IASLT

Speech and language therapy service provision for adults with an intellectual disability and communication needs:

Definition, Service Provision and Recommendations for Change

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IRISH ASSOCIATION OF SPEECH & LANGUAGE THERAPISTS
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Executive summary

This paper has been written by the Irish Association of Speech and Language Therapists (IASLT) to educate Speech and Language Therapists (SLTs), other stakeholders and the public regarding IASLT's position with respect to speech and language therapy service provision for adults (i.e. people over 18 years of age) with an Intellectual Disability (ID) and speech, language and communication needs.

Much of the currently available position papers and guidelines in relation to supporting adults with ID come from the United Kingdom (Royal College of Speech and Language Therapists 2010; 2013) and elsewhere, and while they are invaluable reference points, they are often not directly transferrable to the Irish context. As such, this document sets out the background and context of speech and language therapy provision for adults with an ID in Ireland as well as addressing values and models which underpin speech and language therapy practice when working with this population. Finally, this document closes by highlighting the challenges of working in this area and proposes some recommendations for further development.

The IASLT holds the position that:

- SLTs are fundamental to supporting the communication rights and needs of adults with ID by supporting the development of inclusive communication environments.
- SLTs have the necessary skills to assist their healthcare colleagues in communicating more effectively with adults with ID and enabling equality for adults with ID to access healthcare services.
- Adults with ID should have timely access to SLT services as they require, across their lifespan such as during transitions, during periods of cognition or physical change, when clinical need indicates or when external communication barriers arise.

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1. Background

Service provision for adults with Intellectual Disabilities in Ireland has evolved significantly in recent decades. In 2006, the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) was established. The convention reflected the shifting cultural, social and political landscape for people with disabilities and called for a dramatic change with regards to policy and service provision for people with disabilities internationally (Quinn, 2009).

Alongside international changes in attitudes, expectations and policy relevant to people with disabilities, recent national legislation and policy change is also evident. For example, *New Directions: Review of HSE Day Services and Implementation Plan 2012-2016* (Health Service Executive, 2012), *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (Health Service Executive, 2011) and the *Assisted Decision-Making (Capacity) Act* (2015), reflect and support the rights of people with disabilities to enjoy full and equal participation in society as set out by the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). Following the emergence of new policy and legislation, the Health and Information Quality Authority (HIQA) was allocated responsibility for monitoring, inspecting and registering all residential services for children and adults with disabilities in Ireland in 2013. Facilitating communication rights and appropriate communication supports for adults with an ID are central to achieving compliance with many of the above pieces of legislation and policy.

Historically, services for adults with ID were provided in closed, institutional type settings. Many people with disabilities were excluded from their communities, isolated from their families and had their human rights restricted (Health Service Executive, 2011). Traditionally, SLT support was delivered individually in specialist ID services settings. However, the evolving SLT role now focuses more broadly on supporting the rights and dignity of adults with an ID, with particular emphasis on the right to communicate. SLTs working with adults with an ID now find themselves not only providing individual intervention but also providing interventions that effect change at environmental and social levels. As more intentional efforts are made to support adults with an ID to live ordinary lives as part of their local community there are increased opportunities for positive, everyday communicative relationships to occur, which SLTs strive to support. However, limited SLT resources are available for supporting the development of communicative access and capacity in mainstream settings. Anecdotally, it would appear that the limited amount of SLT posts serving the adult ID population is resulting in an inadequate and inequitable service in many parts of Ireland.

This position paper aims to clarify the evolving role of the SLT when supporting adults with an ID in light of the shifting social, legislative and context in Ireland. Importantly, this position paper also strives to capture the progressive and specialist nature of many aspects of the SLT role when working with adults with an ID with

the overall aim of supporting SLTs practising in this area to deliver a high quality service to adults with an ID. Additionally, this position paper strives to educate other relevant stakeholders about the nature of the SLT role when working with this population to help ensure that adults with an ID receive the high quality SLT service they deserve.

2. Methodology

The process to develop this position statement was as follows:

- IASLT conducted a survey to identify areas in need of position statements and guidelines. IASLT members identified Adults with an ID as a priority area.
- IASLT convened a national working group comprised of experienced SLTs working with adults with an ID.
- The working group held numerous face-to-face meetings to draft the position statement and maintained regular contact via email between these meetings.
- Support was obtained from a librarian to obtain advice on conducting a literature search.
- Consultation was carried out with the relevant national special interest group and with other relevant stakeholders, such as the SLT managers group.
- Comments from all of the stakeholder consultations were analysed and included in the re-writing of the position paper.
- The final draft was ratified by the IASLT council in March 2019 with a proposed review date of 2022.

The following IASLT members participated in the working group:

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3. Definitions and terminology

'Sometimes I find it hard to learn new things.
I need help and more time to learn some things'

(Service User, Ability West,
Personal Communication, 8th October, 2018)

The term *Intellectual Disability* will be used in this document in line with current national policies (e.g., Health Service Executive, 2011; 2012). The terminology used to refer to ID has evolved over the years and varies internationally. ID has been referred to as learning disability, mental retardation, intellectual development disorder and developmental disability (Alborz, McNally & Glendinning, 2005; Braddock, Emerson, Felce, & Stancliffe, 2001; World Health Organisation, 2018). It should be stated that the term ID, while used by many professionals, might not necessarily be the one that is accepted by the people it sets out to define.
Every adult with an ID is unique. ID is a broad term, which encompasses a wide range of strengths and needs including difficulties in the areas of intellectual and adaptive functioning. ID manifests during the early developmental period (before the age of 18) and has lifelong implications on a person's ability to manage independently, understand information and learn new skills (American Psychiatric Association, 2013; Scottish Executive, 2000). The level of support an adult with an ID requires depends on the individual and indeed their circumstances.

