

Improving Lives: The Work, Health and Disability Green Paper Consultation

A Profession Specific Response from the Royal College of Speech and Language Therapists

Developed by the Royal College of Speech and Language Therapists Advisory Group for Work and Health

February 2017

The Royal College of Speech and Language Therapists

The Royal College of Speech and Language Therapists with up to 17,000 members is the professional body for speech and language therapists, speech and language therapy students and support workers working in the UK.

We facilitate and promote research into the field of speech and language therapy, promote better education and training of speech and language therapists and provide information for our members and the public about speech and language therapy.

Work and Health

The RCSLT welcomes the initiative to develop the Work and Health Programme as a cohesive support system for people managing health conditions at work and those with disabilities accessing work in the first instance

However whilst there is an emphasis on personalised support for both physical and mental health conditions, there is no acknowledgement of communication disability, which could cause a significant barrier to accessing work support services unless this aspect was addressed during the design process.

Communication disability affects a diverse group of people of working age. Examples include some people with Autism, Learning Disability, Cerebral Palsy, Developmental Language Disorder, Stammer, Hearing Impairment as well as acquired chronic conditions such as Stroke, Parkinson's disease, Multiple Sclerosis, Head and neck cancer; and acute conditions such as Voice loss.

While musculoskeletal disorders are wide ranging with instances that may require speech and language therapy for rehabilitation, there is a very high incidence and prevalence of speech, language problems associated mental illness.

People with mental health conditions may have difficulties concentrating and / or understanding spoken or verbal communication and / or difficulties expressing clearly complex thoughts, feelings and information pertaining to past or future events – either verbally or in writing. The impact of common mental health conditions include depleted confidence in interacting effectively with others.

For the reasons given above it is crucial that all services which aim to provide access to welfare (in and out of work), support people into work, back in to the work place and / or retain people in the workforce mainstream quality inclusive communication approaches throughout their procedures. For example all information on services must be communication accessible to the broadest population and front line staff should be trained and provided with resources to be able to identify and adapt their own communication to the needs of people with speech, language and communication support needs. More information on quality Inclusive Communication approaches to service provision (at the level of the individual; setting and organisation) can be found at:

https://www.rcslt.org/cq_live/resources_a_z/inclusive_communication/overview.

Speech and Language Therapists on a day to day basis advise and support many organisations to mainstream inclusive communication approaches. RCSLT would welcome the opportunity to advise the Work and Health Unit on how mainstreaming inclusive communication throughout welfare and employment services could be taken forward.

Our response has been developed by an expert group of speech and language therapists covering a range of specialist areas. The response was formed around the key questions that were posed across the six chapters in the Green Paper and should be read as such.

Chapter 1: Tackling a significant inequality – the case for action

What innovative and evidence-based support are you already delivering to improve health and employment outcomes for people in your community which you think could be replicated at scale? What evidence sources did you draw on when making your investment decision?

Members of the Royal College of Speech and Language Therapists have embraced various innovative practices, enabling the provision of effective support to individuals with both acquired and developmental speech, language and communication needs:

Community Based Interventions

Community based health interventions have been utilised to support and enable individuals with aphasia (an acquired, multi-modal language disorder resulting from neurological damage that may affect a person's ability to talk, write and understand spoken and written language, leaving other cognitive abilities intact); as a result of stroke to return to employment.

The "Back to work" project that was initially conceived in the North East as part of the Communication Hub for Aphasia (communication impairment) in North Tyneside (CHANT) initiative is a key example of this.

The CHANT initiative was a time limited project funded in North Tyneside with the specific local authority Stroke Service monies ring-fenced by government in 2008-11 and lead by a speech and language therapist employed at the time by the NHS. The aim of this project was to support people with aphasia and their carers through a combination of direct contact (based on a structured programme of real-life goal setting), provision of information and a bridge to other services, as well as indirect support via training of other key people in the immediate environment about communication access and aphasia.

The direct intervention involved individual quality of life assessments and self-assessment using patient reported outcome measures based on a framework developed for people with communication impairments (the A-FROM). Intervention, including goal-setting, took place in groups; where people were restricted physically (or emotionally) in their ability to engage in groups, individual sessions were offered. The direct support from CHANT staff was supplemented by volunteers recruited to the project under the auspices of the Stroke Association and trained by the CHANT staff in collaboration with 'expert patients' with aphasia.

