

# Special Considerations for Speech Language Pathologists Serving People with Intellectual Disabilities

*A supplementary resource to augment existing practice guidelines*

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# Special Considerations for SLPs serving people with Intellectual Disabilities

## ***Purpose:***

The aim of this paper is to develop practice guidelines which follow available evidence based research for speech language pathologists (SLPs) working with children and adults who have an intellectual disability (ID). This document is meant to complement other relevant regulatory guidelines and to give special considerations when working with people with ID.

## ***Definitions:***

Intellectual Disability is a neurodevelopmental disorder with onset occurring during the developmental period. According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013), the diagnostic criteria include impairment in both intellectual and adaptive functioning in three domains:

- Conceptual Domain includes skills in language, reading, writing, math, reasoning, knowledge and memory.
- Social Domain refers to empathy, social judgment, interpersonal communication skills and the ability to make and retain friendships.
- Practical Domain centers on self-management in areas such as personal care, job, responsibilities, money management, recreation, and organization for school and work tasks.

Based on the level of these impairments, the severity of ID is indicated as either mild, moderate, severe, or profound. Recent heightened emphasis on the adaptive skills described above means that even with a mild intelligence quotient (IQ) score of 50 to 70, a person with very limited independence in personal care and participation could be considered as having a severe disability.

The World Health Organization (WHO) recognizes the importance of the full participation of people with disabilities. In their revised International Classification of Functioning, Disability and Health (ICF) it examines the impairment (loss of bodily structure or function) in relation to the person's activity limitation (limitations on individual execution of a task) and participation (involvement in life situations such as education, employment, leisure, interpersonal relationships), as well as environmental factors which might influence an individual's level of functioning. The ICF is not used for classification but it "explores the interaction of the health characteristics and the contextual factors that produces disability" (WHO, 2001).

## ***Prevalence:***

According to the WHO (2001), the prevalence of people who have an IQ of 70 or below is reported as 3% of the world's population. Ouellette-Kuntz & Paquette (2001) report that individual country estimates vary between 0.2% and 8.5%, and that of those who meet criteria for ID diagnosis, approximately 85% will fall into the mild range.

Clinical experts in the field of intellectual disability, such as Ouellette-Kuntz et al. (2009), have completed extensive literature searches and have found limited Canadian studies to determine the prevalence of individuals living with ID. In addition, further advancements in genetic testing and neurological investigation (Charlot & Beasley, 2013), changed criteria, and improved diagnostic measures have increased our understanding of different etiologies of ID. Greater knowledge of the various causes of ID can have wide-reaching effects. For example, individuals living with Fetal Alcohol Spectrum Disorder (FASD) were often diagnosed with one of the symptoms of FASD, such as attention deficit-hyperactivity disorder (ADHD) rather than the main disorder (Ouellette-Kuntz et al., 2009). Due to their cognitive and adaptive challenges (Jirikowic, Kartin, & Carmichael Olson, 2008), changes have been made to include individuals with FASD among those who can access developmental services (e.g. Ontario Ministry of Community and Social Services, 2009). Intellectual Disability is considered chronic and often co-occurs with other mental health conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder (American Psychiatric Association, 2013; Patel, Greydanums, Calles, & Pratt, 2010).

### ***Historical Preamble:***

Historically, intellectual disability was understood from the perspective of a medical model wherein expertise provided appropriate training and modification to correct the “flaw” of a disability, ideally in an isolated, segregated setting (Griffith, Stavrakaki, & Summers, 2002). In support of this philosophy institutions were created. These hospital-like settings used labels that are now considered derogatory, but were common language of the time. They were considered asylums for “idiots,” “lunatics,” “imbeciles,” and the “mentally retarded” (Brown & Percy, 1999; Ministry of Community of Social Services, 2011).

The types of support, living arrangements and service delivery to people with ID were modified over the years, in large part, by societal influences. Parent, self-advocacy, and human rights groups protested for equality and rights for those who have an ID. This advocacy had a positive impact on political opinion which resulted in an improvement in living arrangements and changes in service delivery.