Additional Diagnoses and Health Needs:

Along with a diagnosis of ID, an individual may also have a co-existing diagnosis such as a physical or a sensory disability or additional health needs. Although the list below is not exhaustive, it provides an overview of some of the co-existing diagnosis that adults with an ID may also experience:

- Hearing Impairment (Fellinger, Holzinger, Dirmhirn, Van Dijk & Goldberg, 2009)
- Visual Impairment (Fellinger et al., 2009)
- Mental health difficulties (Cooper et al, 2015; Hassiotis, Barron & Hall, 2013; Määttä, Tervo-Määttä, Taanila, Kaski & Livanainen, 2006)
- Physical and sensory difficulties (Cooper et al, 2015; Reza, & Miller, 2010)
- Epilepsy and seizure disorders (Matthews, Weston, Baxter, Felce & Kerr, 2007; McCarron, O'Dwyer, Burke, McGlinchey, & McCallion, 2014b)

- Dysphagia/FEDS (Feeding, Eating, Drinking and Swallowing) needs [1] (Robertson, Chadwick, Baines, Emerson & Hatton, 2017)
- Behaviours that challenge (National Institute for Healthcare Excellence, 2018)
- Other health needs (McCarron et al., 2013)
- Health inequalities and unmet health needs (Heslop et al., 2014; Hosking et al. 2016; O'Leary, Cooper & Hughes-McCormack, 2017)
- Unrecognised pain (Regnard, Reynolds, Watson, Matthews, Gibson & Clarke, 2007)

Communication

'Communication is the conduit between the individual and the world'
(Bunning, 2011, p. 46)

'Every time two or more people interact there is a fresh slate, an opportunity for each person to communicate with the other simply as a person and to be open to new meanings, relationships and ways of interaction. Human communication can sound like something quite emancipatory -a tool for change!'
(Williams, 2001, p. 1)

'Communication is vital to us all as human beings. It enables us to socialise with others and make sense of what's going on around us'
(Thurman, 2011, p. 3)

Communication is a process between two or more people which involves the sharing of feelings, information and/or ideas. Successful communication is central to participation in life allowing us to form relationships, establish our identities and to take up meaningful social roles in our communities. Communication enables us to contribute socially, educationally and vocationally. Conversely, the opposite is also true as noted by Thurman (2011, p. 3) when she states:

> 'If we cannot speak, understand words, or read and write very well, we are often excluded, unless others around us are prepared to change. If we are unable to communicate for any reason, we can feel misunderstood, frustrated, isolated and anxious'

[1] Adults with ID may also experience difficulties with Feeding, Eating, Drinking & Swallowing (FEDS)/Dysphagia. The SLT role in this area is outside the scope of this document and is well defined elsewhere. Further information about supporting the FEDS needs of adults with ID can be found in the Irish Association of Speech and Language Therapists (2010) document, *Guidelines for Speech and Language Therapists on Assessment and Management of Eating, Drinking and Swallowing (EDS) in Adults with Intellectual Disability (ID).*

Up to 90% of adults with an ID will experience a communication difficulty at some stage of their lives (Royal College of Speech and Language Therapists, 2009, 2010). Many adults with an ID demonstrate strengths in visual and non-verbal communication modalities (Thurman, 2011). Common speech, language and communication difficulties that may be experienced by adults with an ID include:

- Challenges in understanding language (whether spoken, written or symbolically represented)
- Difficulties and differences in the expression of thoughts and ideas through appropriate vocabulary and grammar
- Difficulties in the area of social skills,
- Reduced Intelligibility
- Dysfluency
  (Royal College of Speech and Language Therapists, 2009, 2010; Ogletree, Bartholomew, Wagaman, Genz, & Reisinger, 2012; Smith and Matson, 2010; Thurman, 2011)

In addition to the internal challenges experienced by adults with an ID (in relation to speech, language and communication skills), external environmental factors also present a significant obstacle to communicative success for adults with an ID. Barriers to successful communication can occur as a result of non-supportive communication environments. For example, adults with an ID may find themselves living, working and spending leisure time in settings which do not compliment their communication skills (such as, adults with an ID who use Lámh being supported by staff who do not use Lámh). Adults with an ID may often have limited social networks and their communication partners may often comprise primarily of paid staff and/or family members (McCausland, McCallion, Cleary, & McCarron, 2016; McConkey, Morris & Purcell, (1999). Therefore, the quality and frequency of communicative interactions experienced by adults with an ID may thus be substantially different to the typical, everyday interactions that people without an ID experience. Research which has explored the interactions between adults with an ID and staff has suggested that:

- Staff over-rely on verbal communications even when interacting with people who are non-verbal
- Staff over-estimate their use of verbal communication
- There are few opportunities for adults with an ID to engage as equal communication partners
- Adults with an ID who require significant levels of support may spend significant periods of time unengaged
- Staff tend to favour use of directives and questions during interactions
- Interactions tend to be more directive than discursive

- Difficulties with comprehension are under-estimated

- Hearing and other sensory difficulties are under-estimated
- Staff may not consistently provide communication opportunities which facilitate adults with an ID to say 'no' or refuse
- Choice-making opportunities are limited

(Banat, Summers, & Pring, 2002; McConkey, Morris & Purcell, 1999; Bradshaw, 2001; Bradshaw et al., 2013; Beadle Brown et al., 2015; Iacono, Bould, Beadle-Brown & Bigby, 2018,Antaki, 2013; Antaki, Finlay, Walton & Pate, 2008; Finlay, Walton, & Antaki, 2008; Antaki, Finlay, Sheridan, Jingree, & Walton, 2006; Williams, 2011; Martin, O'Connor-Fenelon, & Lyons, 2010)

Do adults with an ID require a SLT service?

Bradshaw (2011) stated that up to 89% of people with a learning disability may require some level of SLT intervention which varies across their lifespan. However, although these adults may experience communication difficulties or differences, SLTs do not presume that they require on-going, continuous speech and language therapy. Rather, it is imperative that adults with an ID have timely access to SLT support as they require, across their lifespan when clinical needs indicate or when internal or external communication barriers arise (such as at times of transition or during periods of cognitive or physical change).