The initiative found that individuals with aphasia made significant gains in quality of life (in particular, in communication and psychosocial adjustment to stroke) and self-report measures of change. A total of 82% of real-life goals set as part of intervention were fully or partially achieved at follow-up. Five core themes emerged from the narratives: 'Quality of life', 'Barriers', 'Facilitators', 'Types of CHANT activity' and 'Effectiveness'.

Additionally there was a collaboration with Connect (the communication disability charity) during the project to scope the specific needs of those returning to work and investigate the support in employment contexts (the Back to Work project), which was also documented in a separate report and included development of a program of communication access training suitable for potential employers or job coaches.

The findings from CHANT provide the foundations for further work into long-term recovery, intervention and adjustment to aphasia post-stroke, and the principles have potential to be applied in other contexts.

Key Evidence:

- Back to work: Returning to work after stroke and aphasia A collaborative project between Connect and CHANT February 2010
- Mumby, K., & Whitworth, A. (2012). Evaluating the effectiveness of intervention in long term aphasia post stroke: the experience from CHANT (Communication Hub for Aphasia in North Tyneside). International Journal of Language and Communication Disorders, 47(4), 398-412.
- Mumby, K., & Whitworth, A. (2013). Adjustment processes in chronic aphasia after stroke: Exploring multiple perspectives in the context of a community based intervention. Aphasiology, 27 (4), 462-489.

Work Based Interventions

Speech and language therapist (SLT) input as part of vocational rehabilitation allowing greater support to individuals that have suffered from brain injury, allowing return to work. This has been delivered largely as part of as multidisciplinary approach through groups specifically aimed at return to work.

SLT time has also been used to both shadow individuals in work places in order to assess their day to day interactions alongside their work based responsibilities, but also to provide support to individuals in situations where they would be required to communicate clearly such as meetings with management.

The potential for integrating acquired brain injury clients in to the workplace and contribute in a meaningful way is significant. Educating employers and supporting clients to advocate for themselves through developing 'understanding my brain injury' projects to be shared in the workplace has allowed the development of a shared understanding of the workplace challenges from both perspectives leading to much more successful outcomes.

The programme Traumatic Brain Injury (TBI) Express is one example of a programme teaching communication partners (which may include employers or co-workers) - the best ways of interaction with individuals with communication challenges following TBI – how to provide the scaffolding and structure to allow them to best function.

Assessment findings to pre-empt work situations that might be challenging and using these as a basis for interventions along with input from the employer is a useful way of working. As Douglas et al (2015) suggest indicators on the La Trobe questionnaire (a questionnaire designed to measure perceived communicative ability that assesses communication ability based on information gathered from the patient and close others) correlate with successful work outcomes for people with TBI; this can therefore be used as a basis for interventions.

There are plenty of clinicians with case examples of successful and innovative interventions that have proved successful for work reintegration.

Key Evidence:

 Douglas, J., Bracy, C., & Snow, P. (2015) Return to Work and Social Communication Ability following Severe Traumatic Brain Injury. Journal of Speech, Language, and Hearing Research

- Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (online, 2013). Training communication partners of people with traumatic brain injury improves everyday interactions: A multicenter single blind clinical trial. Journal of Rehabilitation Medicine, 45(7)
- 'Back to work: Returning to work after stroke and aphasia A collaborative project between Connect and CHANT' February 2010

Assistive Technologies / Augmentative and Alternative Communication

Through NHS England's Specialised Commissioning for Rehabilitation and Disability (funding commenced April 2013 - NHS England, 2016), access to assistive technologies has been made available. These include both Environmental controls and Augmentative and Alternative Communication (or AAC).

Environmental controls include technologies enabling individuals who are physically unable to control their immediate environments; such as allowing access to phones or enabling the use of a computer. AAC involves techniques and communication aids that enable people to use technology to communicate with others.

AAC funding is available for specialist assessment and provision provided by fifteen specialist centres across England. Individuals may require assistive technologies as a result of numerous acquired and developmental conditions including stroke, multiple sclerosis, cerebral palsy, motor neurone disease or Parkinson's disease, which can affect speech and language but also physical access to their immediate environments. In the context of employment, assistive technologies and communication aids enable individuals to communicate and interact with both colleagues and clients at work, effective access to information technology (for example the ability to write emails and produce documentation).

