender influence core deficits in ASD? An investigation into Social-Communication and Play of Girls and Boys with ASD. | 80 | Equal  | Mean Female: 40.64 Male: 40.05 months | <5                    | N |
| 10 | Carter et al., 2007                  | Sex Differences in Toddlers with Autism Spectrum Disorder   | 90 | 03:01  | Range 18-33 months                    | <5                    | N |
| 11 | Lai et al., 2011                     | A Behavioural Comparison of Male and Female Adults with High Functioning Autism Spectrum Conditions                         | 62 | ~Equal | Mean Female: 27 Male: 26.9 years      | adult                 | N |
| 12 | Goddard, Dritschel and Howlin., 2014 | A Preliminary study of Gender Differences in Autobiographical Memory in Children with Autism Spectrum Disorder              | 24 | Equal  | Range 8-16 years                      | Including adolescents | Y |
| 13 | Bolte et al., 2011                   | Sex Differences in Cognitive domains and their clinical correlates in higher-functioning Autism Spectrum Disorders          | 56 | 1.7:01 | Mean Females: 14.3 Males:14.0 Years   | Including adolescents | Y |

## The impact of specific language impairment on educational, emotional and social experience in adolescents: a literature review.

Jenny Wilkinson, supervisor

### Abstract

**Introduction** – Evidence that children with speech and language impairments have poorer outcomes than their peers in terms of educational, emotional and social difficulties has been highlighted by recent government reports (Bercow, 2008, Lindsay et. al., 2012). Revealing the need to research these difficulties beyond primary education and into adolescence, an area previously neglected (Conti-Ramsden, 2009). This literature review brings together recent research into adolescent outcomes for those with Specific language impairment (SLI).

**Method** – A systematic review of studies since 2000 was carried out using three data bases (CINAHL, Scopus and PsycINFO). Information was gathered from articles that investigated the progression of those with SLI in terms of educational, emotional and social outcomes in adolescence.

**Results** – Thirty four papers were included in the literature review, showing poorer outcomes during adolescence for those with SLI in terms of exam success, peer relationships, independence, social skills and emotional and behavioural difficulties. However, inconsistencies in methodology, assessments used and participant selection criteria could be seen to effect the validity and reliability of the findings.

**Discussion** – The severity of the language difficulties was shown to impact on educational achievement. However, the development of emotional and social problems had been found partly to relate to the development of autistic spectrum disorder (ASD) symptomology, pragmatic and higher level language difficulties (Durkin et. al., 2012, Helland et. al., 2014, Cohen et. al. 2013). The trajectory of the condition however, is complex in nature. As yet, there is no conclusive evidence as to whether the difficulties faced in adolescence are due to the progression of the condition or the impact of the language difficulties once the demands of language increase in later childhood.

**Conclusion** – Further research into SLI in adolescence would enable appropriate multi-disciplinary interventions to support children in emotional wellbeing, social and academic skills (Yew and O’Kearney, 2013).

### Introduction

The government Bercow report (2008) and I Can’s Cost to the nation (Hartshorne, 2009) outlined a set of discouraging outcomes for children with speech, language and communication needs (SLCN). Poorer outcomes can be seen in terms of academic achievement, employment, criminal behaviour and mental health issues and these issues can become more apparent where a SLCN has been undiagnosed or intervention strategies ineffective. McLeod and McKinnon (2007) investigated the

prevalence of communication difficulties in mainstream schools in Australia, finding thirteen percent of children having some area of difficulty. One subset of SLCN children is those with Specific Language Impairment (SLI). It is thought that approximately around 6-7 percent of children present with language difficulties that are not attributable to any development disorder or medical condition that may be seen as causal. These children also have levels of intelligence (IQ) within the normal range (Scerri et al, 2011.) Traditionally, such children have been given several different labels, the most current being 'specific language impairment (SLI)', denoting a delay in language skills with no causal factors evident.

In light of the Bercow Report (2008) government policy has recognised that improvements to children's communication is vital in improving outcomes for these children in later life. The Better Communication report (Lindsay et. al., 2012) was commissioned in response to the findings in the Bercow report. Effective interventions for those children with SLCN is still a priority within government policy. This includes a move towards investigating the development of language disorders through adolescence where the level of support that can be offered often drops away (Conti-Ramsden, 2009). A recent drive to highlight the difficulties faced by children with SLI, the RALLI campaign (Bishop, 2012), has highlighted the difficulties faced by many children with SLI. This has shown how the condition has affected the children themselves and has revealed the on-going issues often faced by this group.

### ***The Nature of SLI***

SLI is a disorder that comprises deficits in language where there is no known hearing loss, neurological damage, emotional disorder (such as Autistic spectrum disorder, ASD) and where non-verbal IQ is within the normal range (Bishop, 2014). However, Bishop (2014) stated that such criteria are not often as clear cut in some cases. If a hearing loss resolves and still the child does not reach age appropriate language skills can they not be seen to have SLI? Where a child has ASD and language impairment symptoms, should SLI not be diagnosed? Should language impairments not be identified in terms of their presenting language difficulties? Changes to levels of IQ have also been identified by Botting (2005) finding that non-verbal IQ levels of those diagnosed with SLI fell during adolescence. She showed over half of those tested had nonverbal IQ levels lower than what constitutes within the normal range (below 85). Therefore, these children no longer fit the original criteria for a SLI diagnosis. Thus, such research demonstrates the changing nature of SLI as children move through adolescence and into adulthood and shows the difficulties of the current exclusion criteria for a diagnosis of SLI.

Research into the different aspects of SLI that can occur in adolescence has been an area only recently explored. Stackhouse and Wells (2001) describe how language impairments can impact on literacy development and the ability of children to access the curriculum when at school. However, studies in this area often look at literacy skills in primary school aged children. There have been few studies into the longitudinal progression of SLI. However, information pertaining to the trajectory of such language disorders started to become of interest as the long term impact of language impairment became a focus of Government interest (Bercow Report, 2008) and that of researchers. Conti-Ramsden and Botting (2008) used a longitudinal study to show that early childhood language

impairment persisted through into adolescence. Undiagnosed language impairment was acknowledged as a factor in those children at risk from being excluded from school and those receiving mental health intervention (Clegg et. al., 2009, Cohen et. al., 2013). Such studies suggest more subtle higher level language difficulties might not be recognised in the mainstream school system, leading to misunderstandings and inaccurate interpretations of the behaviour being displayed by these children. Primary components of language develop in early childhood. However, other areas of language such as higher level language skills, verbal reasoning and social language skills develop during adolescence. Continued higher level language impairment can affect self-expression, social skills and making inferences in adolescence and beyond (Yew and O’Kearney, 2013).

The poorer outcomes observed for this group could be due to these persistent language difficulties having a greater impact in adolescence, where the language demands, educationally and socially, increase. Conti-Ramsden (2007) argued that this may lead to a child not participating fully in social activities or school, resulting in social failings. However, other studies such as Helland et. al. (2014) found those with SLI demonstrated pragmatic difficulties in adolescence not seen in early childhood. Therefore raising the question of whether the progression of SLI can include the development of further impairments in aspects of social communication. Botting (2005) questioned the notion of ‘specific’ language impairment that views impairment as related to only one part of the cognitive system. She proposed a more developmental view of interactions between language and other cognitive mechanisms such as working memory, that combined produce the SLI profile.

Both those working with SLI and researchers have highlighted the heterogeneous nature of those with SLI, being evident both across and within individuals (Conti-Ramsden and Durkin, 2008.) This makes predicting associated difficulties and longer term outcomes from language ability challenging, as variables influencing outcomes are complex and individual. Conti-Ramsden (2009) stated that as the difficulties of those with SLI change as they reach adolescence, more research in this area and possible interventions would be of benefit.

This literature review investigated the ongoing impact of Specific Language Impairment (SLI) beyond primary education and into adolescence. The review explored possible reasons for any lack of progression in these children such as self-esteem or social interaction issues. An evaluation was undertaken to objectively review current research and thinking around the progression of SLI into adolescence and if associated difficulties are deemed part of the condition or a consequence of persistent language difficulties. Outcomes for those with SLI were examined in relation to educational attainment, such as exam results, further study or employment, emotional issues relating to self-esteem, behavioural or psychiatric difficulties and social issues relating to friendships, sociability and independence. Exploring the difficulties of SLI children in adolescence may provide indications of why this group of children have poorer outcomes than their peers in later life. This may also point to whether there is a need to follow up children with a history of SLI in adolescence and provide further interventions to ensure they are maintaining their skills to a level sufficient to reach their potential.

Therefore, the hypothesis for this literature review is: Adolescents with Specific Language Impairment have language difficulties that have a negative impact on educational, emotional and social aspects of their lives: A literature review.

## Method

The search terms that were used to gather the articles are laid out in the table below. Each of the terms were searched for systematically ensuring each concept was searched for in combination with all the others. The initial phrase in column one and two below were searched for with all of those in column three in turn, then the initial phrase from column one was searched for with the second phrase from column two and as before with all of those in column three in turn. This was repeated until all the terms had been searched for in the second and third columns with the initial phrase in column one. Then the second phrase in column one was searched for in the same way with all the terms in the second and third columns, and this was continued until all of the terms had been searched for in combination with each other.

**Table 1. Search terms used:**

| <i>First term used</i>              | <i>Second term used</i>    | <i>Third term used</i>        |
|-------------------------------------|----------------------------|-------------------------------|
| <i>Specific Language Impairment</i> | <i>adolescence</i>         | <i>outcome</i>                |
| <i>SLI</i>                          | <i>Secondary education</i> | <i>educational attainment</i> |
| <i>Language difficulties</i>        | <i>School leavers</i>      | <i>academic achievement</i>   |
| <i>language</i>                     | <i>11-18</i>               | <i>education</i>              |
|                                     |                            | <i>social</i>                 |
|                                     |                            | <i>emotional</i>              |
|                                     |                            | <i>friendship</i>             |
|                                     |                            | <i>peers</i>                  |
|                                     |                            | <i>independence</i>           |
|                                     |                            | <i>Self-esteem</i>            |

In order to investigate this fully, this literature review concentrated on research conducted with adolescents with SLI. Reasons for exclusion of papers was regarding the use of children with co-existing difficulties such as a learning disability or ASD. Papers were also be excluded if they were studying younger children. Only articles from the year 2000 onwards were included to gain the most current understanding of the issues. Inclusion criteria included studies that examined the impact of SLI in adolescence in respect to education, personal and social issues. To be included in the review studies must have also used appropriate measures of language ability to identify language deficits in those studied.

The data bases used to find the relevant articles were:

- CINAHL

- Scopus
- PsycINFO

The following table shows the number of articles found using each data base, having used the above search terms in every combination. Of those found they were then reduced in numbers by excluding duplicate papers and discarding by irrelevance of title. The remaining articles were then evaluated using the abstracts to establish their relevance to the current literature review.

**Table 2. Papers found from the data bases:**

| <b>Data base</b> | <b>Total papers found</b> | <b>Number left after removing duplicates and discarding by title</b> | <b>Number saved for review after reviewing abstracts</b> |
|------------------|---------------------------|--|--|
| <b>CINAHL</b>    | <b>381</b>                | <b>98</b>  | <b>25</b>  |
| <b>Scopus</b>    | <b>739</b>                | <b>121</b>   | <b>17</b>  |
| <b>PsycINFO</b>  | <b>255</b>                | <b>35</b>  | <b>4</b>   |

Forty six papers were saved and used for the literature review. A further four papers were then found via the reference lists of the above articles. Of the saved articles a further sixteen were later excluded as they were either not investigating issues in adolescence or they were reviews or editorials regarding other included papers. Therefore a total of thirty four papers were fully appraised for the purpose of this review.

Studies with a prospective longitudinal design can give strong evidence of the outcomes for children with SLI and their peers during adolescence. The majority of the papers included in this review are of this design. However, studies using a cross-sectional design were also included in this review as it was felt that the studies added value to the evidence of SLI outcomes. The studies included in the review used methodologies that controlled for factors such as socio-economic status, maternal education and non-verbal IQ or language skills where appropriate.