As a result of an increased understanding about intellectual disability and the required supports, the care provided to these individuals shifted from a medical to a social model in the 1970’s (Bach, 2007). This resulted from understanding that issues facing people with ID were primarily of a social nature rather than medical and that segregation was neither adequate nor suitable (Anglin & Braaten, 1978; Welch, 1973).

Thus, programs, policies, and regulations were implemented to allow for the de-segregation of people with ID, in part, by using the concept of normalization. Normalization is based on the proposition that quality of life improves as one’s access to culturally typical activities and settings increases (Landesman & Butterfield, 1987). This means that people with ID have the same rights as the general population to participate fully in the community and to contribute to the many stages of life from birth to death. These stages include, but are not limited to, being welcomed at daycare, having the opportunity to pursue a purposeful education, being able to have relationships with people of his or her choice, securing meaningful, discrimination-free employment, choosing where to live, getting married, and retiring.

## ***Scope of Practice:***

The Ontario *Audiology and Speech- Language Pathology Act, 1991* states: “The practice of speech language pathology is the assessment of speech and language functions and the treatment and prevention of speech and language dysfunctions or disorders to develop, maintain, rehabilitate or augment oral motor or communicative functions”. Additionally, the College of Speech Language Pathologists and Audiologists of Ontario (CASLPO, 2007) states “providing service for swallowing disorders (dysphagia) is within the speech-language pathologist’s (SLP) scope.”

As well as providing direct assessment and treatment, SLPs act as a resource for individuals, families, developmental service workers, allied health professionals, and the community at large. This may involve educating the public regarding an individual’s speech and language impairments in order to promote his or her social interaction, participation, independence, and ability to live in the least restrictive environment possible.

## ***Collaboration Requirements:***

Although speech language pathologists have the primary responsibility for assessing, implementing and evaluating treatment programs which address communication impairments, it is important to collaborate with other professionals to provide holistic and coordinated services (Engel, 1977). Effective collaboration requires familiarity with roles and expertise of various disciplines including, but not limited to: audiologists, behavioural consultants, caregivers<sup>1</sup>, dieticians, educators, nurses, occupational therapists, physicians, physiotherapists, psychologists, social workers, as well as other speech language pathologists.

People with ID have been generally under-supported by the healthcare system (Scheepers et al., 2005) and tend to present with more co-morbid conditions than the general population, which often go unrecognized (Ahmedani & Hock, 2012; Scott, & Haverkamp, 2014). The biopsychosocial (BPS) model is a useful approach to view the individual holistically and can be used to collect important information from across professionals as a collaborative process (Engel, 1977). The BPS model is a proactive approach that incorporates the effects and interrelations of biomedical and psychosocial factors on challenging behaviours. For example, the BPS model can help identify: impaired neuro-sensory systems, behavioural challenges, medical history, polypharmacy, mental health issues, environmental factors, interpersonal factors, psychological features, and more. These factors are helpful in planning communication interventions.

Person centred practice should guide all steps of involvement. As such the person and his or her family should play an instrumental role in the assessment and treatment process. Many individuals with ID may have limitations in understanding and expressing their needs which necessitate collaboration with others in their circle of support.

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<sup>1</sup> The term caregiver is used in this paper to include family members, friends, educators, and other direct support professionals who may support people who have intellectual disabilities.

## ***Practice Settings and Continuum of Service:***

People with ID may live in a variety of settings, including: with a family or foster family, in a group-home, supported housing or long term care residence. Regardless of setting, the caregivers may have various levels of knowledge and skills to help individuals with ID.

For the paediatric population with intellectual disabilities, there are often requirements for support across both the school and community settings. This can result in concurrent services from more than one SLP; it is crucial that SLPs work together to ensure optimal support for clients (please refer to appropriate guidelines for concurrent care). Transitions between the early intervention, school-age, and adult sectors require strong coordination of services to ensure that clients and families have the support that they need.