The consequences of failing to support the communication needs of adults with an ID may include:

- **Health Inequality:** Adults with an ID are more likely than the general population to have additional health needs and are at a higher risk for having unmet health needs (including mental health) or undiagnosed pain (Cooper et al., 2015; Mencap, 2012; McCarron et al., 2014a; Tuffrey-Wijne & Butler, 2009; Nocon and Sayce, 2008). Adults with an ID may also experience significant difficulty in accessing and navigating mainstream health care services (Mencap, 2012; Mcilfatrick et al., 2011; Gibbs, Brown, & Muir, 2008)

- **Social isolation.** As previously set out, current policies in Ireland support a move towards community living and community inclusion for adults with an ID. Many adults with an ID in Ireland now live in community settings but continue to face environmental, attitudinal and procedural barriers to accessing social services in their communities (McCarron et al., 2014a; McCausland et al., 2016). The literature has highlighted the difference in reality between the policy of social inclusion and the everyday experiences of people with disabilities. Bunning and Horton (2007; 13) warn that "having a philosophy of social inclusion does not necessarily make it so".

- **Increased vulnerability and risk of abuse.** It is perhaps unsurprising that communication difficulty can be associated with vulnerability. The HSE's

Safeguarding Vulnerable Persons (HSE, 2014, p.20) policy highlights 'limitations in communication skills' as a barrier to vulnerable people including adults with an ID reporting abuse. Indeed, victimisation experienced by people with an ID and and disability hate crime is a recognised but not well researched phenomenon (Richardson et al., 2016).

- **Increased occurrence of behaviours that challenge**. Adults with an ID and communication needs are more likely to present with behaviours that challenge (Larkin, Jahoda, McMahon & Pert, 2012). Unsupportive communication environments have been linked with behaviour that challenges (National Institute for Healthcare Excellence, 2018). Communication interventions are often a key component in the provision of positive behaviour support (Bopp, Brown & Mirenda, 2004).

- **Reduced ability to engage in work and education.** It has been noted that communication difficulties can restrict access to education and employment. 'Difficulties with social communication is a predominant feature in reducing access to education, employment and social integration' (RCSLT, 2009, p. 2). Research has demonstrated that adults with an ID can experience difficulties in obtaining and maintaining paid employment (Banks, Jahoda, Dagnan, Kemp & Williams, 2010). Many people with an ID struggle to access formal education at all levels (McCarron et al., 2014a).

4. Current context of speech and language therapy service provision

Recent statistics suggest there are approximately 18,000 adults with an ID living in Ireland (Hourigan, Fanagan & Kelly, 2017). It has been anecdotally suggested that the provision of SLT for adults with ID is inequitably distributed across Ireland. SLTs work, ideally, as part of a Multi-Disciplinary Team (MDT). Direct and indirect speech and language therapy interventions are provided through working collaboratively with an adult with an ID and their relevant supporters and support services. As such, SLTs may carry out their work in many settings including: health centres, voluntary organisations, vocational sites and centres, educational services, day centres and indeed in peoples' own homes (whether adults with an ID are living alone, with their family/friends or living in supported residential arrangements). A more recent initiative, in light of recognition of the high prevalence of mental health disorders among adults with an ID has been the efforts to establish specialist mental health in ID teams, in which the SLT plays a core role.

The current context in which SLTs work has been influenced by several factors, including:

Political and legislative

As noted above, recent government policies have been influenced by the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) which include: *Time to Move on From Congregated Settings Report* (HSE, 2011), *New Directions: Review of HSE Day Services and Implementation Plan 2012-2016* (Health Service Executive, 2012), the *National Housing Strategy for People with Disabilities* 2011-2016 (Health Service Executive, 2012), *National Standards for Residential Care Settings for Children and Adults with Disabilities* (Health Information and Quality Authority; 2013) *Assisted Decision Making Act, (Capacity),* 2015, *Value for Money and Policy Review of Disability Services* (Department of Health, 2012) etc. These policies set out the need for adults with an ID to be supported to live in and avail of services within their own local communities. These policies have resulted in the dispersal of services across wider geographic locations and an increased expectation that mainstream services will have the capacity and skills to provide the required services for people with an ID, including those with complex needs. Additionally, these policy and legislative changes have impacted on the role of the SLT in relation to supporting services to make reasonable adjustments regarding the communication needs of adults with an ID, including supported decision-making and assessment of capacity. SLTs play a key role as part of an MDT in supporting adults with an ID who experience communication differences and difficulties in maximising their decision-making ability and building their capacity, alongside supporting MDT capacity assessments when required.

Economic

The economic downturn has impacted all levels of society but it could be argued that the most vulnerable of our population, including those with an ID were most significantly impacted because of the already well-established high levels of unemployment, health inequality and reduced financial independence among this population (Banks et al., 2010; McCarron et al., 2011)

Social

We are fortunate to live in a time where life expectancy for many, including adults with an ID has increased (Sinai, Chan & Strydom, 2014; World Health Organisation, 2015). In the Irish context, 49% of the people registered with an ID in 2017 were aged 35 and older (Hourigan, Fanagan, Kelly, 2017). Adults with an ID are not immune from diseases of the elderly. Indeed, dementia is overrepresented in this population (Watchman, 2005; Sinai, Chan, & Strydom, 2014; McCarron et al., 2014a) Increasing life expectancy and related health and social issues entail that adults with an ID may require an enhanced level of SLT support as they age and their needs change.

5. Values underpinning practice

Social model

The social model of disability is a theoretical framework that understands disability as a socially constructed phenomenon. The social model of disability suggests that disability is not solely the product of an impairment located within an individual. Instead, disability is viewed as a consequence of interactions between an individual and their environment (Finkelstein, 2007; Oliver, 1983; 1990; 1996; Shakespeare, 2017). The social model of disability recognises the need for the environment (including communication partners) to adapt to support the individual and their specific profile of strengths and needs. SLTs working with adults with an ID aim to provide communication supports which are guided by the social model of disability (Royal College of Speech and Language Therapists, 2010). Correspondingly, SLTs work directly and indirectly to cause change at both societal and individual levels and indeed levels in between (e.g., Law, Reilly & Snow, 2013; Royal College of Speech and Language Therapists, 2010).