## Results

The following papers were reviewed and basic information is laid out in the following table:

**Table 3. Results from analysis of articles:**

| Author   | Year | Design                              | no. participants<br>SLI/TD     | academic | social /<br>friendships | Indepen-<br>dence | self-<br>esteem /<br>emotional | other   | UK / other |
|--|------|-------------------------------------|--------------------------------|----------|-------------------------|-------------------|--------------------------------|---|------------|
| Durkin, Conti-Ramsden & Simkin<br>Wadman, Botting, Durkin, Conti-<br>Ramsden | 2012 | longitudinal                        | 26/26(ASD)/85                  | yes      | yes                     | yes               | yes                            |   | UK         |
|  | 2011 | longitudinal                        | 90/91                          | no       | yes                     | no                | yes                            |   | UK         |
| Durkin, Simkin, Knox, Conti-<br>Ramsden                                      | 2009 | longitudinal                        | 120/121                        | yes      | no                      | no                | no                             |   | UK         |
|  | 2009 | longitudinal                        | 120/121                        | yes      | no                      | no                | no                             |   | UK         |
| Lindsay, Dockrell, Palikara  | 2010 | longitudinal                        | 58/no control                  | no       | no                      | no                | yes                            |   | UK         |
| Wadman, Durkin, Conti- Ramsden   | 2008 | longitudinal                        | 44/54                          | no       | no                      | no                | yes                            |   | UK         |
| Botting, Conti- Ramsden  | 2008 | longitudinal                        | 134/124                        | no       | yes                     | no                | no                             | social<br>cognition                               | UK         |
| Botting  | 2005 | longitudinal                        | 82/no control                  | yes      | no                      | no                | no                             | IQ  | UK         |
| Snowling, Adams, Bishop, Stothard  | 2001 | longitudinal                        | 71/49                          | yes      | no                      | no                | no                             | IQ  | UK         |
| Conti- Ramsden, Durkin   | 2008 | longitudinal                        | 120/118                        | no       | no                      | yes               | yes                            |   | UK         |
| Wadman, Durkin, Conti- Ramsden   | 2011 | longitudinal                        | 90/91                          | no       | yes                     | no                | no                             |   | UK         |
| Conti- Ramsden, Botting<br>Mok, Pickles, Durkin, Conti-<br>Ramsden           | 2008 | longitudinal                        | 139/124                        | no       | no                      | no                | yes                            |   | UK         |
| St Claire, Durkin, Conti- Ramsden,<br>Pickles                                | 2014 | longitudinal                        | 171/ no control                | no       | yes                     | no                | no                             |   | UK         |
|  | 2010 | longitudinal                        | 239/no control                 | yes      | no                      | no                | no                             | reading<br>skills<br>parental<br>concerns         | UK         |
| Botting, Durkin  | 2008 | longitudinal                        | 120/118                        | no       | yes                     | yes               | no                             |   | UK         |
| Conti- Ramsden, Durkin   | 2012 | longitudinal                        | 50/50                          | yes      | no                      | no                | no                             | post 19   | UK         |
| Conti- Ramsden, Simkin, Botting  | 2006 | longitudinal                        | 118/no control                 | no       | yes                     | no                | no                             | ASD   | UK         |
| Reed, Patchell, Coggins, Hand  | 2007 | Cross-sectional                     | 30/30                          | yes      | no                      | no                | no                             | narratives  | Australia  |
| Jerome, Fujiki, Brinton, James   | 2002 | Cross-sectional                     | 40/40                          | no       | no                      | no                | yes                            |   | USA        |
| Pratt, Botting, Conti- Ramsden   | 2006 | longitudinal                        | 52/no control                  | yes      | yes                     | no                | no                             | maternal<br>concern                               | UK         |
| Johnson, Beitchman, Brownlie   | 2010 | longitudinal                        | 112/132                        | yes      | yes                     | yes               | yes                            |   | Canada     |
| Conti- Ramsden, Durkin   | 2007 | longitudinal                        | 80/no control                  | yes      | no                      | no                | no                             | phonological<br>STM                               | UK         |
| Durkin, Conti-Ramsden  | 2004 | longitudinal                        | 120/118                        | no       | yes                     | no                | no                             |   | UK         |
| Brownlie et. al.   | 2004 | longitudinal                        | 76/92                          | no       | no                      | no                | yes                            | antisocial /<br>aggression<br>speech<br>disorders | Canada     |
| Lewis et.al.   | 2015 | longitudinal                        | 170/146                        | yes      | no                      | no                | no                             | psychiatric<br>sample                             | USA        |
| Cohen, Farnia  | 2013 | Cross-sectional                     | 144/186                        | no       | no                      | no                | yes                            | social<br>phobia                                  | Canada     |
| Voci, Beitchmann, Brownlie, Wilson   | 2006 | longitudinal                        | 76/126                         | no       | no                      | no                | yes                            |   | Canada     |
| Howlin, Mawhood and Rutter   | 2000 | longitudinal                        | 19 ASD /20 LI                  | yes      | yes                     | yes               | yes                            | ASD vs LI<br>behavioural<br>problems              | UK         |
| Clegg, Stackhouse, et. al.   | 2009 | Cross-sectional                     | 15/no control                  | no       | no                      | no                | yes                            |   | UK         |
| Clegg, Hollis, Mawhood and Rutter  | 2005 | longitudinal                        | 17/17(siblings)/17             | yes      | yes                     | no                | yes                            |   | UK         |
| Wadman, Durkin, Conti- Ramsden   | 2011 | Cross-sectional                     | 28/28                          | no       | yes                     | no                | no                             | social stress<br>executive<br>function            | UK         |
| Hughes, Turkstra, Wulfeck  | 2009 | longitudinal                        | 21/21                          | no       | no                      | no                | yes                            | behavioural<br>problems                           | USA        |
| Helland, et. al.   | 2014 | longitudinal                        | 40/37                          | no       | yes                     | no                | yes                            | problems<br>subtypes<br>and<br>outcomes           | USA        |
|  |      | longitudinal and<br>cross-sectional | 19/7(pragmatic)/<br>11(ASD)/12 | yes      | no                      | no                | no                             |   | UK         |



Limitations of many of the studies presented could be regarding developments in assessment, therapy and increased awareness of speech and language issues. This will inevitably result in environmental differences at different time points in longitudinal studies as the participants grow older. This in turn may lead to more subtle difficulties being better supported in the current educational system and children may therefore go on to reach their potential more so than in the past. Furthermore, the unknown reasons as to the dropout rate of the longitudinal studies during adolescence may call into question the validity of the findings.

It is also worth noting that a considerable number of the UK based articles were all found to be using the same cohort of children. The Manchester Language Study, a sample originally recruited and studied by Botting et. al. (1998). Although the study used a large sample size, any anomalies within this sample would have been replicated throughout several studies.

For this literature review information gathered will be provided and discussed in relation to three subheadings of educational attainment, emotional and behavioural difficulties and social interaction. However, several papers cover more than one aspect so can provide evidence in other areas also.

### ***Educational attainment***

Deficits in early language skills have been shown to lead to deficits in developing literacy skills and subsequent academic attainment (Snowling et. al., 2001). A study by Snowling et. al. (2001) followed up a cohort of 16 and 17 year olds with a pre-school history of SLI. Their aim was to investigate the long term impact of language impairment on educational achievement. They were interested in the outcomes for children whose language skills resolved early, by age 5;6 or persisted into later childhood. They conducted their research using 103 children originally studied by Bishop and Edmundson (1987). There were three groups one of which was a general delay group who had below average IQ scores. The other two groups had a language impairment not deemed to be attributable to any other disorders. These children were either in the persistent specific language impairment group (persistent SLI) or the resolved SLI group if impairments were considered to have resolved by age 5;6. A control group was recruited by Snowling et. al. (2001) who had typical development from the same area as the original participants. The study investigated the educational outcomes (G.C.S.E. grades) of those with persistent as opposed to resolved SLI. The data was obtained through postal questionnaires to the participants. The responses to the survey showed the persistent SLI group performing less well compared to the control or resolved SLI group, being entered on average for less than half the number of G.C.S.E.'s and achieving lower grades. However, even though the resolved SLI group were entered for the same number of G.C.S.E.'s as the control group they did not go on to achieve the higher A-C grades as the controls did. The paper highlighted the long term impact that SLI can have on educational achievement even when the difficulties are deemed to be resolved, suggesting that subtle language problems such as impairments in phonological processing may continue to hinder their progress. The number of participants used in this study was quite small (103 participants over 4 groups) and a larger sample size would give more generalisable results. Furthermore, the unknown reasons for the non-response to some of the questionnaires may also show differences between the groups.

Conti-Ramsden et. al. (2009) reported however, that the results of their investigation showed that there was no significant differences between children with resolved SLI and those with typical development in terms of exam success.

Durkin et. al. (2009) also investigated the exam success of those with SLI. After controlling for maternal education, socio-economic status, literacy and language skills, they discovered that differences in whether students were entered for exams and their subsequent success was due to the setting in which they were taught. Those attending specialist school provision did less well than those in mainstream school with support even when literacy and language skills were comparable. However, the reasons as to the placement of children in different settings, such as behavioural problems, may be impacting on their exam success.

Subsequent studies such as Johnson et. al. (2010) also showed that educational achievement for those with SLI is compromised. A twenty year, large sample study in Canada reported that those children with SLI had poorer outcomes in terms of academic achievement and occupational status than those with speech impairments or those of a typically developing control group. This was also seen in a study by Lewis et. al. (2015) where those with speech sound disorders or those with typical development had better educational outcomes than those with speech sound disorders and language impairment. Conti-Ramsden and Durkin (2012) also reported lower academic success of those with SLI than their peers. However, the telephone interview also revealed that those with SLI stated that they felt more supported in further education than their peers did.

A study by St. Claire et. al. (2010) highlighted the continued deficits in reading ability of those with SLI. It was found that from age seven to sixteen reading accuracy and comprehension remained below the level of those with typical development. The trajectory of those with SLI follows the same path of those with typical development, not falling further behind, however, and also not catching up. An association was also seen between reading accuracy and phonological memory. Conti-Ramsden and Durkin (2007) followed children into adolescence and found that literacy difficulties can persist into later childhood. They likewise found a relationship between phonological short term memory (STM) in those with SLI and their literacy and language abilities. They proposed a complex set of interactions between different processes involved with phonological STM, language and literacy during adolescence. STM ability stayed the same between the ages of eleven and fourteen in the SLI sample. However, there was no TD control group to compare these results with although the authors stated that in the general population STM ability should increase through adolescence.

Durkin et. al. (2012) studied children with SLI who showed symptoms of ASD along with those that did not and compared these two groups to that of typically developing children. Language ability was shown to be a feature of educational outcome as opposed to the presence of ASD symptoms in this study. This study will also be discussed later in terms of social interaction.

For children to meet the diagnostic criteria for SLI they require non-verbal IQ to be within the normal range. Botting (2005) gave evidence that during adolescence there was a drop in IQ levels for this group. She found that between the ages of eight and 14 IQ dropped on average 23 points, leaving some children no longer meeting the diagnostic criteria for SLI. This is not a pattern seen amongst the normal population and language outcomes were found to relate significantly to IQ indicating IQ

development and language progression being linked in some way. However, at different ages, different IQ measures were used and this may have affected results although the authors doubt to such an extent. There was also no TD control group to compare the results and due to only 34% of the sample taking part in the testing at the upper age range, the reason for this may be significant. For example, those whose parents were more concerned about their cognitive development may have been more interested in participating further in the study. Clegg et. al. (2005) likewise investigated IQ levels and found that IQ levels increased again after adolescence. Although only seventeen people with SLI were used in this study and practice influences or a change in the assessments used may account for some of the variation. Howlin et.al. (2000) questioned whether the decline in IQ and educational achievement was a product of a deterioration of the impairment or as a result of inappropriate education.

### ***Emotional and behavioural difficulties***

Wadman et. al. (2008) conducted a study into the levels of self-esteem and shyness amongst adolescents with SLI compared to typically developing children. Self-esteem is a theoretical concept incorporating cognitive, emotional factors and behavioural features and relates to our perceptions of ourselves. The investigation looked at 108 adolescents, half with SLI and half typically developing. They found that those with SLI had significantly lower self-esteem ratings and were also shyer than their peers, although the two groups were similar in their sociability ratings. They concluded that adolescents with SLI have a higher risk of lower self-esteem and are more likely to suffer from shyness. The association between language skills and these factors is a complex one, this study argued that it was shyness as opposed to language ability that was the biggest predictor of self-esteem, but that also language skills were related to shyness. Limitations of this research may be in terms of the data being collected through self-reported measures. There may be a tendency for one of the groups to over or under play their difficulties. The measures of self-esteem, although lower in the SLI group were still within normal limits and therefore cannot be seen as untypical for the general population.

Conti-Ramsden and Durkin (2008) used self and parental reports to look at levels of independence associated with everyday living at age sixteen. The results revealed that those with SLI were less independent than the control group and that their level of independence was related to poor language and literacy skills. They concluded that language skills are associated with adolescence independence more than non-verbal abilities. Levels of independence were seen to be a factor in emotional wellbeing and self-esteem and lack of language skills deemed the cause of this reduction in independence, in respect to things such as making a telephone call and organising social arrangements. Again over or under reporting of difficulties may affect the validity of the findings. Assessment of literacy skills in the typically developing group were also changed part way through the study. Initially they were not included due to the length of the assessment session, however, were later included as it was felt by the authors that this information was required. This could have impacts regarding the differing lengths of the testing session for half the group and where the researchers have not used all the data the sample size is reduced, therefore decreasing generalisability of the results.

Self-esteem was investigated by Lindsay et. al. (2010). This study reported results from levels of self-esteem at age sixteen and seventeen of those with SLI. It was found that levels of self-esteem rose at age seventeen once the adolescents had left compulsory education. Lindsay et. al. (2010) also concluded that higher levels of self-esteem in those with SLI can be a protective factor in relation to future behavioural and mental health problems. However, no control group was used to compare the effects with typically developing children. Jerome et. al (2002) had also found that increased levels of self-esteem provided children with an increased resilience in their future.

Several researchers explored the nature of depression and anxiety in those with SLI. Conti-Ramsden and Botting (2008) found higher levels of depression and anxiety amongst those with SLI, however found that the level of language ability did not predict these emotional outcomes. Therefore the authors hypothesised that emotional difficulties may be an inherent aspect of SLI, however further studies that examine family histories of emotional issues could provide more information as to such difficulties. Wadman et. al. (2011) similarly investigated emotional difficulties and also found higher levels of depression and anxiety in the SLI sample as compared to a typically developing group. They also reported an association between bullying and depressive symptoms, which was not shown in the TD group. However, this association was based on only one question within the self-report questionnaire. Interestingly, Wadman et. al. (2011) found that depressive symptoms in those with SLI decreased at age seventeen as they moved on from compulsory education whereas this was not replicated in the TD group. This mirrors the findings regarding the increase in self-esteem levels in SLI reported by Lindsay et. al. (2010).