Following discharge, caregivers and other professionals may be responsible for implementing the recommended treatment program. In consideration of the lifelong nature of ID and the prevalence of short-term consultative service models, people with ID may access services many times throughout their lifespan. Along with the challenges related to transitions between early intervention, school-age, and adult services, these factors result in a high rate of re-referral. The responsibility for initiating re-referral and seeking out support often falls on caregivers. Thus clinicians need to inform caregivers about referral processes.

## ***Access to Services:***

It is important for SLPs to advocate for the rights of people with ID to strive for their optimal level of communicative potential. Many people with ID may face barriers to speech language pathology services due to low numbers of SLPs working with this population, long wait-times, or criteria set by administrative policies of certain agencies. This can be a particular challenge for people living in rural areas (Canadian Institute for Health Information, 2007). It is also important to educate other professionals and the public regarding the scope of practice of speech language pathologists.

Regardless of the reasons for the limitation of services, individuals with ID should not be abandoned (CASLPO Ontario Regulation 749/93: Professional Misconduct, section 8). In the case where the employer or funding availability restricts service, the individuals and/or caregivers should be informed of other speech language pathology options (e.g. private practice). Clinicians are strongly encouraged to advocate for timely and coordinated access to service.

The participation of the person and his or her caregivers is important in planning and implementing communication programming in order to promote good treatment outcomes. Limited caregiver availability and/or participation can be a significant barrier to treatment success.

## ***Referrals:***

Speech language pathologists are autonomous professionals who can accept referrals from any source except when the agency of employment or legislation dictates a particular referral pathway (e.g. referrals from school principals, physicians, or other ministry organization). SLPs working with clients with ID are often screening clients for referral to other disciplines such as occupational therapy, behaviour therapy, hearing assessment, or medical services.

Referral for SLP assessment is indicated when it would be beneficial to have a better understanding of an individual's communication skill with respect to: their speech, language, literacy, social-pragmatic skills, voice, and resonance; when there is a change in the individual's communicative ability; and for dysphagia.

It has been noted that speech language pathology referrals for individuals with ID may not happen as often as is appropriate or required. Possible reasons are that caregivers can underestimate or over-estimate hearing ability, language understanding, and/or expressive language skills of people with intellectual disabilities (Purcell, Morris, & McConkey, 1999). In addition, many clients may have had previous services where little gain was achieved, leading to reluctance to re-refer. Such trials might have negatively affected perceptions about the efficacy of service as well as the client's ability to progress. It may be helpful to re-refer in light of new evidence, technology, and techniques for intervention. Even those who function at a very low, pre-intentional level, and/or those who may not be ready for a formal augmentative system, can benefit from intervention directed at the next step toward intentional, symbolic participation in activities and interactions (Beukelman & Miranda 2013; Bodine & Beukelman, 1991; Kangas & Lloyd, 1988; Ogletree, Bruce, Finch, Fahey, & McLean, 2001; Rainey & Mary, 2003).

### ***Consent:***

Prior to initiating services, consent must be obtained from either the person or their substitute decision-maker in accordance with relevant legislation, e.g. the Ontario Health Care Consent Act (1996) and Substitute Decisions Act (1992). The person's capacity to provide informed consent may be impacted by their insight and language skills and/or cognitive ability. In cases where the client is incapable of giving consent, it is important to try to involve others who know him or her best while respecting the highest ranked eligible person identified in the hierarchy with respect to relevant regulations or legislation.

Consent is an ongoing process. Speech language Pathologists must consider the person's competence to give informed consent throughout the assessment and treatment process. In addition, SLPs should make use of their skills in facilitating communication to enhance as much as possible the individual's comprehension for providing consent, for example using simplified language or visual supports (either custom-made for a client or published materials). In cases where the person cannot provide full informed consent, the SLP should be observant of the person's behaviour and participation, which may be indicators of their assent to treatment.

### ***Screening:***

SLPs may be involved in screening people with intellectual disabilities for referrals to speech, language, and swallowing services. Screening is often done by other professionals, such as agency intake workers or other members of an interdisciplinary team. The SLP has an important role to play in educating colleagues to ensure that appropriate referrals are made for SLP services.