Rights based approach

'Communication is both a basic need and a basic right of all human beings' (Brady et al., 2016, p. 121). As reflected in Article 19 of the 1948 *Universal Declaration of Human Rights*, each person has the right to receive and convey messages, to hold opinions and to express themselves regardless of their age, ability or communicative capacity (McLeod, 2018). Drawing on a rights-based approach during speech and language therapy practice focuses on protecting and promoting human rights, particularly those rights pertinent to communication (Murphy, Lyons, Carroll, Caulfield & De Paor, 2018). A key role of the SLT working with adults with ID is to support and develop a person's communicative capacity to be autonomous and self-determined and to exercise control over their lives. The ultimate aim in ID services is to support people to access an ordinary life and participate in socially valuable roles (Wolfensberger, 2000). Communication is a crucial element that enables such participation.

Total communication

Total communication recognises and values all modalities (both verbal and non-verbal) of communication (RCSLT, 2010, 2013). A total communication approach behoves SLTs to expose and empower individual communicative strengths and use these as a foundation to expand and improve interactional success (Bradshaw, 2000; Cambridge and Forrester-Jones, 2003; Jones, 2000). The tools of total communication include speech, intonation, volume, sign language, objects of reference, pictures, photographs, symbols, gestures, body language, eye contact/gaze, technology, behaviour and more. The aim of total communication is to establish a positive communication environment that compliments a person's communication profile.

Evidence based practice

Evidence Based Practice (EBP) is ubiquitous in modern health care. It entails that health care practitioners incorporate current high-quality research with clinical experience and the wishes of the person accessing health care to guide their interventions. Some of the concerns raised about EBP (Morse, 2006) are particularly pertinent when working with adults with an ID. For example, much of the available research evidence relevant to this clinical population would not be considered 'high-quality' from an EBP perspective (Snell et al., 2010), in that much of research applicable to SLT practice in this context appears to have emerged as opinions of respected authorities, descriptive studies, single and small group case studies or reports from committees etc. Additionally, the efficacy of the multi-factorial and situated nature of intervention can be difficult to evaluate using quantitative methodologies which are generally more acceptable as higher levels of evidence (Greenhalgh, 2014). Finally, the voice of the people who access SLT are often not well represented or captured by the methodologies that are considered to be the most robust within the EBP paradigm (Kovarsky and Curran, 2007; Kovarsky, 2008). As noted by Goldbart, Chadwick and Buell (2014), limited resources create challenges in terms of allocating clinical time to access the most recent research. Nevertheless, it has been also noted that the uptake of EBP by SLTs is similar to other allied healthcare professionals (McCurtin & Roddam, 2012).

Functional communication[2]:

In relation to communication supports, the term 'functional' is used to describe interventions that are meaningful, ecologically valid and carried out in naturalistic settings (Penn, 1999). Ideally, assessment and intervention when working with adults with an ID should take place in natural contexts across multiple settings (Brady et al., 2016; Coyne, 2015). SLTs strive to infuse their interventions with a purposeful focus and have moved away from providing impairment-based therapy which targets linguistic or communicative changes that are of no practical use to those accessing speech and language therapy services (as noted in seminal papers such as van Der Gaag, 1998). Everyday conversations and tasks thus provide obvious sites in which the SLT can explore the functional use of speech, language and communication skills and identify opportunities and barriers relevant to an individual.

Person centred practice:

Person-centred practices are well recognised as a cornerstone of quality in the provision of services for people with ID (Bigby & Beadle-Brown, 2016). Person centred practice is guided by how an individual wants to live their life and what is required to make that possible (Ratti, Hassiotis, Crabtree, Deb, Gallagher & Unwin, 2016). Historically, speech and language therapy practice had been guided by the expert model where clinical perspectives were accorded priority and intervention was focused solely on identifying and managing impairments (Duchan, 2005; van der Gaag, 1998). SLTs working with adults with an ID recognise the need to engage in person centred practice and acknowledge adults with an ID as experts by experience. In this vein, the person with an ID and their significant others should be actively empowered by SLT to participate in intervention and clinical decision-making (Brady et al., 2016).

[2] To avoid confusion please be aware that the term 'functional communication training' is also used more specifically with reference to a MDT approach to support positive behaviour (e.g., Kurtz, Boelter, Jarmolowicz, Chin & Hagopian, 2011; LaRue, Weiss & Cable, 2009; Tiger, Hanley, & Bruzek, 2008).

6. Models of service provision

The role of the SLT working with adults with an ID is multi-factorial, complex and may involve specialist skills. Speech and language therapy practice in this context is resource heavy and time consuming. Assessment and intervention are on-going and dynamic processes that evolve over time. In this setting, assessment can be lengthy and multi-site rather than a discreet process. Correspondingly, speech and language therapy intervention becomes a responsive and situated process tailored to the changing needs of an adult with an ID, their supporters and their circumstances. Different issues that require speech and language therapy support may arise at different stages in a person's life (such as transitions, medical or age-related issues etc.). SLTs recognise the need to collaborate with MDT colleagues in supporting adults with an ID. Relevant MDT members vary depending on the specific profile and needs of an individual.

Models of speech and language therapy service provision for adults with an ID have evolved from a traditional direct and expert based approach to a more collaborative and consultative approach. As stated previously, the SLT's role is to deliver a high quality, rights based, person centred service in partnership with the adult with and ID and their significant communication partners. This service should be informed by total communication, EBP, functional communication and the social model of disability. Recognition of this role has influenced the model of speech and language therapy service provision discussed below.

The model below (diagram 1) is used to explain the multifaceted role of the SLT when working with adults with an ID. This model has been adapted from a number of others including Royal College of Speech and Language Therapy's (2006, 2010) 4-tiered model and some facets of the balanced system (Gascoigne, 2012). The following areas are addressed: the role of the SLT at different interlinked levels, expected outcomes of speech and language therapy supports and the possible risks of limited or no speech and language therapy service provision. Examples of evidence are also presented as are hypothetical case vignettes which provide an illustrative summary of speech and language therapy intervention at each level. As speech and language therapy support in this context is multifaceted, intervention may simultaneously be provided at more than one level. For example, the SLT may work with the person directly (effecting change at an individual level), as well as working indirectly with the staff who communicate regularly with the person with an ID (effecting change within targeted communication environments including specialist ID services). The levels overlap in that communication is at the heart of all speech and language therapy support.