There is robust data of the prevalence or incidence of communication impairment in the population, and the proportion of this population who may benefit from the use of AAC techniques and equipment. The OCC Report however suggests there would be a significant level of under-reporting of need if prevalence was based on existing service provision figures.

Recent work has been undertaken to estimate the actual level of need:

- Enderby, Pam, et al. "Examining the need for, and provision of, AAC in the United Kingdom." (2013): 1-168.
- Scope (2007) suggests that between 0.4 and 1% of the population would benefit from AAC and the figure of 0.6% of the population is the most commonly quoted.
- Blackstone (2007) refers to 0.4-0.6% of the population requiring AAC based on international evidence.
- The mid-2009 population of England was 51,809,7008 which would indicate that there were 310,858 people in England who would benefit from AAC of whom 74,330 were 19 or under and 236,533 were 20 years of age or over.

It is likely that these figures will increase as the numbers of adults in the population living with a long term condition increase and as the survival rate improves for children born with complex disabilities.

Key Evidence:

• Enderby, Pam, et al. "Examining the need for, and provision of, AAC in the United Kingdom." (2013): 1-168.

- Blackstone, S. (1990) Populations and Practices in AAC Augmentative Communication News Vol. 3 No.4
- NHS England (2016) Guidance for commissioning AAC services and equipment NHS England NHS England, London.
- Scope (2007) 'Communication Aid Provision: A Review of the Literature' SCOPE: London
- NICE clinical guideline for multiple sclerosis (2010) 19
 - "...any person with Multiple Sclerosis who cannot communicate effectively should be assessed by a specialist Speech and Language Therapist for an augmentative aid to communication, which should then be provided as soon as possible".
- NICE clinical guidelines for Parkinson's Disease (2006) 20

Speech and language therapy should ensure 'an effective means of communication is maintained throughout the course of the disease, including use of assistive technologies'.

• The National Service Framework for People with Long-term Neurological Conditions 22

'People with long-term neurological conditions are to receive timely, appropriate assistive technology/ equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health, and improve their quality of life' and to 'access to integrated community and specialist assistive technology/ equipment services' and to 'specific arrangements for joint funding of specialist assistive technology provision' (e.g. communication aids..)'.

• NICE Guidelines Motor Neurone Disease (2016) Healthcare professionals and social care practitioners should:

- Ensure that the assessment and review is carried out by a speech and language therapist without delay.
- Provide AAC and EC equipment that meets the needs of the person without delay to maximise participation in activities of daily living and maintain quality of life. Discuss face-to-face and remote communication, for example, using the telephone, email, the Internet and social media.
- Liaise with, or refer the person with MND to, a specialised NHS AAC hub if complex high technology AAC equipment (for example, eye gaze access) is needed or is likely to be needed.
- Ensure regular, ongoing monitoring of the person's communication needs and abilities as MND progresses, and review their ability to use AAC equipment.

Innovative treatments

Evidence based speech treatment such as Lee Silverman Voice Treatment (LSVT) and computer interventions to improve communications skills if those with Parkinson's disease (for example), with speech that has become quiet and mumbled as an effect of the disease.

LSVT is a 4 week intensive course enables them to return to normal speech levels tailored to their own voice use and thus remain at work in jobs such as teaching, phone contact, meetings or customer facing responsibilities.

Key Evidence:

- Sackley, Catherine M., et al. "Lee Silverman voice treatment versus standard NHS speech and language therapy versus control in Parkinson's disease (PD COMM pilot): study protocol for a randomized controlled trial." *Trials* 15.1 (2014): 213.
- Palmer, Rebecca, et al. "Clinical and cost effectiveness of computer treatment for aphasia post stroke (Big CACTUS): study protocol for a randomised controlled trial." *Trials* 16.1 (2015): 18.
- Ramig et al (1996) Intensive speech treatment for patients with Parkinson Disease. Neurology 47; 1496-1504
- Ramig, Sapir et al (2001) Intensive Voice treatment (LSVT) for patients with Parkinson Disease: a 2 year follow up
- Journal of Neurology, Neurosurgery and Psychiatry, 71:493-498 Liotti, Ramig et al (2003)
- Hypophonia in Parkinson Disease: neural correlates of voice treatment revealed by PET Neurology 60:432-440

What evidence gaps have you identified in your local area in relation to supporting disabled people or people with long-term health conditions? Are there particular gaps that a Challenge Fund approach could most successfully respond to?