People with ID often have language difficulties related to their cognitive functioning; as such, screening often involves determining whether the person wants to work on their communication skills or whether their caregivers would like support to maximize communication skills. Care must be taken to avoid determining eligibility for service based on previous intervention outcomes, cognitive limitations, discrepancies between cognitive and communicative functioning, or prerequisite skills (National Joint Committee for the Communication Needs of Persons with Severe Disabilities, 2003).

Screening for dysphagia and related eating difficulties is an important part of the care of people with ID as they have higher rates of dysphagia and may have atypical presentation compared to the general population (Chadwick & Jolliffe, 2009). It is critical that caregivers and other professionals are aware of the unique presentation of dysphagia in people with ID. See Appendix A for further discussion of dysphagia.

### ***Assessment:***

Assessment of communication in people with ID may be comprehensive or focussed depending on the desired goals for the service. In either case the process must include a thorough case history and assessment across environments and caregivers. Assessment may include standardized measures as well as informal assessment procedures, observation, evaluation of the environment and caregivers' skills in facilitating communication interactions. Often, the SLP may use standardized tools in a non-standard fashion, for example: using tests which are for a different age range, adding visual supports, and modifying test instructions. Assessment reports should include descriptions of performance and relate the information to the person's communicative competence in everyday environments.

Assessment may be interdisciplinary, particularly considering clients who may have challenging behaviours that serve a communicative function. SLPs should be prepared to work together with behavioural consultants in assessment of developmentally appropriate replacement skills for challenging behaviours. In addition, it should be recognized that information about broader communication issues such as hearing acuity, language comprehension and expression, and social skills can be vital in increasing participation, positive interactions, reducing communication breakdowns and in so doing, achieving lasting behavioural change.

Interpretation of the assessment results by a Speech Language Pathologist should provide a holistic picture of the individual's communicative functioning, nature of the impairment, limitations on activity, and participation. It should include influences of the environment and communication partners on the person's communication.

The SLP should be aware that assessment results pertaining to receptive language, understanding of consequences and choice-making may be used by other professionals in evaluation of capacity.



## ***Treatment:***

The National Joint Committee for the Communication Needs of Persons With Severe Disabilities (1992) states that the focus of intervention is to “establish communicative repertoires that permit persons with severe disabilities to act on their social environments to achieve their rights to live, play, and work in ways that meet their basic needs and preferences” (ASHA 2005a; Brown, Nietupski, & Hamre-Nietupski, 1976). Goals for treatment may include any areas of oral or written communication; social interaction; and, eating and swallowing function. Goals should be determined jointly by the clinician, person, and caregivers. Goals must be individualized, achievable, and have a meaningful impact on the client’s life participation. Many individuals with ID will have ongoing communication challenges; the interplay of ongoing needs and time-limited service models must be addressed when selecting appropriate goals and methods of treatment.

Treatment should incorporate building on the client’s strengths and remediating areas of weakness, and may take the form of direct therapy or mediator model services. Mediator model services may include: environmental modifications, collaboration with primary communication partners, and general or specific training. The person’s environment (activities, caregivers, materials, etc.) is important for successful communication and should be considered as a part of any intervention (National Joint Committee for the Communication Needs of Persons With Severe Disabilities 1992). Generalization of new skills can be a particular challenge for individuals with ID and should be a focus of any treatment program. Education and consultation for the individual, family and other care providers is also a crucial component of treatment, particularly in areas such as augmentative communication and cognitive communication disorders.

Augmentative and alternative communication (AAC) is a specialized area of intervention. It is important to note that AAC treatment is not limited to speech replacement but should incorporate any appropriate communication or literacy goals that the person may have. Treatment should also take into account the technical support and maintenance aspects of any AAC system.