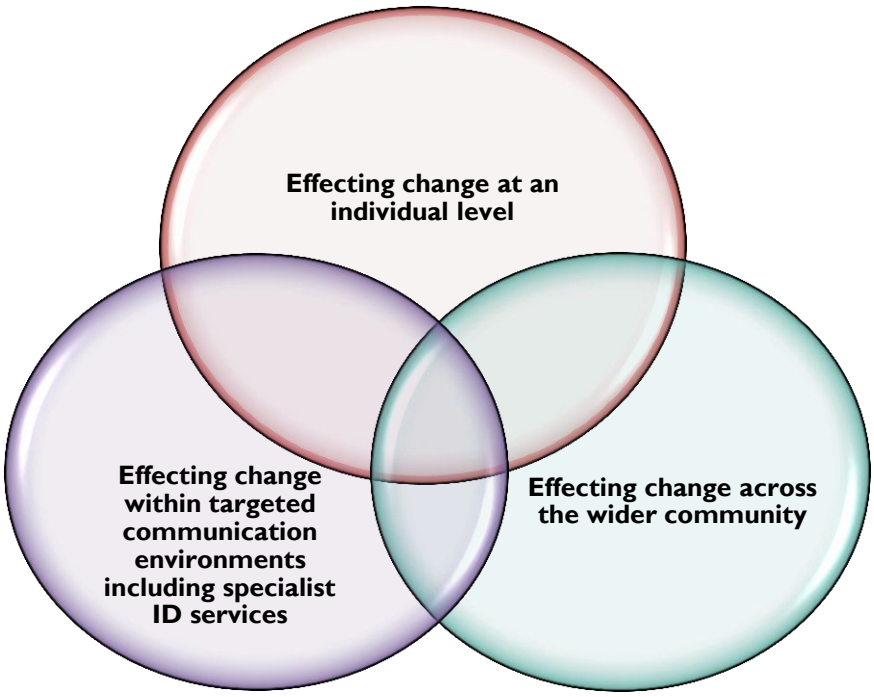

***Diagram 1**: Model of speech and language therapy service provision when supporting adults with an ID*

6a. Models of service provision: Effecting change at an individual level

Speech and language therapy input at this level aims to explore speech, language and communication abilities of the adult with an ID as well as identify environmental barriers and opportunities relevant to speech, language and communication. Speech and language therapy assessment and management at this level aims to identify and support the implementation of appropriate communication strategies and supports via both direct and indirect intervention approaches (Money, 1997, 2000). Intervention should be specifically focused on the speech, language and communication strengths and needs of a particular individual. As such, SLTs will also liaise with relevant stakeholders as part of the implementation of a communication support plan for an individual.

Effecting change at an individual level

Role of SLT at this level

- Assessing the speech, language, and communication strengths and needs of the adult with ID.
- Assessing the communication barriers and opportunities in an individual's environment
- Augmented & Alternative Communication (AAC) assessment and intervention
- Valuing, respecting and promoting all modalities of communication (RCSLT 2010).
- Liaising with MDT and relevant other stakeholders as appropriate
- Developing and supporting the implementation of communication recommendations (e.g. strategies and supports)
- Supporting and carrying out capacity assessments as part of an MDT, as required.
- Advocating for an individual's communication rights
- Onward referral as appropriate

Expected outcomes of providing SLT supports at this level

- Effective individualised communication supports (which are person centred and take account of the person's context, culture and aspirations).
- Improvement in emotional and mental wellbeing.
- Reduction in communication frustration and distress.
- Increased personally meaningful engagement and interactions.
- Increased communicative success
- Reduction of communication barriers
- Increased inclusion and participation
- Crisis prevention

Risks of not providing SLT support at this level

- Unmet communication needs and barriers.
- Misdiagnosis leading to mismanagement (e.g. diagnostic overshadowing).
- Increase in people communicating their distress through behaviour that challenges.
- Increased vulnerability and safeguarding issues.
- Negative impact on wellbeing and quality of life.
- Placement and/or support services breakdown
- Failure to meet current legal and best practice policy requirements including for example: *Convention on the Rights of Persons with Disabilities* (United Nations, 2006); *Time to Move on From Congregated Settings* (HSE, 2011); *New Directions: Review of HSE Day Services and Implementation Plan* 2012-2016; *National Standards for Residential Care Settings for Children and Adults with Disabilities* (Health Information and Quality Authority; 2013); *Assisted Decision Making* (Capacity) *Act,* 2015.

Examples of evidence for speech and language therapy at this level

Evidence for SLT interventions that effects change at the level of the individual is often found in single and small group case studies and discussion papers which examine theoretical aspects of communication in this context or implementation of specific therapeutic approaches (e.g., Firth, 2006, 2009; Griffiths, & Smith, 2016; Kagohara, et al, 2013; Elgie, & Maguire, 2001; Leaning, & Watson, 2006; Meuris, Maes & Zink, 2014, 2015; Zeedyk, Caldwell, & Davies, 2009). In recent years, more systematic reviews are also emerging (e.g., Kent-Walsh, Murza, Malani & Binger, 2015; van der Meer et. al., 2017). In addition, evidence for this level of speech and language therapy input also comes from consensus documents and clinical guidelines developed by expert committees and professional organisations (e.g., Brady et al, 2016; Goldbart & Canton, 2010; Royal College of Speech and Language Therapists, 2010). As examples, interventions which involve AAC (Alternative and Augmentative Communication) and FCT (Functional Communication Training) are discussed below.

There is a growing body of evidence to support the use of AAC with people who present with complex communication needs (Light & McNaughton, 2015, Allen et al. 2017). Light and McNaughton (2012) highlighted how this evidence extends across the lifespan of individuals and emphasised that with the societal changes in how adults with disabilities are now being supported, adults are now using AAC to access employment, to volunteer and to take part in recreational activities within their communities. Despite the growing body of research, the lack of ongoing support for people who require AAC, in particular adults, has been highlighted as a significant concern (Enderby et al, 2013). In addition to evidence supporting the communicative benefits that AAC can have for a person, there is also an increasing amount of research into specific intervention strategies. Beck, Stoner and Dennis (2009) investigated the use of aided language stimulation as an intervention for adults with developmental disabilities and found that AAC use increased for all participants as a result of this intervention. Kent-Walsh et al (2015) identified in their meta-analysis that communication partner interventions were highly effective in improving the communication of individuals who use AAC.