Voci et. al. (2006) studied SLI and social phobia. They revealed that those with SLI at age five were 2.7 times more likely to develop a social phobia by age nineteen. This shows the variety of issues that can go on to effect those with SLI in adolescence. Cohen et. al.(2013) examined higher level language skills, working memory and reading ability amongst adolescents receiving mental health services. Forty five percent compared to only fifteen percent of a control group showed higher level language deficits in the clinical range. Although, the sample was gathered by self-selection, in that, of those approached the participants were the ones who offered to take part. This may have influenced results if those more likely to take part were already concerned about their language skills. Behavioural difficulties have also been investigated by authors such as Clegg et. al. (2009) who tested language skills of those at risk of school exclusion. Out of fifteen adolescents, ten were found to have language difficulties, five of which were deemed severe. Although this was a relatively small sample and less than half of those approached participated, it provides evidence of the possible impact of language ability on behaviour in adolescence. Behavioural difficulties and aggression at age nineteen were also found by Brownlie et. al. (2004) to correlate with language impairment at the age of five.

In a recent study similar to that of Clegg et. al. (2009) by Helland et. al. (2014) adolescents with behaviour problems were tested for language impairment. The authors reported that seventy percent of those assessed had language difficulties within the clinical range, including pragmatic difficulties. They argued that due to a lack of obvious speech difficulties, those with language impairments in adolescence may not fully comprehend situations and therefore may be seen as non-compliant by others. Hughes et. al. (2009) in a similar study examined executive function in those

with SLI and a group of typically developing adolescents. Using parent and self-report measures they found that fifty seven percent of those with SLI had parental ratings of executive function within the clinically impaired range compared to only ten percent of the control group. However, executive function is challenging to measure due to the complexity of interactions with other cognitive functions. The authors used parental and self-report measures of daily activities for ecological validity of the results. The study suggests a relationship between executive function and language ability, however, the characteristics of such a relationship is not clear. Therefore, the link between them could be co-morbid or casual in nature, bi-directional or a set of complex interactions with other cognitive abilities.

### **1.1 Social interactions**

Botting and Conti-Ramsden (2008) stated that some children with SLI are presenting with social difficulties as they reach adolescence. These difficulties appear to increase through childhood causing problems with friendships and social interactions during adolescence (Howlin et. al, 2000). Conti-Ramsden (2007) suggested that could this be due to higher language demands once they reach secondary school or that these issues are fundamentally associated with the disorder.

One of the earliest papers used in this review, Howlin et. al. (2000) examined the long term outcomes for children with language impairment compared to those with ASD. Although a relatively small sample size was used and no control group was studied, it highlighted a decline in social functioning and a more complex picture of outcomes for those with language impairment as they matured.

Conti-Ramsden et. al. (2006) examined the prevalence of ASD traits in children with SLI. Findings showed 3.9% of the SLI group as having Autistic spectrum disorder (ASD). They also found that a greater number of those with SLI displayed ASD traits. They concluded that children with SLI have an increased risk of developing ASD as a quarter of those with SLI presented with behaviours consistent with ASD.

Social problems of SLI children in adolescence could be due to their underlying SLI, mimicking ASD traits or the two disorders could be linked. A study by Durkin and Conti-Ramsden (2012) found that children with SLI often reported social difficulties through childhood and adolescence, often developing ASD type symptoms during adolescence although not to the severity that would give rise to a diagnosis. The study examined 52 participants with SLI, half of the group had ASD type symptoms and half did not. They found that those with ASD traits fared less well on measures of friendships, independence and work experience. The ASD traits noted in this study were in relation to social interaction difficulties and not repetitive or stereotypical behaviours, therefore not involving all ASD symptoms. Limitations regarding this study were that there were differences in the format used to assess various areas of functioning. There was a mixture of self and parental report for the different areas, with only friendship quality gathering evidence from both parents and the adolescents. Reported information may also be subject to over or under reporting, therefore possibly impacting on reliability. However, the authors stated that the correlation between parental and self-reporting on the friendship information was very high suggesting that the two ways of

reporting were comparable. Whitehouse et. al. (2007) also described the development of pragmatic difficulties in adolescence in those with persistent SLI.

Several researchers investigated parental concerns regarding their children's future (Pratt et. al. 2006, Botting and Durkin, 2008). These studies indicated that the majority of parents of children with SLI are concerned about the lack of social skills their children have and the effect this may have on their vulnerability and future prospects. Results identified many influencing variables that effected parental concern, such as quality of friendships, levels of independence, behaviour problems and amounts of pro-social behaviour. With the lower the level of independence the higher the parental concern (Botting and Durkin, 2008). There was also a concern regarding the lack of services once the children reach adolescence and beyond.

Social interactions in adolescence with SLI were also the subject of investigation by Botting and Conti-Ramsden (2008). They argued that deficits in language skills could have a complex relationship with the development of social skills in adolescence. Those with SLI had fewer friends and participated in fewer social activities than their typically developing peers, with language skills being a predictive factor. Also seen was a considerable association between language ability and social cognition and less so social skills. However, measures of social cognition may by their very nature pick up on language deficits, resulting in lower scores for those with SLI. Although this was controlled for as much as possible by the researchers using tests for younger children that should aid understanding and results were not used if the individual did not understand the control stories. The authors debated whether language deficits lead to decreased social competence, therefore leading to reduced social or conversational opportunity resulting in lower social functioning. Or are language impairment and social difficulties co-morbid? One area of language, that of spoken narratives, was studied by Reed et. al. (2007). This highlighted the fact that those with SLI gave fewer informative and cohesive narratives than their typically developing peers. Thus, it could be supposed that this in turn would impact on the quality of friendships those with SLI have, as friendships are heavily dependent on communication.

Durkin and Conti-Ramsden (2007) reported only fifty four percent of adolescents with SLI felt they had a normal range of friendships. Compared to ninety eight percent of those in the TD group. They also found that language ability was correlated with the quality of friendships, once pro-social behaviour, conduct difficulties and non-verbal IQ were controlled for. Wadman et.al. (2011) also discovered using self-report measures that twenty four percent of those with SLI fell in the category of poor emotional engagement. This compared to only two percent of the TD control group. However, nearly all of the 180 children studied reported having one best friend. The presence of close friendships were associated with higher levels of self-esteem and psycho-social adjustment. Wadman et. al. (2011b), employing a cross-sectional design compared the amount of stress adolescents with and without SLI felt in social situations. Using self-report measures they concluded that those with SLI found social interactions more stressful than their peers. However, they considered themselves to be socially accepted and have sufficient social skills.

## Discussion

The evidence presented in this literature review provides increasing evidence that the presence of SLI has a negative effect on adolescence outcomes in regards of academic, emotional and social factors. The methodology used in these studies however, has not been consistent variations in inclusion criteria have resulted in differing levels of impairment being explored. Inadequate diagnostic criteria have also added such inconsistencies (Bishop, 2014). There are also variations due to individual differences of those with SLI and little is known about any features that could be associated with a variation in the progression of these children. Further limitations of direct comparison of studies is that different assessments of language abilities were used and different ways of reporting difficulties such as psychiatric review, ASD assessments, self-report and parent / teacher report. Therefore, potentially making some studies more valid than others as some measures may not be sensitive enough to detect difficulties and some may over emphasise problems (Conti-Ramsden and Botting, 2008.)

Weaknesses of the current literature review include university time and word count constraints that resulted in methodological restrictions. The articles retrieved were limited to those written in English, containing the previously defined search terms and use of the three databases chosen. Therefore, it is acknowledged that there may have been some appropriate articles that were absent from this review due to these limitations.

### ***Educational achievement***

Snowling et. al. (2001) and Dockrell et al. (2007) presented findings that showed even those with resolved SLI went on to gain lower educational success than their peers. However, Conti-Ramsden et. al. (2009) reported that there was no significant differences between children with resolved SLI and those with typical development in exam success. Therefore have developments in the awareness of language difficulties and support improved, to enable these children to now get the same results as their peers? Such finding show the need to closely monitor those with SLI through adolescence, whether their difficulties have resolved or persisted to ensure they achieve the best educational outcomes. Howlin et. al. (2000) had questioned whether the lower educational outcomes for those with SLI in adolescence are due to a deterioration of the disorder or inadequate education provision. Increasing awareness and emphasis on communication following government reforms in education (Lindsay, 2012), may have led to increased support for those with subtle language difficulties to bring them in line with their peers over time.

More persistent SLI however, in many studies does not lead to the same levels of success in the educational system (Johnson et. al. 2010, Durkin et. al. 2012). It has been shown in studies (Durkin et. al., 2012, Lewis et. al. 2015) that language ability is the main factor in predicting educational outcome as opposed to other speech difficulties. However, Durkin (2009) provided evidence that external factors such as school setting, mainstream or specialist school provision, played a role in variations of educational achievement. Although other influences such as behavioural difficulties may have impacted on these results.

Evidence to suggest language deficits are impacting during adolescence are shown in studies such as St. Claire et. al. (2010) who identified a continued reading deficits in those with SLI in later childhood. Conti-Ramsden and Durkin (2007) also linked deficits in phonological STM with continued language impairment. IQ levels were also found by Botting (2005) to drop during adolescence however, were found to increase again after adolescence (Clegg et. al., 2005). Further research into measurement of IQ and the impact of any drop in adolescence is necessary to expand understanding in this area.

Therefore, deficits in language ability are currently resulting in lower educational outcomes for those with SLI. Interventions to support those with language difficulties as the demands of language increase in adolescence may enable these children to reach their full potential.

### ***Emotional difficulties***

Emotional and behavioural difficulties are evident in this review of studies of those with SLI. However, the nature of these problems appear to be wide-ranging, although still clinically significant within this group. The current literature points to either a general lack of ability to manage emotions during adolescence, resulting in a variety of difficulties, a co-morbidity with other disorders such as ASD or other developmental pathways that due to intrinsic or extrinsic factors may result in emotional or behavioural difficulties (Yew and O’Kearney, 2013).

The impact of low self-esteem and shyness found in the Jerome et. al. (2002) and Wadman et. al. (2008) studies could indicate possible explanations for the increased risk of mental health problems and behaviour difficulties within this group. If language levels have not been seen to be associated with emotional difficulties (Wadman, 2011, Conti-Ramsden and Botting, 2008) are emotional or behavioural difficulties encountered more indicative of future mental health issues? Conti-Ramsden and Botting (2008) also provided evidence that the level of language ability was not associated with depressive symptoms, therefore arguing that emotional difficulties could be an inherent part of the development of SLI. Although Conti-Ramsden and Durkin (2008) did provide evidence that language levels do factor in lower levels of independence, which in turn is associated with lower levels of self-esteem within this group. Wadman et. al. (2008) stated that as a profession Speech and Language Therapists should be aware of these issues when working with adolescents and that they are more likely to be related to a history of SLI rather than a psychosocial difficulty.

Language difficulties may be seen by others as social withdrawal, lack of attention or non-compliance (Helland et. al., 2014, Cohen et. al., 2013), therefore impacting on behaviour and increasing areas of conflict. Higher level language difficulties may also be missed by educational settings. Studies by Conti-Ramsden and Botting, (2008), Voci et. al., (2006), Wadman et. al. (2011) all suggest that those with SLI are more susceptible to emotional difficulties in adolescence. Such findings indicate a link with SLI and emotional problems found both through psychiatric samples such as the Cohen et. al. (2006) study and in speech and language samples such as Conti-Ramsden and Botting (2008).

A reduction of depressive symptoms and an increase of self-esteem measures were found by Wadman et. al. (2011) and Lindsay et. al. (2010) once those with SLI left compulsory education. This



could indicate that those with SLI may find it more difficult to cope with the pressures of exams at age sixteen (Wadman et. al., 2011). Some authors found that the presence of positive self-esteem was a protective factor for those with SLI and increased resilience as they matured (Lindsay et. al., 2010, Jerome et. al., 2002) and Wadman et. al. (2011) put forward a complex relationship between emotional problems, language and friendship difficulties.

More research would aid our understanding of the relationship between SLI and emotional and behavioural problems. There is a requirement to explore such difficulties at a younger age, as many studies do not have data on any emotional or behaviour difficulties seen originally in these children. However, from a clinical standpoint there is a need incorporate a psychological element into services for those with SLI (Yew and O’Kearney, 2013) and for this to be followed through into adolescence. This in turn could lead to more positive outcomes for those with SLI and reduced risk of school exclusion or emotional difficulties (Clegg et. al., 2009, Cohen et. al., 2013).

### ***Social interactions***

As children reach adolescence, language plays an increasingly crucial role as demands on this skill increase in educational and social domains and the gap between those with SLI and TD peers can widen (Howlin et. al., 2000). Language is a central tool for social interactions and the development of social relationships as discussed by Reed et. al. (2007). They examined the role of language via spoken narrative aptitude, showing one way in which language may be the factor impacting on social development in regards to friendship instigation and maintenance. Botting and Conti-Ramsden (2008) and Helland et. al. (2014) also reported that those with SLI were displaying social difficulties and pragmatic language problems in adolescence that were not present during initial assessment. They questioned whether difficulties were too subtle at this age and only presented themselves when the language demands of the environment increased or if pragmatic difficulties were a result of initial core language deficits.

Durkin et. al.(2012) argued that the main factor affecting friendship, independence and early employment outcomes for those with SLI was the development of ASD symptoms rather than language ability. They again wrote about heterogeneity of this group making outcomes difficult to predict. However, this study had highlighted the development of ASD symptoms and the changing nature of SLI through childhood. Yew and O’kearney (2013) discussed the potential similarity between ASD and SLI and that the two disorders share comparable risk factors.