## ***Treatment Efficacy:***

Speech language pathologists need to have knowledge of evidence-based practices and skills in applying these principles in intervention. Special consideration should be given to:

- Using meaningful interactive contexts (Halle, 1987; National Joint Committee for the Communication Needs of Persons With Severe Disabilities 1992; Prizant & Wetherby, 1998).
- Utilizing/teaching all modes of communication, e.g. verbal, gestural, graphic (Beukelman & Miranda, 1992; Murphy, Marková, Collins & Moodie, 1996).
- Providing training in everyday contexts, using a variety of methods (Kent-Walsh, Murza, Malani & Binger, 2015; Purcell, McConkey & Morris, 2000).
- Collaborating with families, other professionals and paraprofessionals (van der Gaag, 1998; Duchan, 1997; Girolametto, Sussman, & Weitzman, 2007; National Joint Committee for the Communication Needs of Persons With Severe Disabilities 1992).

SLPs are not typically provided with the time or resources to conduct large, well-controlled studies using group treatment designs. Additionally, there is difficulty in applying generic approaches with such a heterogeneous population. Literature that may not be specific to people with ID can provide valuable information for development of individualized treatment approaches. In the absence of research evidence, clinicians may need to develop novel approaches to treatment but should always ensure that outcomes are measured.

### ***Discharge Criteria/Planning:***

People with intellectual disabilities will most often have lifelong need for support in developing communication skills. Collaboration throughout the intervention process is key to discharge planning. If the goals reflect the issues most relevant to enhancing the person's quality of life, and were set in collaboration with the person and their caregivers, then discharge planning can flow naturally as part of discussions regarding service delivery.

Ideally, intervention should continue until the person and key communication partners have been provided with adequate follow-up to the assessment or treatment, and training to continue supporting the person's communication development without formal clinical support. People using alternative and augmentative communication systems will require specific instruction regarding development, maintenance and information regarding re-referral.

Reasons for lack of progress should be carefully investigated before discharge is considered. Inclusion of other clinicians or support providers to potentially improve therapeutic readiness could be considered in these cases. For example, resolution of psychiatric and/or medical problems may help a person to be more amenable to therapeutic communication intervention (Sullivan et al., 2011). Limited clinician skill level, the person's cognitive functioning level relative to communication abilities, diagnoses, age, or failure to benefit from previous services are not considered as adequate reasons for discharge (ASHA, 2005b).

When agency policies set criteria for discharge before it is clinically advisable, or before all that could be done has been accomplished, the SLP should provide as much information as possible regarding other treatment options, including private and community services. The SLP should also identify any other professional services that might be appropriate and make recommendations for future intervention needs. As much as possible, the SLP should continue to advocate for services when clinical indications are present.

Discharge may be the appropriate action when the person or the substitute decision maker declines service, there is limited follow-through on recommendations, or the person transfers to another service or moves. If this is the case, risks and options for the best strategies under the circumstances should be clearly explained and documented.

## ***Reporting Requirements:***

The complexity and long-term nature of intellectual disabilities necessitate special consideration when documenting. Detailed reports can be of significant assistance in making accurate diagnostic and treatment decisions over the lifespan. For example, accurate comparison of testing and sample analysis could help to determine if functional decline is part of a biological degeneration or the result of acute health or environmental issues. Clinical records could also assist in gaining additional history for individuals who have experienced frequent changes in care providers and residential placements.

When preparing reports and documenting intervention plans, information should be written in a format that is easily understood by all those who provide care and support to the person and, where possible, to the client. Visual tools such as picture displays or video modeling are recommended as means of helping the person being supported to understand and be included in the decision making process. These tools can also assist the family and care providers in understanding of treatment recommendations and thus promote adherence both during and after professional involvement.

The relevance of communication delays and disorders to health, sensorimotor integration, social-emotional and behavioural issues should be explained and recorded as this facilitates integrated, interdisciplinary service for people with complex needs.

For further detail regarding reporting requirements please see relevant legislation and regulations (e.g. CASLPO, 2015-b).

## ***Clinical Competencies:***

Clinicians must “practice within the limits of their competence as determined by education, training and professional experience” (CASLPO’s Code of Ethics, 2011). This presents a particular challenge since the needs of this population are complex, evidence-based research is minimal, and standardized tests and treatment materials are limited (Lennox et al., 2005; Snell et al., 2010; U.S. Public Health Service, 2001). Because it would not be ethical to provide less service to those with ID than to the general population, it is incumbent upon the SLP to seek appropriate training and/or mentoring or refer to another SLP or agency with the resources and experience needed to ensure equitable access to effective intervention.