Functional Communication Training (FCT) is an effective method of reducing socially reinforced behaviours of distress that people with ID and/or ASD may present with (Carr & Durand, 1985; Durand & Merges, 2001; Heath et al, 2015). Heath et al (2015) completed a meta-analysis of 39 studies utilising FCT and found it to have strong effects overall. While FCT has a larger evidence base with regards to supporting children with ID/ASD, Heath et al (2015) compared its use across age groups and found that results can still be effective for people as they grow older. Walker and Snell (2013) completed a meta-analysis of effects of AAC on challenging behaviour and found that AAC interventions are most effective when used in FCT. While much of the literature on FCT is found in the field of behaviour analysis, the expertise of both the behaviour analyst and the SLT in a team approach is warranted in practice (LaRue et al, 2009).

Case vignettes: Effecting change at an individual level

Supporting 'Eoghan ' to use AAC

Eoghan, a young man with a mild intellectual disability, was referred to speech and language therapy for an AAC assessment. Eoghan was outgoing, friendly and loved socialising with his friends. His speech was, however, highly unintelligible even to familiar listeners. This often made Eoghan feel frustrated. The SLT worked with Eoghan to explore AAC options. Eoghan and the SLT chose appropriate communication software to use on his smart phone to augment his speech. The SLT supported Eoghan and his significant communication partners to introduce and maintain the use of this AAC device during everyday interactions. Eoghan reported increased positive communication experiences and less communication breakdowns as an outcome of this intervention.

Developing Capacity

'Jack', a man with Mild ID and Cerebral Palsy was referred for a FEDS (Feeding, Eating, Drinking and Swallowing)/Dysphagia review with his local SLT. It had been previously recommended that Jack should have a Texture B Minced and Moist diet. Jack did not follow this recommendation and it was leading to conflict with staff in his residential and day services. SLT worked with Jack to help him to understand the eating, drinking and swallowing process. An education piece was completed using visual supports and accessible language. Jack demonstrated the ability to understand and recall the information across sessions. It was agreed by the MDT that Jack had demonstrated capacity to make his own decisions in relation to his eating and drinking and understood the risks of not taking a modified diet. However, the result of this speech and language therapy intervention was an increased compliance with FEDS recommendations, reduced conflict with staff and reported increased feelings of autonomy for Jack.

6b. Models of service provision: Effecting change within targeted communication environments including specialist ID services

Speech and language therapy input at this level focuses on identifying and managing environmental supports and challenges to functional and/or successful communication for adults with an ID. As such, external opportunities and barriers related to communication are explored by the SLT and interventions may often include staff training as well as information sharing and education with relevant stakeholders. Current national policies dictate a move to more mainstream service access for people with disabilities but as outlined in the 'current context' section of this document, many adults with an ID continue to spend much of their time and to receive many of their support services from specialist ID services rather than mainstream services (Hourigan, Fanagan & Kelly, 2017). Intervention at this level therefore focuses on effecting change in communication environments which may often include settings such as residential, vocational and education centres which serve people with ID.

Effecting change within targeted communication environments including specialist ID services

Role of SLT at this level

- Assessing individual and environmental communication needs
- Devising and supporting the implementation of communication recommendations
- Implementing communication support plans that target the environmental context of the person e.g. supporting the creation of an inclusive and total communication environment
- Educating communication partners about a person's communication strengths and needs
- Developing communication policies and procedures
- Communication partner training and coaching
- Linking with relevant stakeholders including MDT members and service managers
- Developing and supporting total communication environments
- Staff and family (communication partner) training
- Consultation and collaborative working with relevant MDT members

Expected outcomes of providing SLT supports at this level

- Increased recognition of a person's communication strengths and needs
- Access to a high-quality supportive communication environment
- Improved communication knowledge and skills of communication partners
- Increased communication opportunities and communicative success

- Reduction of communication barriers
- Coherent clinical care and collaborative practice between relevant MDT members
- Increased opportunities for exercising human rights such as self-determination and choice making.

Risks of not providing SLT support at this level

- Inadequate and potentially restrictive communication environments
- Failure to meet the needs of adults with an ID due to communication partners lack of understanding and awareness of communication opportunities and barriers
- Decreased participation and potential exclusion within an adult with ID's immediate communication environment
- Increased communication anxiety and distress for adults with an ID and their communication partners
- Decline in well-being and possible need for access to mental health services
- Increase in people communicating their distress through behaviour that challenges.
- Increased number of inappropriate SLT referrals.
- Placement and/or support services breakdown
- Failure to meet current legal and best practice policy requirements including for example: *Convention on the Rights of Persons with Disabilities* (United Nations, 2006); *Time to Move on From Congregated Settings* (HSE, 2011); *New Directions: Review of HSE Day Services and Implementation Plan* 2012-2016; *National Standards for Residential Care Settings for Children and Adults with Disabilities* (Health Information and Quality Authority; 2013); *Assisted Decision Making* (Capacity) *Act,* 2015.

Examples of evidence for speech and language therapy at this level

Evidence for this level mainly comes from the grey literature as well as other sources such as consensus documents and clinical guidelines (Coyne, 2015; Goldbart and Canton, 2010; Royal College of Speech and Language Therapists, 2010, 2013). However, there is also some guidance available from studies exploring indirect interventions such as staff training (e.g., Purcell, McConkey, & Morris, 2000; Dobson, Upadhyaya, & Stanley, 2002; van der Meer et al., 2017). It is generally accepted that the SLT has an important role to play in maximising communicative potential by developing positive communication environments. For example, SLTs are uniquely placed to advise on individualised communication supports that take account of environmental opportunities and barriers (including those related to communication partners). Communication partners play a vital role in the success or otherwise of communicative events. SLTs should be involved in developing the skills of communication partners to ensure they can use an appropriate suite of communication supports that complement the needs and strengths of adults with an ID. The sway of the literature suggests that once off teaching or coaching sessions are not effective for promoting changes in interaction patterns between staff and adults with an ID. Communication partner training that is on-going, mentor led, individualised and facilitated in a person's natural communicative environment has been suggested as having better outcomes (Purcell, McConkey, & Morris, 2000; Dobson, Upadhyaya, & Stanley, 2002).