Clegg et. al. (2005) likewise debated the reasons behind such a decline in social skills during adolescence. They suggested that social difficulties may be part of the developmental pathway of SLI and is therefore an intrinsic component of the condition. Whether pragmatic difficulties may develop through the lack of social interactions due to reduced language competence or if short comings of the educational system may be in part responsible. Research has identified some mechanisms that describe some of the co-morbidity of SLI and ASD. Deficits in language can result in a lack of meaningful social interactions, this in turn can reduce opportunities for social exchange, therefore impacting on the development of social skills (Lindsay et al., 2007). Helland et. al. (2014) argued for the need for training in social skills for adolescents with SLI to try to work through potential difficulties.

Parental concerns regarding the issues facing those with SLI pointed to the requirement for support through adolescence and the implementation of further services. As once children left primary education it was felt that they were left with inadequate provision to develop their full potential (Pratt et. al., 2006, Botting and Durkin, 2008.) Self-reports from the adolescents themselves revealed fewer close friendships and that social interactions were more stressful than for their peers (Durkin and Conti-Ramsden, 2007), (Wadman et. al., 2011).

The influences involved in the development of social difficulties and in turn the effect of these on social outcomes are yet to be examined fully. The more information the Speech and Language profession has on this issue the more they may be able to direct services and support to where it may be needed. However, to isolate differing variables will need extensive further research (Conti-Ramsden and Botting, 2008).

## **Conclusion**

The results from this literature review show those with SLI do have language difficulties that persist through adolescence. These difficulties develop for some children into educational, social and emotional problems as a result of these language difficulties or as part of the development of SLI in later childhood. There is a need for more research to follow up and to inform services for those with SLI through adolescence and into adulthood. However, the outcomes for those with SLI over the long term are varying, with conflicting views as to the trajectory of the problems faced during adolescence and beyond (Howlin et. al., 2000). However, this recent research has highlighted the long term difficulties faced by those with SLI. The specific nature if the impairment during early childhood has been shown to develop into a range of possible difficulties as they mature and educational and social demands increase. Whether it is the language difficulties that result in social and emotional difficulties in adolescence or whether these challenges are part of the condition itself, the current research is inconclusive, however unpicking the differences in outcomes with all the influencing factors may never be achieved. Nevertheless, the research does show that educational, emotional and social outcomes are poorer for those with SLI. Therefore, multi-disciplinary input may be required as those with SLI progress through adolescence into adult life. Regrettably, specialist schooling and Speech and Language services often reduce once a child leaves primary education. This in turn leaves little help to improve social skills or progress academically at a time where this is seen to be vital (Bercow, 2008)

There is also a need to look further into protective and risk factors for those with SLI. As found by Conti-Ramsden and Durkin (2008) increased levels of independence can improve outcomes and positive self-esteem can be a protective element against negative outcomes (Lindsay et. al., 2010). Differences in parenting styles, family and peer support may also be impacting on outcomes as well as family histories of difficulties (Conti-Ramsden and Botting 2008). Another area that needs addressing is the lack of services and awareness of the difficulties faced by those with SLI, there is a need for society to address these concerns to enable the best outcomes for those with language difficulties (Bercow, 2008).

Overall, this literature review demonstrates the diversity amongst outcomes of those with SLI and the need for further research into this area. Yew and O’Kearney (2013) stated the need for interventions to support children that enable them to develop emotional wellbeing, resilience and problem solving skills, more than are presently available. Others working with children and adolescents with SLI should aim to develop pro-social behaviour and lessen problematic behaviour in this group to increase positive outcomes in adolescence and beyond.

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## **Public knowledge and perceptions of the speech and language therapist and their role: a pilot study.**

Hariet Wills, supervisor

### *Abstract*

This thesis presents the findings of a study exploring the public's knowledge and perceptions of the speech and language therapist and their role.

The speech and language therapy service has a significant role to contribute to effective outcomes related to education, employment and health which underpin many current public health strategies. Limited research into the public's knowledge of the profession means that uncovering the opportunity to positively affect these outcomes by identifying the need for raising awareness, is currently impossible.

Self response questionnaires were distributed to members of the public, within a single place of work. Open questions provided in depth, qualitative responses which were thematically analysed in order to identify and interpret themes emerging from the data.

Findings showed that knowledge of the profession relies upon relevant education or experience. Where this occurs, participants demonstrated a well informed and varied insight into the speech and language therapy profession, acknowledging many client groups supported, as well as the varied settings in which a therapist might work. The role is above all understood to be a client focused, caring profession.

Many limitations of this study have lead to its failure to identify whether there is a need for raising awareness of the profession, resulting in the need for future research in this area. Future, larger scale studies should attempt to guarantee external validity by recruiting participants who reflect the variation observed within the wider general population.

### **Introduction**

This study aims to gain insight into what the public know and understand about the speech and language therapist (SLT) and their role. For the purpose of this study, references made to the 'public' are intended to denote the population residing in the United Kingdom (UK).

In order to demonstrate why this study has been designed, it is firstly important to understand what the speech and language therapy (SLT) profession is and why it is so valuable in today's society; a discussion of value in relation to education, employment and health is provided. These factors contribute to a final discussion summarising why knowledge and understanding of the profession is so important.

A review of the literature follows this discussion, further highlighting the relevance of this study. What is known about the profession and whether the scope of practice is acknowledged are the key themes reviewed.

### ***What is Speech and Language Therapy?***

The Royal College of Speech & Language Therapy describes speech and language therapists (SLTs) as 'Allied Health Professionals' (AHPs) who 'work closely with parents, carers and other professionals' (RCSLT, 2015, para. 2). Their work is described to provide 'life-changing treatment, support and care for children and adults who have difficulties with communication, or with eating, drinking and swallowing' (RCSLT, 2015, para. 1).

### ***Understanding the Value of Speech and Language Therapy: Education***

Starting well, through early intervention and prevention, is a key priority for the Government (Great Britain, 2010). Speech, language and communication needs (SLCN) are the most common disability in childhood with approximately 7% of children at around age five suffering from specific SLCN (Tomblin et al, 1997) and as many as 50% of children suffering from more transient difficulties (ICAN, 2006). The intrinsic link between language skills and subsequent reading and writing skills (Snowling & Stackhouse, 2013) demonstrates how language underpins literacy competency. A deficit in literacy skills increases the likelihood of poor academic achievement (ICAN, 2010) which in turn increases the risk of school exclusion, falling into the 'not in education, employment or training' (NEET) category or worse, potential to offend (Bryan, 2004). The cost to the nation of individuals falling into these categories is immense (ICAN, 2006) therefore ensuring that the support available is both acknowledged and accessible, provides a greater opportunity for better individual outcomes.

### ***Understanding the Value of Speech and Language Therapy: Employment***

Going to work is good for an individual's long term health, well being and self esteem (Waddell & Burton, 2006). Language is central to many job roles and employers value good communication, literacy and interaction skills (ICAN, 2010) disadvantaging many individuals who have underlying SLCN. A deficiency in these highly desired skills results in increased difficulty of gaining employment; this is particularly pertinent when considering those already at high risk of becoming NEET. Although many initiatives have been designed to support young individuals who are NEET to transition into the workplace (ICAN, 2010), without the language and literacy skills to access such schemes, their success is often compromised. SLT has an important role to play in preventative work and early intervention to support and tackle poor communication skills, improving outcomes later in life. To make the best use of available services, individuals need to be aware of the support available.

### ***Understanding the Value of Speech and Language Therapy: Health***

Evidence demonstrates a clear link between low literacy and poor health (Morrisroe, 2015). Literacy is intrinsically related to health as a result of the skills required by individuals to obtain, process and understand information and the ability to apply knowledge to make informed decisions in light of their own health and behaviours (Morrisroe, 2015). Speech and language therapy has a role in the primary prevention of poor health through early intervention and education to support literacy competency, but also through secondary prevention by supporting recovery from ill health and promoting rehabilitation and reengagement (RCSLT, n.d.).



Many public health strategies (Great Britain, 2009; Great Britain, 2010; PHE, 2014a; PHE, 2014b; PHE & Spindlow, 2015) make reference to the importance of achieving positive outcomes in factors underpinned by speech, language and communication skills, such as language development and school readiness. This demonstrates the growing awareness of such factors in relation to public health and highlights the role that SLT services can contribute to improving the effectiveness of associated outcomes.

### ***Why is Public Knowledge and Understanding of Speech and Language Therapy Important?***

Poor awareness of the profession results in a higher chance of individuals going unnoticed, untreated and un-referred (Breadner, Warr-Leeper & Husband, 1987). As previously mentioned, knowledge contributes to an individual's ability to make informed decisions in light of their own health and behaviours (Morrisroe, 2015) therefore, if services are to be accessed by those who will benefit most from support, knowledge and understanding of the profession is essential.

More generally, the public have a central role to play in improving outcomes in public services; public knowledge and awareness of an issue can be important to its resolution (Great Britain & Halpern, 2004). Increasing the public's awareness of SLT services promotes greater engagement with the service as well as an increased understanding of the possible positive outcomes. Greater engagement often equals greater effectiveness as individuals and communities are helped to help themselves (Great Britain & Halpern, 2004). This is particularly relevant when considering the necessity for public involvement in the public health strategies, previously discussed, if effective outcomes are to be observed.

Health services such as SLT are frequently at risk as a result of funding constraints upon public services (Giving Voice, 2015). If SLT services are to be continually commissioned, local and national decision makers must recognise the efficiency and value for money of the service. The Giving Voice Campaign (Giving Voice, 2015) aims to champion and protect the SLT service in this way, targeting both commissioners and the public. Greater public understanding enables more people to act as sources of information about the profession (Byrne, 2010) which is imperative in ensuring that the service is understood, accessed, valued and advocated, positively contributing to its security as a public health service.

### ***Summary: Implications for this study***

The speech and language therapy service has a significant role to contribute to effective outcomes in many aspects related to education, employment and health which underpin many current public health strategies; the wider determinants of health including education, employment, good health and wellbeing, are positively affected as a result of good speech, language and communication skills (Morrisroe, 2015).

As discussed, enhanced knowledge and awareness of the service can positively influence these outcomes therefore it is essential to ascertain what the public know about speech and language therapy in order to determine the need for raising awareness.

## Literature Review

### ***Existing Research: Knowledge of the Profession***

The lack of awareness of the SLT profession is a common theme highlighted within the limited research available (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987; Greenwood, Wright & Bithell, 2006; Sullivan & Cleave, 2003; Byrne, 2008; Byrne, 2010).

Only two of these studies specifically consider the knowledge of members of the public however neither are UK based research. Parsons, Bowman & Iacono's study (1983) originates from Melbourne, Australia and Breadner, Warr-Leeper & Husband's study (1987) from Ontario, Canada. Both studies comprise substantial numbers of participants and provide useful insight into what participants know about the profession however a flaw in their design has resulted in impossibility in identifying how the four hundred (Parsons, Bowman & Iacono, 1983) or two hundred and fifty two (Breadner, Warr-Leeper & Husband, 1987) participants have acquired their knowledge. One study only asks about personal experience or experience of family members (Parsons, Bowman & Iacono, 1983) whilst the other provides forced alternative options relating to where participants have read, seen or heard about SLT (Breadner, Warr-Leeper & Husband, 1987). This means that ascertaining whether findings can be generalised and to whom is, to some extent, compromised.

The findings of these studies show that many members of the public had heard of the term SLT but were unable to name it (Parsons, Bowman & Iacono, 1983) and others had never seen, heard or read about SLT or admitted to having limited knowledge of the subject (Breadner, Warr-Leeper & Husband, 1987). Where participants did show awareness, the most common sources of information reported were: magazines, newspapers, brochures, television and books however as previously mentioned, these were included in the forced alternative questions and are possibly influenced responses (Krosnick & Presser, n.d.). Some respondents who chose to add additional comments at the end of the questionnaire indicated that a family member's needs had resulted in their awareness of the profession (Breadner, Warr-Leeper & Husband, 1987), further highlighting the likelihood that the most common sources of information might vary from those listed. Although the validity of these findings are questionable given their method, age and overseas origin, it is important to acknowledge that in the past, public knowledge of what the profession is has been relatively poor.

Other research regarding knowledge and understanding of the SLT profession has predominantly been student focused (Sullivan & Cleave, 2003; Greenwood, 2006; Byrne, 2008; Byrne, 2010; Litosseliti & Leadbeater, 2013) with many of these studies restricting the criteria further to prospective or current SLT students (Litosseliti & Leadbeater, 2013) or those who study closely related subjects such as education or other allied health profession (AHP) subjects (Sullivan & Cleave, 2003; Byrne, 2008; Byrne, 2010). Findings of one of these studies in particular demonstrates how allied health professional students exposure to SLT through their learning opportunities, contributes heavily to their knowledge (Sullivan & Cleave, 2003). This demonstrates that although these studies provide insightful information, their findings are not necessarily transferrable to the wider population; the learning experiences of the members of the public will differ from those studying subjects closely related to SLT.

Many school and college students reported that 'professional', 'high prestige' and 'scientific' were not characteristics which they associated with SLT, some commenting that SLTs need to speak in specific ways (Greenwood, Wright & Bithell, 2006). In terms of selecting SLT as a career choice, comments regarding the profession being too specific, limited to speech and narrow in opportunities arose (Byrne, 2010). This shows a naivety regarding the profession, especially when considering the variety of locations that SLTs work, the diversity of professionals they must work alongside, the nature of their role and the many scientific elements that underpin the knowledge required by an SLT (RCSLT, 2015).

Knowledge of and exposure to the profession has been found to contribute to consideration of SLT as a career choice (Greenwood, Wright & Bithell, 2006; Byrne, 2008; Litosseliti & Leadbeater, 2013). This indicates how knowing about a topic contributes to the underpinning rationale when decision making. If knowledge contributes to decision making in this way, it is probable that knowledge of the profession will also contribute to consideration of accessing the service, although there is insufficient evidence to support this hypothesis.