Specific knowledge related to the following issues is required:

- Causes and implications of specific disabilities and disorders;
- Impact of multiple disabilities;
- The relevance of health and sensorimotor issues to communication, feeding and swallowing disorders;
- Psychological and psychiatric diagnoses and characteristics of people with ID (i.e. dual diagnosis);

- Awareness of the interplay between communication skills and challenging behaviours;
- Impact of environmental conditions on speech, language, hearing, and swallowing;
- Medications and side effects on speech, language, hearing, eating and swallowing and behaviour;
- Appreciation of the social issues which may impact a person's communication and participation (e.g. social isolation, misperceptions regarding the skills and abilities of people with ID, etc.);
- Knowledge of the developmental services sector and how to help the person and/or their caregivers exercise rights, access services, and make appropriate referrals in a timely manner; and,
- Awareness and training related to possible safety risks such as: self-injury, aggression, wandering.

### ***Resource Requirements:***

- Forms and materials for non-standardized/qualitative assessment procedures (e.g., checklists, questionnaires, etc.).
- Access to technology for assessment and treatment:
  - Display making software (e.g. SymbolStix®, Boardmaker®, Pixon™)
  - Low tech (e.g. Tech/Talk, GoTalk, BIGmack® Communicator)
  - High tech (e.g. iPad with assessment and therapeutic applications)
  - Video and/or audio recording equipment (e.g. for caregiver training).
- Capacity to conduct community visits in order to assess/treat/consult in client's everyday environments.
- Environments that may be controlled with respect to sensory distractions, physical comfort and physical access.
- Ability to access evidence-based practice information and the time to research & plan individualized programming as needed.

### ***Moving Forward:***

All people with intellectual disability (ID) communicate in some way, even if unintentionally. As SLPs, we understand the importance of life-long learning and the ability to make changes at any stage in one's life, no matter the person's level of functioning. We strive to identify ways to help someone with ID reveal their thoughts, dreams, choices, and interests and to not let limitations in conventional communication skills be a barrier. However, in preparing this document, it became clear that there is insufficient research in the field of intellectual disabilities, in particular for adults with ID. In moving forward, it is hoped that this document serves as a support for SLPs new to the area of intellectual disabilities, but that more and more SLPs take it upon themselves to initiate research to help further promote this extremely rewarding area of practice.

## Appendix A: ID and DYSPHAGIA

It is important to ensure that people with intellectual disability are able to access dysphagia services. Estimates of the prevalence of dysphagia in the ID population vary; for example Chadwick and Jolliffe (2009) estimate 8.15%, while Sheppard & Hochman (1989; cited in Sheppard, 2006) report that up to 49% of adults with ID required specialized eating and swallowing services. Within the ID population, certain subgroups have increased prevalence of dysphagia, for instance the prevalence of dysphagia increases with severity of co-morbid physical disabilities (Sheppard & Hochman, 1989; cited in Sheppard, 2006). As a result, SLPs may regularly have people with ID on their caseload for dysphagia assessment and treatment. There are special considerations that need to be taken into account to ensure best practice is in place. Below are recommendations compiled from a variety of sources in guiding dysphagia assessment and treatment for the population of people with an intellectual disability. The information outlined below should be used in conjunction with relevant regulations and guidelines regarding dysphagia management.

### ***Determination of Need:***

The determination of need is similar to that of the general population; however, additional health factors should be taken into consideration (Jolliffe & Chadwick, 2006).

These include:

- seizure activity;
- oral health issues;
- underlying respiratory problems;
- digestive issues (e.g., gastro-esophageal reflux, allergies, food sensitivities);
- physical disabilities (e.g. postural differences, muscle tone, oral structure anomalies);
- sensory differences;
- unmanaged pain (as this can distract from the eating task);
- dual diagnosis (intellectual disability with a mental health diagnosis); and,
- medication effects.