Case vignettes: Effecting change within targeted communication environments including specialist ID services

Supporting 'Raymond' to understand his health

Raymond, a young man with moderate ID and Down Syndrome, was diagnosed with a subarachnoid cyst. He found it difficult to understand the explanations given to him about his health condition and was worried that he was going to become very ill and die. As a result, he stopped attending his day service and going out with his friends, preferring to stay at home in his bedroom. His family became concerned that he could be suffering from depression. A referral was sent to the clinical psychologist who, in turn, contacted SLT services. His SLT worked with the clinical psychologist and GP to develop materials which would be accessible for Raymond in order to explain his health condition and management of same. SLT also provided support to the clinical psychologist in understanding Raymond's communication strengths and needs and how best to communicate with him during assessment and intervention. Raymond succesffuly completed a piece of work with psychology and experienced less anxiety around his health condition. Raymond re-engaged with his day services and his support staff noted an improvement in his mood as well as an increase in Raymond's health literacy and health related vocabulary.

Creating a total communication environment

Following a referral, an SLT worked collaboratively with staff in a day service which provided supports for adults with autism and severe to profound intellectual disabilities. The SLT provided training in total communication and supported staff to implement total communication strategies inlcuding: objects of reference, intensive interaction, responsive communication partner style and use of multisensory equipment and activities for fostering increased communication opportuinities. The results were an increased understanding by staff of service users' communication strengths and needs, an increase in the observed use of facilitative communication strategies and supports being used by staff, a reduction in behaviors that challenge and a reported increase in service users levels of engagement and interaction in day service activities.

6c. Models of service provision: Effecting change across the wider community

Communication access and inclusion is a cornerstone of participation in society (Thurman, 2011). The SLT working with the wider community provides intervention aimed at a general population (or 'mainstream' level) to address the communication needs and social inclusion of adults with an ID. As discussed in greater detail above, it is well recognised that people with disabilities (including adults with ID) face challenges in participating as equal citizens including challenges in accessing healthcare, leisure and employment (*European Disability Strategy,* 2010-2020).

Effecting change across the wider community

Role of SLT at this level

- Generating awareness of communication needs, opportunities, barriers and supports for adults with an ID in mainstream contexts.
- Advocating for and supporting the development of positive communication environments for adults with an ID in mainstream educational, vocational, health and other social contexts.
- Supporting user led advocacy and reference groups.
- Promoting communicative access in mainstream amenities or services
- Developing and/or participating in initiatives and awareness campaigns regarding communicative rights and access
- Consulting with relevant agencies about the development of accessible information at local, regional and national levels (Chinn & Homeyard 2016; RCSLT 2013, 2106)
- Consulting with mainstream agencies about communicative access and related policies (Coyne, 2015)

Expected outcomes of providing SLT supports at this level

- Increased communicative access and inclusion of adults with an ID in mainstream services
- Increased likelihood of having healthcare needs met
- Increased meaningful roles for adults with an ID in mainstream society
- Increased awareness and availability of accessible information and appropriate communication supports for adults with an ID in mainstream services

Risks of not providing SLT support at this level

- Less accessible mainstream services for adults with an ID
- Exclusion of adults with an ID from mainstream services
- Limited awareness and evidence of total communication practice across mainstream settings
- Lack of reasonable adjustments being made to support access to mainstream services
- Tokenistic adjustments being made at mainstream level which fail to adequately meet the communication needs of people with ID
- Over reliance on more costly specialist services to advise on and provide reasonable adjustments related to communication
- Restricted access to an ordinary community-based life for adults with ID
- Lack of compliance with good practice standards, policy and legislative requirements including for example: *Convention on the Rights of Persons with Disabilities* (United Nations, 2006); *Time to Move on From Congregated Settings* (HSE, 2011); *New Directions: Review of HSE Day Services and Implementation Plan* 2012-2016; *National Standards for Residential Care Settings for Children and Adults with Disabilities* (Health Information and Quality Authority; 2013); *Assisted Decision Making* (Capacity) *Act,* 2015.

Examples of evidence for speech and language therapy at this level

The overall aim of speech and language therapy support at this level is to facilitate greater mainstream inclusion and ultimately access to an ordinary life for adults with an ID. High quality evidence for informing speech and language therapy practice at this level is limited. Available evidence mainly comes from the grey literature and discussion papers, consensus documents and clinical guidelines (Brady et al., 2016; McLeod et al., 2018; Royal College of Speech and Language Therapists, 2016).

SLTs recognise communication as a holistic and situated process involving not only communication partners but also appreciate the influence of the social, cultural and political context in which communication occurs. SLTs have a role to play in advising and supporting the generation of positive communication contexts in mainstream settings and services. In this vein, SLTs may explore external barriers to communication for adults with an ID, and in doing so, SLT support may address less tangible aspects of the communicative access by supporting advocacy, inclusion, person centred-practices and the generation of relevant policy. For example, SLTs have a role in advising on reasonable adjustments in the context of communication differences and difficulties and the creation of accessible information (Chinn & Homeyard, 2016; Mander, 2015; Royal College of Speech and Language Therapists, 2013, 2016).

Supporting communciation access in mainstream services

Following on from a service development initiative, an SLT was asked to support a local hospital in improving communication access for patients with an ID. The SLT linked with a patient group to facilitate staff training on total communication, communication access and accessible information. The SLT was also consulted by hospital staff when revising some of their patient information leaflets. The SLT guided them in linking with local patient and advocacy groups relevant to ID and also alerted them to other good practices in this area.