### ***Existing Research: Understanding of the Scope of Practice***

In an attempt to determine the scope of practice understood, Parsons, Bowman & Iacono's (1983) study asks participants to name etiological factors which caused friends or relatives difficulties. This however, does not facilitate participant's opportunity to impartially disclose their wider knowledge; it is possible that participants have knowledge of difficulties outside of those experienced by friends or relatives. A similar downfall occurs within Breadner, Warr-Leeper & Husband's (1987) study. A list of difficulties from which participants identify who an SLT would support is provided; forced alternative choices can restrict and possibly influence responses (Krosnick & Presser, n.d.) meaning their findings, that most participants were able to indicate three quarters of the disorders that SLT encompasses but less than ten percent were able to identify them all (Breadner, Warr-Leeper & Husband, 1987), are not necessarily reliable.

On balance, the sentence completion task, which formed part of Breadner, Warr-Leeper & Husband's (1987) study of public awareness, facilitates impartial narrative responses to be provided by participants. Findings revealed vague or limited information, typically referring to correction of speech or pronunciation, often with references to 'children who can't say their sounds properly' (p.10). This is suggestive that members of the public have in the past, been unaware of the wide variety of clients and difficulties contributing to the SLT caseload and further questions the validity of the findings from the question comprising of forced alternatives.

A recent UK based study of school and college students (Greenwood, Wright & Bithell, 2006) found that one third of participants knew nothing about SLT, with many students struggling to describe what SLTs do. In more recent studies of AHP students, some participants made reference to swallowing impairments and working with the elderly population (Byrne, 2010). Although this demonstrates enhanced knowledge of the scope of practice, it should be considered that AHP students have greater knowledge as a result of exposure to SLT through their learning opportunities; knowledge of the dimension of disorders treated increases with course progression and attendance at interprofessional events (Sullivan & Cleave, 2003). If professional education significantly

contributes to increased knowledge of the scope of the profession, the public's knowledge is likely to be significantly less, concurrent with the findings of Greenwood, Wright & Bithell's (2006) study. The limited research in this area makes substantiating this hypothesis impossible.

### ***Summary: Implications for this study***

The limited research available highlights a deficit in knowledge regarding the SLT profession, particularly the varied scope of practice. Although these studies provide useful insight, a number of drawbacks within the available research makes generalisation of their findings to the public, impossible.

- Most of the research is biased towards those whose knowledge of the subject will be greater as a result of exposure to SLT through learning opportunities (Sullivan & Cleave, 2003; Byrne, 2008; Byrne, 2010; Litosseliti & Leadbeater, 2013).
- Most studies were carried out overseas (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987; Sullivan & Cleave, 2003; Byrne, 2008; Byrne, 2010).
- Underrepresentation of male participants was often noted (Parsons, Bowman & Iacono, 1983; Greenwood, Wright & Bithell, 2006; Byrne, 2008; Byrne, 2010).

Ascertaining what the public know about the profession will determine whether trends concur or oppose those identified within this research.

### **Aims of this Study**

The speech and language therapy service has a significant role to contribute to effective outcomes related to education, employment and health which underpin many current public health strategies.

Limited relevant research into the public's knowledge of the profession means that uncovering the opportunity to positively affect these outcomes, by identifying the need for raising awareness, is impossible.

This pilot study is therefore designed to ascertain:

- Do the public know what speech and language therapy is?
- Do the public recognise the varied scope of clients and difficulties comprising the speech and language therapy caseload?
- How do the public know about the speech and language therapy profession?

### **Methodology**

#### ***Rationale***

When collecting data, quantitative data collection presents the potential risk of ignoring factors which are relevant to the explanation of findings; results are often quantified with little expansion of their meaning and do not always support more complex, dynamic 'wholes' (Patton, 1975). It was therefore decided that collecting qualitative data would be more comprehensive and provide more in depth responses, facilitating richer descriptions of findings (Braun & Clarke, 2006).

A questionnaire was considered the most appropriate method of data collection and deemed most practical given the small scale of this study and initial stages of this research. Although the flexibility of setting up interviews or focus groups often encourages richer data (Charmaz, 2006), a questionnaire eliminates the need to overcome the practical barriers associated with doing so, as well as the pressure or influence, such as social desirability bias (Krosnick & Presser, n.d.), that an interviewer can impose. To reflect the format of standardised open interviews (Gall, Gall & Borg, 2007) and to gain insight into any preconceived ideas that the participant might have, open questions were chosen. These have been favoured over forced alternative questions which restrict and possibly influence responses (Krosnick & Presser, n.d.).

The questionnaire (Appendix 3) was made up of ten questions, chosen in relation to those from previous studies encompassing the views of members of the public (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987). Key themes were identified within these studies: knowledge of what SLT is, what difficulties or disorders an SLT can support, in which settings an SLT might work and factors contributing to participant's knowledge of the profession. These themes were therefore used to form the questions of the current study. The opening question was identical to the original sentence completion task from Breadner, Warr-Leeper & Husband's (1987) study, whilst subsequent questions were designed to facilitate further detailed responses in these areas. Demographic data formed the final part of the questionnaire. In order to ensure that the questionnaire was optimally formulated, consideration was given to 'conventional wisdom' factors (Krosnick & Presser, n.d.).

To verify the suitability of the questionnaire design, a pilot study with two participants was carried out. The primary aims were to ensure that the order and clarity of the questions were appropriate and that enough detail could be elicited from the use of the selected open questions. The findings indicated that the questionnaire design would enable meeting the aims and methodology of the study.

Twelve participants were recruited for this study. Braun and Clarke (2013) recommend that small qualitative projects should comprise of six to ten participants for interviews and ten to fifty participants for participant generated text. To reach an optimum figure, a number of additional factors were considered: the demands of this questionnaire, the practicality of collecting data within a single company, the time consuming process that is qualitative analysis and the imposed time constraints surrounding this study. Based on these factors, it was felt that twelve participants fell within the recommended guidelines (Braun & Clarke, 2013) and was an appropriately sized sample to offer informative results.

### ***Procedure***

Twelve participants were recruited from a local, relatively large company. Roles varied from highly paid, professional and skilled positions to modestly paid, repetitive and unskilled positions; a variation deemed to reflect that of the public's socioeconomic and academic status, although only encompassing those in employment from one geographical area. As a result of the small number of participants and to promote external validity, the use of stratified random sampling was employed to evenly represent people within a variety of roles. Unfortunately people's roles and time available

compromised this recruitment process. It was however maintained that both genders were evenly represented to eliminate this bias; a drawback highlighted by past research (Parsons, Bowman & Iacono, 1983; Greenwood, Wright & Bithell, 2006; Byrne, 2008; Byrne, 2010).

Consent was given by the company, chosen in support of practicality; the managing director is known to the student researcher, for data collection to be carried out on the premises. Employees were approached individually and invited to participate in the study. An information sheet (Appendix 1) and consent form (Appendix 2) were provided and once written consent was obtained, the questionnaire (Appendix 3) was supplied. Participants were asked not to research or discuss the topic. A unique reference number was provided to protect anonymity in the event of withdrawal from the study. The questionnaire format excluded the opportunity to clarify or request expansion of responses. Data collection was carried out during November-December 2015, as recruitment of participants permitted.

Questionnaires were typed onto Word documents and randomly assigned a letter as a pseudonym to further protect anonymity. The qualitative coding programme 'NVivo' (NVivo, 2008) was used to support coding and retrieval of the data. Any information which was not applicable or could not be understood was ignored. In order to appropriately identify themes and their meaning from the data and reduce the likelihood of poor rater reliability, the data was systematically analysed following Braun and Clarke's (2006) phases of conducting thematic analysis. To ensure the context was not lost during this process, data extracts were coded inclusively (Bryman, 2001). This enabled the student researcher to interpret and elaborate on emergent themes in order to represent patterned responses and meaning, whilst facilitating the opportunity to analyse the results inductively (Braun & Clarke, 2006). To reduce the likelihood of personal bias, which can compromise validity and reliability of findings (Pring, 2005), the following factors were considered:

- During coding of data, checks were carried out by the student researcher a number of times to ensure that codes were relevant and applicable.
- Quotations were used to support the themes which emerged from the data.

### ***Ethical Considerations***

Approval for this study was granted by De Montfort University's Faculty of Health and Life Sciences Ethics board and adherence to the Health and Care Profession Council's guide to conduct and ethics (HCPC, 2012) observed throughout.

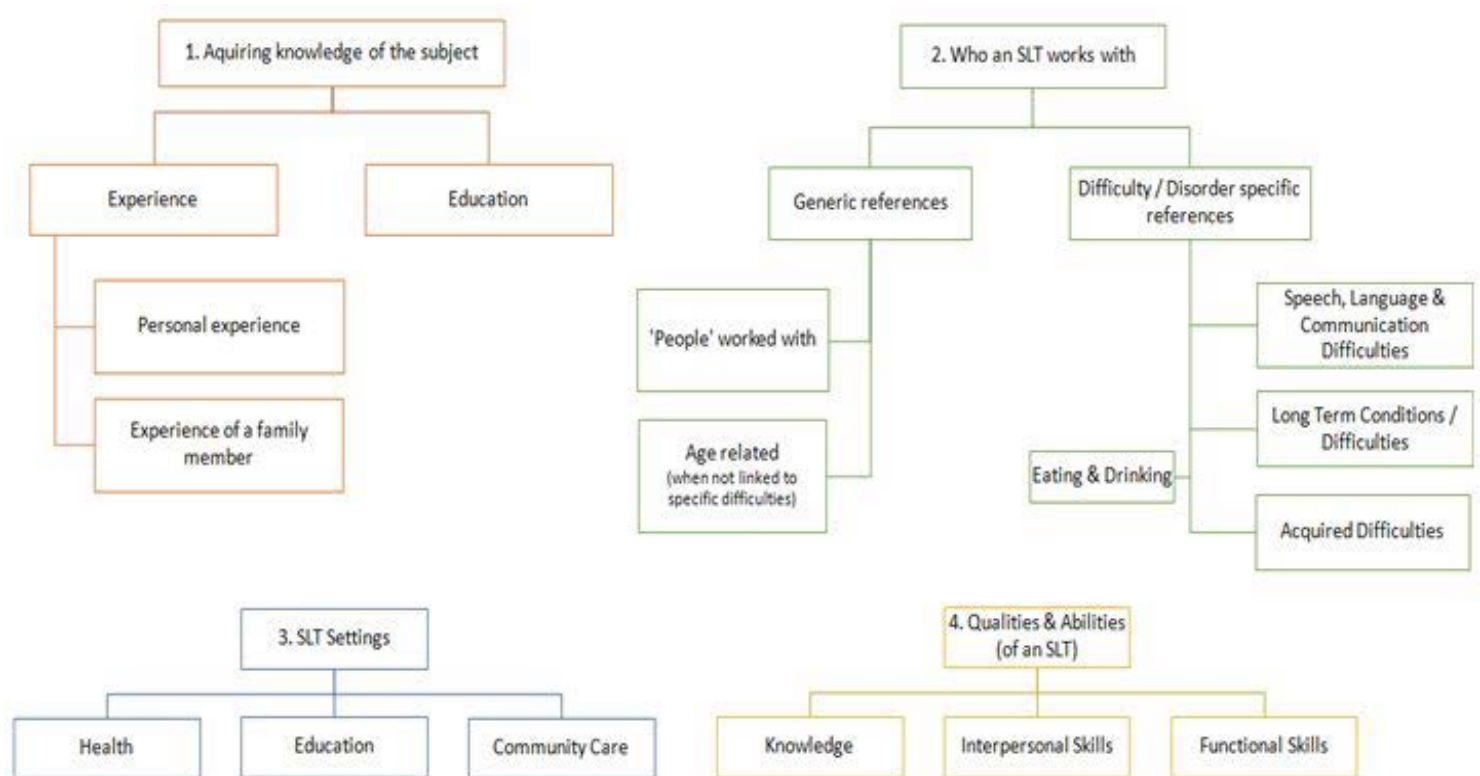
Participants were made aware of all associated risk factors (Appendix 1) and written consent (Appendix 2) obtained. Complete consent forms and questionnaires were stored securely and electronic data encrypted in line with the data protection act (Great Britain, 1994). Confidentiality was observed throughout the study; research findings have been shared only with the project supervisor, as the participant consensual agreement states.

This study did not compromise the welfare of participants. Speech and language therapy information sheets, including signposts of where to find more information were provided. A feedback report will be available to participants upon completion of the study.

## Results and Discussion

A table which encompasses participant responses to questions is included within this document (Appendix 4). To protect anonymity, each participant is identified and referred to throughout this discussion using a letter, the column title, as a pseudonym.

The qualitative design of this study has been successful in attaining uninfluenced, informative responses from participants, facilitating the systematic thematic analysis of data. Figure I below depicts the themes identified from the findings.