People with ID may not be able to recognize health and safety aspects of eating and drinking such as volume, temperature, rate of eating, and presence of inedibles (Jolliffe & Chadwick, 2006). Signs and symptoms of dysphagia may not be as overt as in the typical population and individuals with ID are much less likely to self-identify or be identified by support personnel as having swallowing issues (Migliore, Scoopo, & Robey, 1999). Therefore, education plays an important role in a community setting to help caregivers identify warning signs of swallowing impairment. Caregivers may also benefit from training in general safe swallowing procedures and how to follow care plans. It can be difficult to differentiate between challenging mealtime behaviours and a genuine feeding or swallowing problem; thorough assessment of oro-pharyngeal structures and function is recommended.

Guidelines for determining candidacy for Modified Barium Swallow Studies (MBSS), also known as videofluoroscopic swallow studies, in the typical population should be considered. However, it is important to note that certain groups within the ID population (for example: children, people with Down syndrome [Frazier & Friedman, 1996] and cerebral palsy [Rogers, Arvedson, Buck, Smart, & Msall, 1994-a]) have increased prevalence of silent aspiration compared to the general population (Rogers et al., 1994-b). Respiratory diseases, often linked to aspiration, are the second most common cause of death in patients with ID according to Patja, Molsä and Livanainen (2001). Heslop and al. (2014) estimate respiratory illness related to aspiration to be the third leading cause of death for people with intellectual disability.

### ***Assessment:***

The SLP should be prepared for deviations in the typical swallowing assessment protocols. A variety of factors, such as comprehension difficulties or behavioural challenges, may impact on assessment procedures including oral-mechanism exam, oral (per os [PO]) trials, difficulty trialing positions, maneuvers, or equipment. Bedside assessment of swallowing for individuals with ID may rely more heavily on caregiver report than in the typical population. Collecting screening information and sufficient data before the assessment may provide valuable information to support the assessment.

For people with ID undergoing an MBSS, the radiologist and technicians should be advised regarding special considerations or challenges that may occur during the procedure. Preplanning may include: allotting extra time, creating and using social stories about the assessment, attempting to address anxiety and/or impulse control in collaboration with caregivers, and brainstorming ways to combat refusal.

Examples of key points to consider in striving for the most optimal clinical or radiological exam are: asking if the caregiver who brought the person to the appointment is familiar with typical meals and able to explain the current observations; and attempting to simulate the natural environment as much as possible, e.g., seating, utensils, and dishes.

### ***Treatment:***

It is important to ensure that recommendations are presented in ways that are accessible to the person with ID and their caregivers, for example simple language, and visuals such as demonstration videos, graphic displays, and social stories. As with treatment of communication disorders, people with ID may have decreased insight into their feeding and swallowing, difficulties with generalization, etc. and may therefore benefit from intervention which involves caregiver training and environmental modifications. It may be helpful to collect data on the effectiveness of strategies being implemented.

### ***Collaboration Requirements:***

The need for team collaboration is especially important when working with people with ID in dysphagia assessment and treatment. SLPs should strive to identify and share information between acute and community settings. Depending on equipment requirements and agency policies, hospital and community SLPs may share the process of assessment and treatment; collaboration between the two groups of clinicians is crucial to ensuring a smooth continuum of care and should be done in such a way that it promotes the patient's best interest (CASLPO, 2015-a).

The physician's role in dysphagia assessment and treatment is integral. Scope of practice for family doctors indicates annual counselling for patients about nutrition and physical activity, promotion of dental health through regular oral hygiene practices, and screening for dysphagia and aspiration in patients with ID and neuromuscular dysfunction (Sullivan et al., 2011).

In order to meet the needs of a diverse population SLPs may need to advocate for additional services including dietitians, occupational therapists, behaviour therapists, etc.

### ***Discharge Criteria:***

Discharge is indicated once treatment is completed and the person and/or caregivers demonstrate understanding and competence in managing the eating and swallowing difficulties. Provisions will need to be made for the training of new staff in residential care settings, as a high rate of turn-over of caregivers may present ongoing challenges with following through on recommendations and implementing safe swallowing strategies.

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