Developing a more accessible cafe

A local cafe requested SLT support as they regularly received custom from a number of adults with an ID who use Lámh. The SLT and a small group of adults with an ID developed a communication training programme for staff from the cafe including teaching staff some core Lámh signs and also advising staff on the use of a reduced language load and a photo based menu. Staff reported greater confidence in communicating with people with an ID who used their cafe, while customers with an ID reported greater satisfcation with staff communication.

7. Challenges of providing speech and language therapy services to adults with an ID

- **SLT resources and prioritisation:** Anecdotally, SLT services for adults with an ID appear to be inequitable nationally and under resourced. Where there is a speech and language therapy service available, stretched resources may result in assessment and management of FEDS/dysphagia being prioritised over communication supports. However, as SLTs strive to work holistically when they support adults with an ID, it is not always advised that communication needs are demoted or considered less worthy of intervention in the face of other needs. As discussed previously, the assessment process when working with this population is on-going and cyclical requiring an extensive time commitment and often involves specialist skills (e.g., Beukelman & Mirenda, 2012; Brady et al, 2016). Additionally, intervention is often medium-long term, multifaceted and necessitates considerable time, MDT working, multi-site interventions and, as such, considerable SLT resources.

- **Training communication partners:** Many adults with ID are marginalised and may not be facilitated by high quality active support or high quality communication opportunities in their daily environments (Beadle-Brown, 2015). Indirect speech and language therapy interventions which involve training communication partners are challenging for a number of reasons. For example, some of the challenges faced by SLT in attempting to develop positive communication environments include high staff turnover, reliance on communication partners to utilise strategies, communication partner attitudes and beliefs, as well as staffing and other resource limitations etc. (e.g., Firth, Elford, Leeming & Crabbe, 2008; Meuris, Maes, & Zink, 2014; Purcell, McConkey, & Morris, 2000).

- **Communication environments:** As discussed above, it is well established that adults with an ID are marginalised and many adults with an ID face significant challenges in accessing meaningful communicative environments. Adults with an ID may be reliant on staff and families to provide access to leisure, social, educational and vocational events and experiences including meaningful interactions (McCarron et al., 2011, McCarron et al, 2014a). Adults with an ID may also require the support of family and staff to access and participate in speech and language therapy interventions and to implement communication support strategies.

Adults with an ID may face challenges in exercising their rights, accessing meaningful social roles and living an ordinary life, all of which impacts the quality and quantity of interactions they experience. Simply being present in the community does not necessarily compare with living in that community (McCarron et al., 2011). As such, it can be challenging for SLTs to promote communication opportunities and support communicative success in achievements when the appropriate environment for achieving same is not a reality for an individual with an ID.

- **Dearth of high quality research focusing on ID and communication** It is well recognised that sufficient high quality research in this area is lacking (Goldbart & Canton, 2010). However, this situation has begun to change and research interest in this area continues to grow. When research is available, SLTs are often challenged in accessing research due to resourcing issues (O' Connor & Pettigrew, 2009).

- **Shortage of relevant training opportunities.** As the speech and language therapy role when working with adults with an ID may involve specialised skills, access to continuous professional development opportunities is vital to develop high quality practice in this area. However, opportunities for training can be difficult to source and access due to limited funding in the health and social care sector.

- **Multi-Disciplinary Team working:** SLTs recognise the importance of working collaboratively in general but specifically when working with this population. In light of the lack of fully resourced MDTs (which serve adults with an ID) and the broad nature of communication, it is challenging for SLTs to preserve strong MDT working relationships and practices while also ensuring professional boundaries are not compromised.

- **Capturing use of SLT resources adequately:** Many SLTs are asked to describe their productivity quantitatively in terms of regularly submitting metrics. However, the resource heavy nature of providing speech and language therapy support to adults with an ID is difficult to capture and specify fully using many of the available metrics. Much of the work of SLTs supporting adults with an ID may be consultative and indirect which is often not valued in the same terms as direct 1:1 interventions when generic metrics are used to capture the use of SLT resources in this area.

8. Recommendations and future directions

It is recognised that speech and language therapy services for adults with an ID, have been historically under resourced and many remain so. The following should function as points of departure when considering how to develop and progress quality speech and language therapy services for adults with an ID:

1. The aim of SLT provision with this population is to deliver a right's based, person-centred SLT service. It is necessary to ensure that the adult with an ID's voice is heard when making decisions regarding the provision of services related to them (including speech and language therapy). This includes ensuring that the views of adults with a severe-profound ID are represented in this regard.
2. Policies are continuously evolving. Adults with an ID should be supported to contribute to local, regional and national policies which impact on their lives.
3. SLTs are uniquely placed to comment on communication and thus should be appropriately involved in policy development relating to adults with ID and communication.
4. The speech and language therapy role is most established at effecting change at the individual level and in specialist ID services. Further development is required to establish and enhance the SLT role in effecting change across the wider community for adults with an ID.
5. Adults with an ID enjoy longer life expectancy than ever before. Speech and language therapy services need to be prepared to meet the changing and increasingly complex needs of this population across their lifespan and in a timely fashion.
6. In light of the lack of high quality evidence for guiding speech and language therapy practice in this area, support is required for practising clinicians to contribute to the evidence base.
7. Considering the high demands placed on SLTs working in this area and the challenges of allocating time to exploring the available research evidence in this context, SLTs need to prioritise continuing professional development in the area and be supported to do so.
8. It is well established that specialist skills are required to work with this population. Further consideration should be given to the establishment of clinical specialist SLT roles in this area.
9. Practising SLTs have a core role in educating SLT students. SLTs need to continue to collaborate with third level institutions in order to develop their role in the education and training needs of speech and language therapy students in the area of ID.

10. In light of the oftentimes intensive work involved in supporting adults with ID from a speech and language therapy perspective, development of appropriate outcome measurements which captures this level of intervention is necessary.
11. Accessible/easy read materials have been developed to support the sharing of this document with adults with an ID. Consultation with adults with an ID regarding this position statement would no doubt improve the quality and robustness of the document. It is recommended that future versions of this position statement include a consultation process with adults with an ID (and their supporters) who use or have used SLT services.

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