**Figure I: An overview of the themes identified through thematic analysis.**

As figure I shows, participant responses have revealed key themes within the following four areas:

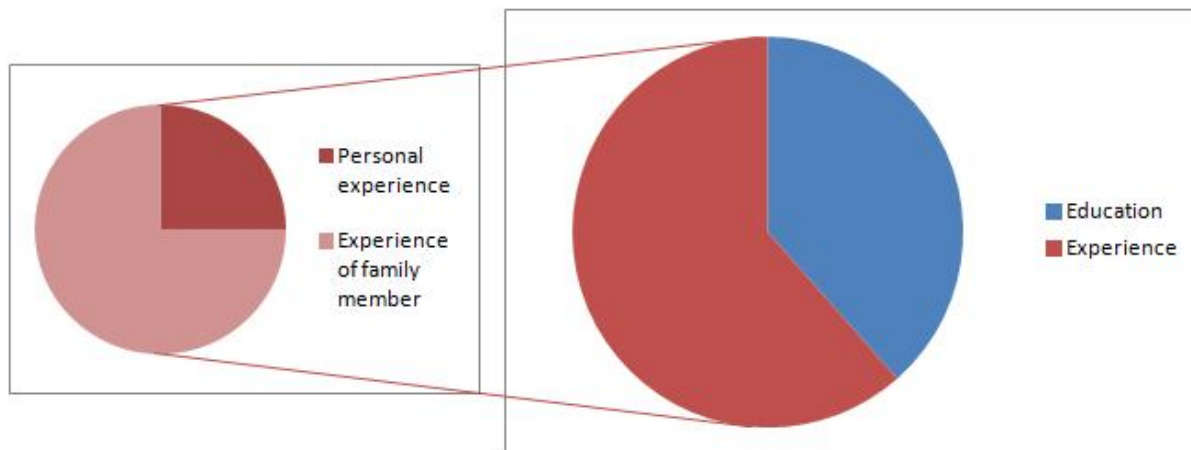
- How knowledge of the subject is acquired
- Who can be supported by an SLT
- The settings most commonly recognised as workplaces of an SLT
- Qualities and abilities deemed significant to the role of the SLT

The most significant themes contributing to the above areas are presented and discussed in turn. In support of this, where appropriate, visual representations of findings have been developed.

It is of note that no significant patterns emerged from the demographic data collected from participants. Participants who have children were no more likely to have an increased knowledge of

SLT only in relation to children and participants who knew someone in education were no more likely to reference SLT in relation to children or school settings than those who did not. The responses contributing to each theme were varied across genders and age groups; no single category of individuals seemed to know significantly more than another.

### ***How knowledge of the subject is acquired***



**Figure II: Two pie charts depicting the distribution of participant responses referring to acquisition of knowledge.**

The main themes identified in relation to the acquisition of knowledge were education and experience, with eleven out of twelve participants contributing responses to these categories. Responses were mostly related to SLT, for example personal experiences of therapy 'I used to go to a speech therapist when I was younger' (C, Appendix 4), experiences of a family member 'daughter received speech therapy at school' (H, Appendix 4) which concur with anecdotal information attained previously (Breadner, Warr-Leeper & Husband, 1987), or an educational source 'cousin is a maxillofacial surgeon specialising in trauma' (J, Appendix 4). Two participants felt that their knowledge had been gained throughout life (B & I, Appendix 4) which were categorised within the education bracket due to the reference to the continual learning process that is life. No participant referred to magazines, newspapers, brochures, television or books as a source of information contributing to their awareness, as previously reported (Breadner, Warr-Leeper & Husband, 1987).

It is anticipated that these findings, that such a high percentage of people have relevant education and experience, are not reflective of the entire public. In a previous study (Parsons, Bowman & Iacono, 1983), out of four hundred participants only six reported personal experience and just twenty three reported friends or relative's experience of speech therapy intervention. Although the number of SLTs has grown in recent years (HCPC, 2014) increasing the likelihood of exposure, these findings suggest that a larger scale study is likely to yield different results.

Further interpretation of findings reveals the influence of education and experience, in informing participant's responses. Figure III below provides nine examples to demonstrate this; participant responses are interpreted in turn.



**Figure III: A table demonstrating the influence of education and experience on participant's knowledge.**

| Education / Experience   | Resulting Knowledge   |
|--|---|
| 'my son who has aspergers, required assistance at the age of three. He was unable to articulate his words when frustrated or use the correct words. Would... ..because he couldn't say the words he needed to' (A, Appendix 4) | Refers to 'frustration to find words to communicate', 'help making correct sounds to make letters and words', 'confidence to be able to communicate correct words for correct things' when describing what an SLT can do to help.<br><br>Refers to 'Schools (special needs)' when commenting where an SLT might work. |
| 'I used to go to a speech therapist when I was younger and couldn't say my 'f' or 's' (C, Appendix 4)  | Refers to young children having difficulty pronouncing new sounds.  |
| 'my sister who has a special needs child who has severe anxiety and classed as a special mute' (D, Appendix 4)   | Only acknowledges SLT in relation to children: 6-18 yrs and working within schools or at the person's home.   |
| 'my cousin picked up a virus abroad that affected her spinal cord somehow, she lost all speech and had to learn again completely' (E, Appendix 4)  | Defines SLT as 'helping to teach someone who has lost the ability to speak following an accident or illness..'.<br><br>Limited references to working with difficulties which do not result from accident/illness.   |
| 'I did work experience in a hospital for 3 weeks' (F, Appendix 4)  | Only acknowledges SLT working in health settings.   |
| 'daughter received speech therapy in nursery/school (H, Appendix 4)  | Only participant to mention nursery as a location an SLT might work.  |
| 'cousin is a maxillofacial surgeon specialising in trauma' (J, Appendix 4)   | Only participant to reference 'post operation' and 'trauma',<br>Only participant to query 'dental surgeries (?)' as a location an SLT might work.   |
| 'a family member has received this type of therapy at school and a family member who has suffered a stroke' (K, Appendix 4)  | Acknowledges SLT working in a variety of settings, with 'people of all ages'.<br>Refers to difficulties associated with adults and children.<br>1 of 2 participants to reference eating and drinking difficulties (common post stroke).   |
| 'I know a speech therapist and I had experience as a child..' (L, Appendix 4)  | Comprehensive references describing what an SLT is.<br>Only participant to mention understanding.<br>1 of 2 participants to reference eating and drinking difficulties.   |

These findings are useful when considering how participants know about the profession and facilitates their interpretation in terms of generalisation; overlooked in previous studies (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987). Members of the public who have experiences of SLT or some relevant educational experiences are likely to have similar levels of knowledge to participants in this study.

No participant in this study had heard of the Giving Voice campaign. This might be as a result of the campaigns aim, which is predominantly to protect the service by raising awareness to commissioners (Giving Voice, 2015), or due to the fact that much of the campaigning is carried out by university SLT

students; this study was not carried out within a university town reducing the likelihood of participant's exposure to the campaign.

### ***Who can be supported by an SLT***

One of the most significant themes identified in this area was participant's tendency to refer to people an SLT works with using generic terminology such as: 'clients', 'people', 'patients', 'they', 'them', 'anybody', 'the recipient of therapy' (Appendix 4). This demonstrates an increasing awareness of the scope of practice and demonstrates an understanding that the SLT caseload is not limited to one client group, for example children.

A second theme which emerged whereby participants commented that an SLT works with any age person using terminology including: 'any' (age), 'this could vary across age groups', 'all age groups', 'variety', 'birth to old age' (Appendix 4), supports the first theme identified. In comparison to the results of Breadner, Warr-Leeper & Husband's study (1987) where only one third of participants believed that SLT's work with all age groups, this study's findings show an increased awareness of participant's knowledge regarding the range of clients an SLT can support.

The final theme to emerge, as figure IV below shows, is the variety of difficulties and disorders identified by participants Responses which refer to language continue to be limited in number (Breadner, Warr-Leeper & Husband, 1987) however many more references were made to a number of difficulties which result in language problems such as stroke, brain injury and learning disability (Figure IV; Appendix 4). This suggests that although the participant's knowledge did not extend to descriptions of language difficulties themselves, many are able to recognise how or why they occur and that an SLT is a professional qualified to support such difficulties.

As previously noted (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987; Sullivan & Cleave, 2003), participants in this study were able to recognise difficulties associated with speaking or speech more often than other difficulties such as language or eating and drinking. That said, some participants were able to acknowledge such difficulties (A, B, I, K & L, Appendix 4) and overall a much wider variety of difficulties and disorders have been reported compared to previous studies (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987) therefore the awareness of the scope of the profession in this study appears to be greater.

Although these findings are positive, they must be considered in light of the small sample of participants and the knowledge available to these participants, as discussed, informing their responses.

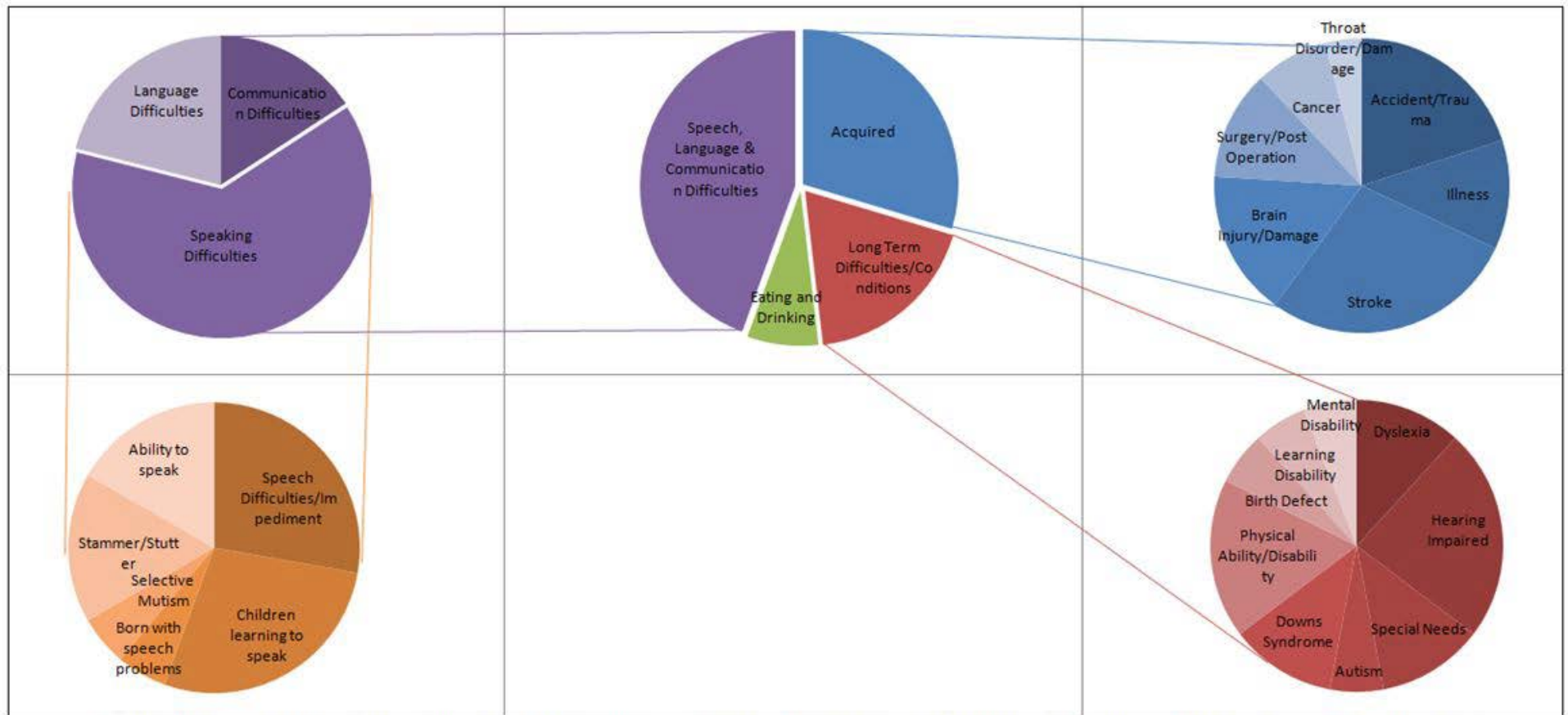
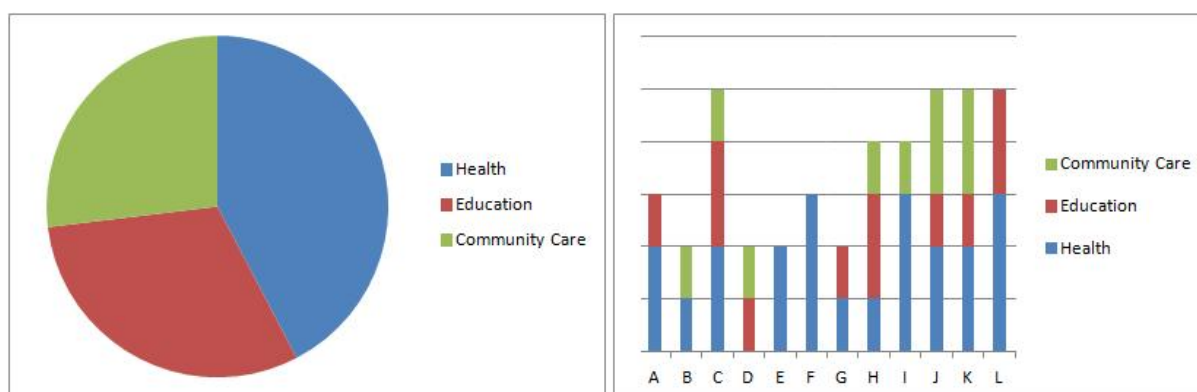


Figure IV: A series of pie charts depicting the distribution of participant responses referring to difficulties or disorders that an SLT can support.

### ***The settings most widely recognised as workplaces of an SLT***

Health settings, educational settings and community care settings were the primary themes identified in the acknowledgement of where SLT's might work, as depicted by figures V1 and V2 below.

It is encouraging to note that all participants were able to name settings in which an SLT might work. This suggests that participants would be able to successfully obtain information or locate services if required.