Evidence Base for Speech, Language and Communication Needs

There is a lack of information about the scale of the needs of people with speech, language and communication needs (and in addition those who have communication impairment as part of cognitive impairment).

While musculoskeletal disorders are wide ranging with instances that may require speech and language therapy for rehabilitation, there is a high incidence and prevalence of speech, language and swallowing problems associated with mental health in both children and adults.

People with mental health conditions may have difficulties concentrating and / or understanding spoken or verbal communication and / or difficulties expressing clearly complex thoughts, feelings and information pertaining to past or future events - either verbally or in writing. The impact of common mental health conditions include depleted confidence in interacting effectively with others.

For the reasons given above it is crucial that all services which aim to provide access to welfare (in and out of work), support people into work, back in to the work place and / or retain people in the workforce mainstream quality inclusive communication approaches throughout their procedures.

Supporting Employers: Phased Returns to Work

Many of our members provide support to their clients as they seek to return to employment namely through phased returns. These are largely through volunteer programmes and placements; however these opportunities are scarce as they are simply not viable for many employers as many are unable to provide the necessary work place support for such individuals.

The challenge fund may enable a programme of support or finance should be in place to enable employers to allow them to provide such opportunities alongside other return to work funded schemes currently available.

Assistive Technologies in the workplace

Although the benefits of assistive technologies such as AAC are apparent and there is clear evidence of this as outlined above, there is little workplace specific evidence of the application of AAC.

The challenge fund may address the clear deficiency in the technological support provided to individuals that have specialist equipment required for work to enable communication or environmental control (such as the use of a computer), finance for which may be provided through the challenge fund.

Service Provision in the NHS

Research of current service provision is necessary to demonstrate the consequences of pressures on acute services in the NHS, which have been taking priority over long term resourcing in Outpatients and the Community. We would encourage funding to be diverted to the NHS to alleviate pressures on acute services which may include the delivery of treatments such a LSVT.

Supporting Individuals on the Autistic Spectrum

Mentoring and help for employers who are managing and supporting employees who have Autism Spectrum Disorder (ASD) into work - in particular an understanding of the benefit of routine, clarity of communication and the challenge of the unpredictable for many people who are on the autistic spectrum.

Although the Autism Act 2009 (with its updated statutory guidance of 2015) makes statutory provision for public sector organisations to increase their awareness around autism, this challenge needs to be taken into smaller, less resourced employment environments.

The Challenge fund could be used to help managers of small or medium sized enterprises to support their employees who have ASD - developing innovative and practical communication plans developed with the person and the manager and potentially a third party communication mentor / SLT resource. The key to success would be its flexibility and responsiveness to the tangible communication issues on the ground, in the workplace.

How should we develop, structure and communicate the evidence base to influence commissioning decisions?

Our view is that joint there should be joint commissioning for the purposes of work and Health (such as is through the commissioning joint committee) including both NHS Social care and the Department of Work and Pensions.

There needs to be joined up so that inter-agency cost savings can be identified. Prevention of depression for example not only saves the NHS money but also enables individuals to be much more independent and fulfil a role in society, costing less in benefits or potentially enabling them to be earners.

The changing demands of the workplace should also be considered, particularly in the context of mechanisation replacing manual work and increasing emphasis on management and communication skills, both verbal and information technology use. For example, there is now significant evidence of the effects of vocal strain on call centre employees.

Key Evidence:

Hazlett, D. E., O. M. Duffy, and S. A. Moorhead. "Occupational voice demands and their impact on the call-centre industry." BMC Public Health 9.1 (2009): 108.

Chapter 2: Supporting people into work

Building work coach capability

How do we ensure that Jobcentres can support the provision of the right personal support at the right time for individuals?

There is little evidence of the practical adaptation and reasonable adjustment in communication approaches by the jobcentre staff where the person has a communication impairment which may be linked to a cognitive impairment. Under the Equality Act 2010, all public sector organisations, including employers and providers of services, are required to make reasonable adjustments to services with the aim of ensuring they are accessible to disabled people, including people with speech, language and communication needs (including cognitive impairments such as autism).

Our view is that jobcentre staff should receive communication access training. With effective training, they would have a greater awareness of speech, communication and language allowing them to identify instances where they may need to vary their communication methods. This would enable Jobcentre staff to engage much more effective with individuals seeking support, enabling greater engagement and the provision of a much personalised support system.

What specialist tools or support should we provide to work coaches to help them work with disabled people and people with health conditions?

<u>Informing and Profiling Augmentative and Alternative Communication (AAC)</u> Knowledge and skills

Basic training in assistive technology features for disabled individuals such as accessibility features on Windows or Apple software is available via Informing and Profiling Augmentative and Alternative Communication (AAC) Knowledge and skills (IPAACKS). This is a framework which helps to support the learning and skills of individuals working with individuals who use AAC.

Reference:

• IPAACKS: http://www.nes.scot.nhs.uk/media/2507407/nesd0214aacframework-re.pdf

A greater awareness and knowledge of the assistive technology services available to them in their area that they may refer individuals to; this may include their local environmental controls service for computer access or access to environment, or access to their nearest AAC service for access to a communication aid.

The Back to Work Toolkit

The 'Back to work' toolkit which was developed as part of the CHANT / CONNECT project, to educate potential employers or voluntary organisations about communication access and aphasia may be used to train jobcentre staff.

Reference:

 'Back to work: Returning to work after stroke and aphasia A collaborative project between Connect and CHANT' February 2010

Supporting people into work

What support should we offer to help those 'in work' stay in work and progress?

The Allied Health Professional Fitness to Work Advisory Report

We would recommend the use of the "Allied Health Professions Fitness to Work Advisory Report." This is a formalised and nationally recognised structured method of reporting and is appropriate for physical or mental health related, work-related issues which would include communication needs.

The report is designed to help employers and GPs understand workplace adaptations required, to be agreed between employers, managers and the employee to enable them to remain engaged with or return to work. It is designed to be clearly recognisable and easily read, with contact details for employers to follow up recommendations with practitioners if necessary.

Reference:

• http://www.ahpf.org.uk/AHP_Advisory_Fitness_for_Work_Report.htm

The Employers Stammering Network

The Employers Stammering Network is a group of employers committed to creating a culture where people who stammer can achieve their full career potential. Existing members employ 1.5 million people. Employees who stammer play a leading role in the Network.

Reference:

• https://www.stammering.org/help-information/professionals-and-business/businesses/unlocking-talent-employers-stammering-network

Peer Support

In terms of aphasia and cognitive communication disorders post head-injury, peer support is a crucial ingredient to avoid negative consequences such as experiences of bullying and harassment.

Direct contact with employing organisations to provide information and training would avoid the onus being on those with communication impairment having to educate those in the work environment about modifications required for them to access their employment ('communication ramps')

Key Evidence:

• Pearl, G. Sage K. and Young. A (2011) Involvement in volunteering: an exploration of the personal experience of people with aphasia Disability and Rehabilitation, 33(19–20): 1805–1821

Improving access to employment support

Should we offer targeted health and employment support to individuals in the Support Group, and Universal Credit equivalent, where appropriate?

What type of support might be most effective and who should provide this?

How might the voluntary sector and local partners be able to help this group?

We agree with the Work and Health programme recommendation of personalised, tailored, practical employment support.

Communication support should however be included as part of the core element of any support package as many of those eligible to receive support through the support group as they may also have a communication disability alongside other conditions. We would as such strongly recommend investment in a dedicated speech and language therapist resource.

The CHANT project as outlined above was particularly robust and we would therefore recommend adoption of that model; which demonstrated an integrated approach between the NHS, Social Services and 3rd Sector organisations to provide evidence based Health interventions with work related.

Key Evidence:

- Douglas, J., Bracy, C., & Snow, P. (2015) Return to Work and Social Communication Ability following Severe Traumatic Brain Injury. Journal of Speech, Language, and Hearing Research
- Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (online, 2013). Training communication partners of people with traumatic brain injury improves everyday interactions: A multicenter single blind clinical trial. Journal of Rehabilitation Medicine, 45(7)
- 'Back to work: Returning to work after stroke and aphasia A collaborative project between Connect and CHANT' February 2010

How can we best maintain contact with people in the Support Group to ensure no-one is written off?

We would recommend a much more personalised form of contact; to reflect the tailored support that will be provided to participants of the support group. Each participant of the support group should be assessed as to determine the frequency of face to face contact while other forms of contact is also adopted and readily utilised. This may include regular phone calls or even video calls via the internet. Depending on their condition and skillset, some individual's people may also require home visits.