***Figure V1: A pie chart depicting the distribution of participant responses referring to the settings in which an SLT works.***

***Figure V2: A bar chart depicting the breakdown of participant responses referring to the settings in which an SLT works.***

As shown in figure V1 health locations were the most common locations acknowledged with eleven participants contributing twenty two responses to this category. In accordance with previous findings (Parsons, Bowman & Iacono, 1983), the highest number of responses referred to SLTs working within hospitals. Responses comprising education and community care settings were more similar in number; eight participants contributed eleven responses related to educational settings whilst seven participants contributed nine responses to community care settings. To depict these findings and facilitate further interpretation, figure V2 was developed.

Participant's ability to acknowledge settings across more than one category, as highlighted by figure V2, demonstrates that participants are aware that the role of the SLT is not limited to a single location, which can be interpreted as is not limited to a single client group or type of difficulty or disorder. Those who were able to name multiple settings within a category and more than one category (A, C, H, I, J, K & L) demonstrate the most insightful knowledge. Concurrent with the findings of the variety of difficulties and disorders discussed above, this is demonstrative that there is an increasing range in the knowledge of participants and in their understanding of the varied scope of practice contributing to the SLT profession.

### **Qualities and abilities deemed significant to the role of the SLT**

Figure VI below depicts the three main themes identified. Stand alone examples listed are those which emerged during the final stages of thematic analysis, prior to identifying the overarching themes. Direct quotes provide examples of specific participant responses which have contributed to the theme.

Each theme is discussed in turn however it is noted that many of the qualities and abilities are likely to be intrinsically linked across categories. Although themes are discussed in turn, this does not propose disassociation of themes.

| <b>Figure VI: Participants responses contributing to the classification of the three themes identified.</b>   |   |   |
|---|---|---|
| <b>Column 1: Knowledge</b>  | <b>Column 2: Interpersonal Skills</b>   | <b>Column 3: Functional Skills</b>  |
| <p>'of how human vocal system works' (G, Appendix 4)</p> <p>'of how sounds are made, how vocal cords work and how the brain controls these when illness rather than damage is the cause' (E, Appendix 4)</p> <p>'good education' (B, Appendix 4)</p> <p>'full understanding of their progression' (A, Appendix 4)</p> | <p>Patience</p> <p>Communication &amp; Listening</p> <p>Information gathering</p> <p>Understanding, Sympathy &amp; Empathy</p> <p>Calm &amp; Relaxed</p> <p>Friendly &amp; Encouraging</p> <p>Teamwork</p> <p>Other: Creative, Assertive, Tenacity,</p> | <p>Organisation</p> <p>Assess &amp; Solve symptoms</p> <p>Problem Solving</p> <p>Plan &amp; Deliver therapy</p> <p>Teach:</p> <ul style="list-style-type: none"> <li>- how to speak or communicate</li> <li>- 're-teach the basics' (F, Appendix 4)</li> <li>- 'demonstrate mouth positions' (G, Appendix 4) , 'how to shape their mouths to form sounds' (E, Appendix 4)</li> </ul> <p>Help &amp; Support:</p> <ul style="list-style-type: none"> <li>- Help with speech and communication</li> <li>- 'help with throat and mouth problems' (K, Appendix 4)</li> <li>- 'help with eating' (L, Appendix 4)</li> <li>- 'help them develop skills to improve their quality of life' (A, Appendix 4)</li> <li>- Increase confidence</li> </ul> |

#### *i. Knowledge*

Two participants demonstrate insight into some specific, scientific knowledge that an SLT should attain, including knowledge of 'how the human vocal system works' and 'of how sounds are made, how vocal cords work and how the brain controls these when illness rather than damage is the cause' (Column 1, Figure VI). In a previous study, participants have failed to acknowledge the scientific underpinning of the SLT profession (Greenwood, Wright & Bithell, 2006). In contrast, this study indicates that some individuals do have an understanding of this.

In line with previous studies (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987) one participant in this study has acknowledged that an SLT requires a 'good education' (B, Appendix 4). Previous studies have explicitly asked questions regarding the perceived educational requirements for an SLT however this study did not. This demonstrates that even without the prompt of a question some people are able to recognise the academic nature of the profession indicating a genuine, uninfluenced awareness. If further questions were asked specifically regarding knowledge, it is likely that more participants would have demonstrated this awareness, as observed in previous studies (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987).

#### *Interpersonal Skills*

The clearest theme to emerge from the data was the interpersonal skills deemed important for an SLT to possess (Column 2, Figure VI), demonstrating participant's ability to associate such characteristics with the profession. Previous studies, encompassing the public (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987) have not considered this viewpoint therefore it has not been possible to draw conclusions based upon associations or correlations.

Participant responses include the terms 'patient', 'understanding', 'empathetic' and 'calm' (Column 2, Figure VI) with many participants highlighting the importance of communication and listening skills (A, B, C, D, I, K & L, Appendix 4). In addition, some participants chose to justify why the interpersonal skills they had mentioned are vital to a client's care: 'clients may be obstructive and frightened' (K, Appendix 4), 'because of dealing with vulnerable people in different locations' (B, Appendix 4). This insight demonstrates that participants in this study realise the significance of interpersonal skills and suggest that they acknowledge SLT as a client focused, caring profession.

#### *Functional Skills*

The final theme (Column 3, Figure VI) emerged as a result of participant's responses referring to abilities which contribute to an SLT's role. Relevant responses primarily include wide-ranging concepts such as 'plan and deliver therapy', 'problem solving', 're-teach the basics', 'help with communication' etc. (refer to Column 3, Figure VI for the complete list).

One participant, who produced insightful responses throughout the questionnaire, stated that 'although I think I know what a therapist does, I have no idea how this is achieved' (I, Appendix 4). This highlights that even those with a comprehensive awareness of the profession will not necessarily be aware of specific methods used by an SLT. This is further supported by the views of some AHP students in a previous study who did not select SLT as a career choice due to their uncertainty as to what the job involves (Byrne, 2010). This uncertainty is likely to explain the high number of relatively vague responses referring to helping and supporting clients amongst participants (A, B, C, E, F, G, H, I, K & L, Appendix 4).

Although uncertainty suggests that participants lack knowledge regarding the role of the SLT, the difference between the knowledge of a professional person who is educated in their field, to fulfil their role vs. the knowledge of a member of the public must be taken into account. Participant's responses demonstrate both insight and awareness of the many qualities and abilities which

underpin the role of the SLT, further highlighting acknowledgment of SLT as a client focused and caring profession.

### ***Summary of Findings***

In relation to the research questions identified within the aims of this study, the findings of this pilot study have revealed that:

- Members of the public do know what speech and language therapy is. Overall, participants within this study have revealed a good awareness of the profession, the scope of practice and the attributes of a speech and language therapist.
- Members of the public are able to recognise the varied scope of clients and difficulties comprising the speech and language therapy caseload. This was demonstrated by participant's ability to acknowledge a diversity of the difficulties and disorders that can be supported by a speech and language therapist.
- Members of the public within this study know about the speech and language therapy profession as a result of relevant education and experience, contributing to their knowledge.

These findings imply that the public possess well informed knowledge and perceptions of the speech and language therapist and their role, suggesting that the need for raising awareness of the profession does not exist. Findings must however be considered in light of the many associated limitations, discussed in the following section.

### **Limitations of this study**

This study attempted to recruit participants from a variety of roles, within the chosen company, deemed to reflect the varied socioeconomic and academic status of the public. Participant recruitment by stratified random sampling was compromised resulting in the possibility of an uneven representation of people across roles. Consequently, there was an increased risk of selection bias during recruitment.

In addition, a considerable drawback of this study was that the academic and socioeconomic status of participants, or their role within the company, was not measured as part of the data collection process. This information would have determined whether the inconsistent recruitment process resulted in an uneven representation of people across roles, ascertaining to what extent findings could be generalised to the public.

Together with socioeconomic and academic status, many additional attributes contribute to the variation of people constituting the public. These include employment status, ethnicity and geographical location. In order for the participants within this study to credibly reflect the public, representation of all of these attributes would have been necessary. Recruiting participants from a single company, within one geographic location, results in an insufficient representation. The use of a control or comparison group was not considered, ruling out the opportunity to extend, compare or validate findings.

It is possible that participant knowledge was predisposed as a result of the links the student researcher has with the company through the managing director. Also, it cannot be guaranteed that participants within this study did not research or discuss the topic prior to completion of the questionnaire, although this instruction was given. Both eventualities would greatly compromise findings therefore reliability of findings cannot be guaranteed.

The presence of experimenter bias within this study cannot be ruled out; a possible effect of the student researcher's affiliation with the speech and language therapy profession. Peer reviewing of findings, using someone who had no preconceptions of the profession, would have helped to identify any gaps or discrepancies which might not have been acknowledged, improving the credibility and internal validity of findings.

The questionnaire format excluded the opportunity to clarify or request expansion of responses. This would have been beneficial where participant's responses were vague or unclear highlighting one benefit of interviews (Charmaz, 2006) alongside or instead of questionnaires.

This study has not considered whether participants acknowledge the value of the profession. This is likely to be a contributory factor to engagement with the service thus the effectiveness of individual outcomes and outcomes of public services, whilst contributing to the security of speech and language therapy as a public health service, though continued commissioning of services.

As a result of these drawbacks, external validity is greatly compromised; it is impossible to ascertain whether or to what extent findings of this study can be generalised, or to whom. This combined with the many flaws in the study's design, means the aim 'to identify whether there is a need for raising awareness of the speech and language therapy profession' has not been achieved.

## **Conclusion**

This study's aim was to consider participants knowledge and perceptions of the speech and language therapist and their role. Information was attained, through self response questionnaires and analysed using thematic analysis.

The most pertinent themes to emerge from this data have proved to demonstrate that this narrow sample of participants have a good insight into the speech and language therapy profession. The role of the SLT is understood to some extent, mostly in relation to the concepts which underpin the role as a caring profession. Insight into the varied scope of practice has increased compared to previous studies (Parsons, Bowman & Iacono, 1983; Breadner, Warr-Leeper & Husband, 1987) with participants demonstrating their ability to acknowledge many different client groups and difficulties and disorders that an SLT can support, as well as the varied settings in which an SLT can work.

Although this study has yielded insightful information and highlighted that members of the public who have relevant education or experience of speech and language therapy are likely to have similar levels of knowledge to participants in this study, the failure to ensure external validity means the findings cannot be generalised to the wider public. This study has therefore failed to meet its aim of



identifying whether there is a need for raising awareness of the profession. This results in a need for future research in this area.

The speech and language therapy profession have an opportunity to positively affect many outcomes related to education, employment and health which underpin many current public health strategies. Further research aiming to identify the need for raising awareness of the profession will help to uncover this opportunity.

Full scale studies must encompass a larger sample, representative of the general public, to guarantee external validity. The qualitative design of this study should be employed due to its success in attaining informative responses from participants however the use of follow up interviews would be useful to facilitate the opportunity to clarify or request expansion of responses. Overcoming the limitations associated with this study will help to ensure that the findings of future studies are more reliable, can be effectively interpreted and can be generalised to the public.

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### 3. Appendices

#### a. Appendix 1: *Participant Information Sheet*



#### PARTICIPANT INFORMATION SHEET

***Title of Project: Knowledge and perceptions of the speech and language therapist and their role: A pilot study.***

**Lead Investigator:** Harriet Wills

**Email:** p12223258@myemail.dmu.ac.uk

You have been invited to take part in a research study. Before you decide whether to take part it is important to understand why the research is being done and what the study involves. Please read this information carefully.

#### **What is the study about?**

There is limited research into the public's knowledge of the speech and language therapy profession. This study aims to discover what the public know which will help to identify areas which might benefit from further research and campaigning to raise awareness.

#### **What does the study involve?**

You will be asked to complete a questionnaire which should take no more than 20-30 minutes. This will include some basic details about you.

#### **Why have I been chosen?**

You have been selected at random from a list of contacts known to the investigator.

#### **Do I have to take part?**

No! Only if you want to.

If you decide to take part you will be asked to sign a consent form. A unique reference number will be given to you so that your identity remains anonymous.

Should you change your mind, you are free to withdraw at any time, without giving a reason.

#### **I am interested in taking part, what do I do next?**

Once the consent form is signed, the questionnaire will be given to you to complete.

Please do not research/discuss the topic before you complete the questionnaire.

#### **What if I agree to take part and then change my mind?**

You can withdraw from the study at any time, without giving a reason.

#### **What are the possible disadvantages and risks of taking part?**

No safety risks have been identified.

Experience of speech and language therapy can be emotional. You do not have to share sensitive information or anything that makes you feel uncomfortable.

Your identity is protected however you can withdraw from the study, without giving a reason.

Information about the profession and signposts of where to go for further information will be available following completion of the questionnaire.

**What are the possible benefits of taking part?**

You will help to inform the direction of future studies and help to highlight areas which would benefit from campaigning to raise awareness of the speech and language therapy profession.

**What if something goes wrong? / Who can I complain to?**

If you have a complaint, you should contact the lead investigator. If this does not achieve a satisfactory outcome, you should contact the Administrator for the Faculty Research Ethics Committee, Research & Commercial Office, Faculty of Health & Life Sciences, 1.25 Edith Murphy House, De Montfort University, The Gateway, Leicester, LE1 9BH or [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk)

**Will my taking part in this study be kept confidential?**

All information will be kept on a password protected database and is strictly confidential.

You will be given a unique reference number which will be used instead of your name. All identifiable information will be removed and made anonymous.

**What will happen to the results of the research study?**

The research study will be reported as part of a university dissertation thesis for the named investigator at De Montfort University. By consenting to participation in the study, you are consenting to the findings being shared/published.

All participants have the opportunity to receive a feedback report of the findings.

**Who has reviewed the study?**

This study has been reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee.

**Contact for Further Information**

**Lead Investigator:** Harriet Wills - email: [p12223258@myemail.dmu.ac.uk](mailto:p12223258@myemail.dmu.ac.uk)

**Study Supervisor:** Ali Tempest - email: [atempest@dmu.ac.uk](mailto:atempest@dmu.ac.uk)

Information sheet date of issue: October 2015

Information sheet version number: Version 3

**b. Appendix 2: Participant Consent Form**



**CONSENT FORM**

**Name of Researcher:** Harriet Wills

**Title of project:** Knowledge and perceptions of the speech and language therapist and their role: A pilot study.

Please initial all boxes if you agree:

1. I confirm that I have read and understood the information sheet [Oct 2015, Version 3] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
3. I understand that data collected during the study may be looked at by a supervisor from De Montfort University. I give permission for the supervisor to access to my data.
4. I agree that the findings of this study, including non identifiable quotes, may be published in articles or used in conference presentations.
5. I agree to take part in this study.

\_\_\_\_\_

Print name of participant

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Print name of person taking consent

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

If you would like to receive a feedback report of the findings from this study, please provide your email address below.

\_\_\_\_\_

**Participant Unique Reference Number Given:**

Consent form date of issue: April 2015

Consent form version number: Version 1

### **c. Appendix 3: Participant Questionnaire**



Knowledge and perceptions of the speech and language therapist and their role: A pilot study.

#### **PARTICIPANT QUESTIONNAIRE**

- 1. Complete the following sentence, giving as much detail as possible:**  
A Speech and Language Therapist is someone who...
- 2. Are there any specific skills/characteristics you think a Speech and Language Therapist needs? Why?**
- 3. Where would you expect to find a Speech and Language Therapist working?**
- 4. What kind of people would you expect a Speech and Language Therapist to work with? What age groups does this include?**
- 5. What types of difficulties/disorders can a Speech and Language Therapist support?**
- 6. What kind of things can a Speech and Language Therapist do to help someone?**
- 7. Is there anything else you would like to add about Speech and Language Therapy or your participation in this study? (your comments might be used towards informing results)**
- 8. Please tell us how you know about Speech and Language Therapy.**
- 9. Have you heard of Giving Voice? If Yes, please provide details of how/when.**
- 10. Your Details - To help us to interpret the results!**
  - Gender: Male / Female
  - Age: 18-19                      20-24
  - 25-34                      35-44
  - 45-54                      55-64
  - 65-69                      70 +
  - Please confirm whether you have children: Yes / No
  - Do you know anyone who works in the education sector? Yes / No  
*If yes, please provide details* \_\_\_\_\_
  - Do you know anyone who works in the health sector? Yes / No  
*If yes, please provide details* \_\_\_\_\_
  - Do you know a speech and language therapist? Yes / No  
*If yes, please provide details* \_\_\_\_\_

**Participant Unique Reference Number:**

**10.4 Appendix 4: Table of Participant Responses to Questionnaire**

| Q | Participant Responses   |   |  |   |   |   |  |  |   |   |   |   |
|---|---|---|--|---|---|---|--|--|---|---|---|---|
|   | A   | B   | C  | D   | E   | F   | G  | H  | I   | J   | K   | L   |
| 1 | Helps children and adults with speech and language difficulties helping them to communicate with people, help them develop skills to assist them to improve their quality of life.          | Helps people with speech problems.  | Helps people of all ages to regain confidence. Younger children may have difficulty pronouncing new sounds or elderly/stroke victims may need help learning to talk all over again. The therapist not only helps them with this, they also give the client hope! | Will need patience and understanding and listening.   | Would help to teach someone who has lost the ability to speak following an accident or illness to learn how to speak again.   | Assists those who for a variety of reasons, need to regain the use of their voice.  | Assists young children who have difficulty with vocal/oral communication | Helps and supports people who require extra help with a variety of needs such as speech impediments, new to the language or people who can't express or communicate their needs. | Helps people with language and communication problems to improve their ability to speak and/or communicate.   | Works with people of lower abilities with respect to physical ability to speak and with hearing difficulties. Perhaps also those post operation or trauma or strokes etc. | Works with people of all ages who may have speech problems and/or physical disabilities.  | Provides treatment, care and support for people of all ages with difficulties with communication and other issues with the mouth. |
| 2 | Compassion, to help understand lack of confidence and frustration of patients. Listening to speech and concerns of patient. Confidence to make both patient and relatives at ease, and that | Caring, patience, good listener, good education, driving license. Because of dealing with vulnerable people in different locations. | Patience: some people may understand better, some may take longer. Good Listener: to make clients feel comfortable and trustworthy. Caring: they need to care about their  | A lovely smile could put the person at ease. Talking can help, depending on the person. Listening to the persons needs. | I imagine for the patient it would be very a frustrating time so the therapist should be calm, friendly, relaxed and encouraging. Skills would include having a knowledge of how sounds are made, how vocal cords | Patience and understanding . It could be a long road to recovery, so I imagine there would be frustration if things don't progress as quickly as desired. | Knowledge of how human vocal system works. A lot of patience.            | Patience: I imagine there will be a lot of repetitive tasks and frustrations. An upbeat attitude: Need to be able to help boost morale and confidence.                           | A range of skills are required – listening, evaluating, documenting, planning and delivering of the therapy. As each recipient of therapy will have a different requirement, the therapist has to be able | Patience, understanding, empathy/sympathy, tenacity.  | Communication and listening skills, patience, creative, teamwork, assertive. You are likely to be part of a team, clients maybe obstructive and frightened. | Patience, problem solving, organisation skills, communication skills, calm, empathetic, team player.                              |



|   |  |  |   |   |   |  |  |   |   |  |   |  |
|---|--|--|---|---|---|--|--|---|---|--|---|--|
|   | the correct plan to help them. Full understanding of their progression.  |  | clients future enough to help them in the present. Hardworking: long hours, determination to help the client.   |   | work and how the brain controls these when illness rather than damage is the cause.   |  |  |   | to assess and plan the therapy based on what he/she has found out about the patient. As with any other healthcare professional, care and empathy are also paramount characteristics |  |   |  |
| 3 | NHS, hospitals, schools (special needs).   | Hospitals, in patients own homes.  | Hospitals, children and parent centres, doctor surgeries, day cares, old peoples homes.   | In a school or at that persons house.             | In a hospital or private clinic.  | Hospitals, medical centres, private practice.  | Hospitals, schools for disabled children.  | Schools, nurseries, hospitals and people's homes.                           | As part of the local health service (GP practice, health centre, hospital). Physically the therapist is likely to work at the house of the patient.                                 | Hospitals, schools, at home with patient, dental surgeries (?), old folks homes. | NHS, schools, care homes, private medical schemes, home visits.   | Hospital, GP clinic, private clinic, private practice, school. |
| 4 | Children with speech impediments, hearing impaired, special needs. Adults – stroke victims, brain injury, speech impediments. Ages: 2/3 – 80 | Children of all ages, adults who have speech or language disability. Ages: Ranging from babies to senior citizens. | All different ages, races, disabilities, stroke victims, children, elderly, anyone who has been in a life changing accident, people who have had brain surgery. Ages: From children through to elderly. | Mainly children (junior/senior age) Ages: 6-18yrs | People that have had throat or brain damage due to an accident. Stroke sufferers. Other illnesses (my cousin picked up a virus abroad that affected her spinal cord somehow, she lost all speech and had to learn | Those recovering from strokes, surgery. Those born with speech problems. Those children who speech doesn't progress as naturally as hoped. Ages: Variety | Children, accident/illness victims where vocal ability has been affected. Ages: All ages | Anybody could require a speech and language therapist. Ages: All age groups | People with any language or communication difficulty which could be caused by learning, physical or mental disability. Ages: This covers all age groups.                            | Anyone Ages: Birth to old age  | Persons with talking difficulties, eating, drinking and swallowing. Also those that have suffered brain damage by accident or illness. Ages: All groups, children to the elderly. | Any. Ages: Any   |

|   |  |  |  |  |  |  |   |   |  |  |  |   |
|---|--|--|--|--|--|--|---|---|--|--|--|---|
|   |  |  |  |  | again completely).<br>Ages: This could vary across age groups.   |  |   |   |  |  |  |   |
| 5 | Autism, Autistic spectrum, Downs syndrome, stroke, brain injury, hearing impaired.   | Stammerers, stroke victims, throat cancer sufferers, speech impediments.   | Stuttering   | Close contact with schools and family is vital.  | Stroke victims, throat disorders (following surgery for cancer for example). Downs Syndrome, specials needs. | Stroke victims. Cancer sufferers.  | Dyslexia  |   | Therapists can support deaf people either to speak or communicate in other ways. They are also able to help those with physical disabilities in the mouth or larynx. | Deafness, trauma, muscular disability, birth defect, brain injury, disease affecting muscular control. | Deafness, physical ability, dyslexia, stroke victims. Delayed speaking due to lack of social interaction.        | Difficulties with communication: use and understanding . Stammer. Feeding and swallowing. |
| 6 | Frustration to find words to communicate. Help making correct sounds to make letters and words. Confidence to be able to communicate using correct words for correct things. | Gain confidence to overcome their difficulties by spending time with them. | Unsure   | Learn the history background of the person, might be an underlying issue. Listening and talking, could be something simple to fix (like myself). | Can teach them how to communicate in different ways. How to shape their mouths to form sounds.               | Be there and reteach the basics. Help and support as they start their journey. Encourage and motivate. | Demonstrate mouth position to achieve different sounds. | Speech impediments help young children who are learning to speak, confidence – lack of. | After assessment of what is needed to help – I don't know what form the help would take.   | Communicate , develop self confidence.   | Help with speech and the ability to communicate, give self confidence. Also help with throat and mouth problems. | Treatment plans, solve symptoms, improve communication , help with eating.                |
| 7 |  |  | I think the job of a speech therapist is highly underappreciated by the general public, mainly through not really knowing what the job entails. They | Does this study include learning about selective mutism, those who do not speak.   | Can teach them how to communicate in different ways. How to shape their mouths to form sounds.               | I think anyone able to do this work needs a lot of recognition for their skills.                       |   | Nope  | Although I think I know what a therapist does, I have no idea how this is achieved. It is a vital role in any caring society.  |  |  | Great job!  |

|    |   |  |   |   |  |  |   |  |   |   |   |  |
|----|---|--|---|---|--|--|---|--|---|---|---|--|
|    |   |  | give hope to people in their final days and encourage people to believe in themselves.                              |   |  |  |   |  |   |   |   |  |
| 8  | My son who has aspergers, required assistance at the age of three. He was unable to articulate his words when frustrated or use the correct words. Would scream and beat his head against the floor because he couldn't say the words he needed to. | Knowledge gained over many years.  | I used to go to a speech therapist when I was younger as I couldn't say my 'f' or 's'                               | I have an interest due to my sister who has a special needs child who has severe anxiety and classed as special mute and has had very little help over the years however speech and language therapy is not required due to her problem is actually speaking. | Other than my cousin needing to learn how to talk again I've never had any contact with a speech & language therapist so the subject has never really crossed my mind. | I did work experience in a hospital for 3 weeks and had a very quick conversation with someone so the little I know, I learnt from them. | Other than knowing that the therapy exists, I know absolutely nothing about it.   | Teach, support and encourage to help deal with their issues.                                 | Don't know. Information that gets absorbed through life I suppose but I don't know if I'm right.  | Cousin is a maxillofacial surgeon specialising in trauma.   | A family member has received this type of therapy at school and a family member who has suffered a stroke.        | I know a speech therapist and I had experience as a child with a therapist in 1960.  |
| 9  | No  | No   | No  | No  | No, sorry.   | Not until now but I will now learn about it.   | No  | Nope   | No  | No  | No  | No   |
| 10 | Gender: F<br>Age: 35-44<br>Children? Yes<br><br>Education? Yes – My sister is an LSA<br>Health? No<br>SLT? No   | Gender: F<br>Age: 70+<br>Children? Yes<br>Education? No<br>Health? No<br>SLT? No | Gender: F<br>Age: 20-24<br>Children? No<br>Education? Yes – not specified<br>Health? Yes – not specified<br>SLT? No | Gender: F<br>Age: 45-54<br>Children? No<br>Education? No<br>Health? No<br>SLT? No   | Gender: F<br>Age: 45-54<br>Children? Yes<br>Education? Yes – teacher x 2, school head x 1<br>Health? Yes – Nurse x 3<br>SLT? No  | Gender: F<br>Age: 35-44<br>Children? No<br>Education? Yes – lecturer from college<br>Health? No<br>SLT? Yes – former colleague           | Gender: M<br>Age: 55-64<br>Children? Yes<br>Education? Yes – Sister in law is a secondary school teacher<br>Health? No<br>SLT? No | Gender: M<br>Age: 25-34<br>Children? Yes<br>Education? Yes – Mother<br>Health? No<br>SLT? No | Gender: M<br>Age: 55-64<br>Children? Yes<br>Education? Yes – Several friends are teachers<br>Health? Yes – My daughter is an optometrist<br>SLT? No | Gender: M<br>Age: 45-54<br>Children? Yes<br>Education? Yes – Not specified<br>Health? Yes – Doctor , Maxillofacial Surgeon, Psychologist<br>SLT? No | Gender: M<br>Age: 55-64<br>Children? Yes<br>Education? Yes – Teaching assistant<br>Health? Yes – Nurse<br>SLT? No | Gender: M<br>Age: 45-54<br>Children? Yes<br>Education? Yes – step Education? Yes – school class assistant<br>Health? Yes – Doctor<br>SLT? Yes – <i>name removed to protect</i> |