Chapter 3: Assessments for benefits for people with health conditions

Should the assessment for the financial support an individual receives from the system be separate from the discussion a claimant has about employment or health support?

A key risk here would be the potential delineation of responsibilities across agencies; this may lead to information compiled by one agency to be considered or reviewed at a later date by another, each with a difference of priorities which may lead to inconsistencies in accounts. A joined-up approach (i.e. healthcare support and financial support) would ensure that a much more robust and sustainable plan is developed.

This discussion should be about what is realistic to expect of the claimant and this must be predicated on a clear understanding of the impact that conditions such as communication impairments can have (and its implication for employment sustainability). Often individuals may feel pressured into return to work too early due to financial pressures and ultimately this fails and ends up adding to the financial costs. A joint assessment will help ensure the right decisions are made about timing of return to work and at what level which ultimately will be more successful and cost effective.

There is a need for joined-up assessment that considers the individual as a whole. Claimants with communication disabilities such as aphasia would be unable to clearly communicate explanations or background to assessors to enable them to make connections between separate assessments. As highlighted by the Cochrane Review, self-management (though advocated for long term conditions) is much harder for people with communication impairment (as a result of stroke for example):

'Supported self-management improves quality of life and self-belief after stroke Training people to take an active role in managing the consequences of their stroke improves their quality of life.

These self-management programmes are usually led by health professionals. They cover a range of skills including problem solving, goal setting, and decision-making and provide advice about stroke. The improvement appears to act through "self-belief". For example, promoting independence in people appeared to foster a greater belief in their own abilities. This Cochrane review pooled data from 14 trials comparing supported self-management with control interventions in people who had experienced a stroke one month to a year previously and lived in the community. Participants varied in their level of disability after stroke.

These findings from a well conducted review support the principles that people with stroke should take an active role in their on-going care and receive training in how to manage everyday activities.

Further research is needed to determine the ideal format, duration and frequency of self-management sessions. The cost effectiveness of self-management also needs to be assessed.'

It is essential that the two areas are looked at together; coordination of financial support and assessment of work capacity is required to ensure that workers with financial need do not return to employment before they are ready and able which may be further to chronic illnesses (including stroke or head injury), then fail at the workplace and subsequently fall out of work on a long term basis.

Key Evidence:

• Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self-management programmes for quality of life in people with stroke. Cochrane Database Syst Rev. 2016:8:CD010442

How can we ensure that each claimant is matched to a personalised and tailored employment-related support offer?

We would recommend the use of client profiles that highlight communication and linguistic ability, while ensuring that the assigned officer has relevant training pertaining to an awareness of health issues.

This should include an awareness of communication need and the appropriate training of communication access enabling them to communicate appropriately and effectively.

The training needs to hold an understandable narrative of the effects of communication disability – officers should be able visualise concrete, simple examples of how communication impairment would change every moment of human interaction in the day.

Communication access involves presenting written materials in an aphasia-friendly way, for example, and this has been well-researched.

Key Evidence:

• International Journal of Speech-Language Pathology, 2012; 14(1): 11–23 Guiding principles for printed education materials: Design preferences of people with aphasia TANYA A. ROSE 1,2, LINDA E. WORRALL 1,2, LOUISE M. HICKSON 2 & TAMMY C. HOFFMANN 2,3

What other alternatives could we explore to improve the system for assessing financial support?

Consideration should be given to the accessibility of the system as a whole: individuals with communication difficulties may not be able to access a telephone service, and if they also have physical difficulties (conditions such as Motor Neurone Disease or Musculoskeletal - where they may have both communication and physical difficulties) they may have difficulties accessing a computer for online applications. These individuals need to be given the option of assistance, whether it is through a third party intermediary, a carer or even a relative to complete an assessment; they may also require home visits for face to face elements of assessments due to co-morbidities and the need to gain a whole-person picture.

We would also recommend a continuity of officer, and/or location for assessment would be helpful for the individuals on the autism spectrum. Some predictability and structure for this would be helpful.

The complexity of language used in the application process should be considered primarily, including specialist vocabulary and the length of the format of applications forms or assessment, which may be barriers for people who have communication impairments or concentration problems. Where possible plain English should be used and information should be presented in an accessible format. Both the Royal College of Speech and Language Therapists 5 good communication standard and principle of inclusive communications can be readily applied here.

Key Evidence:

• https://www.rcslt.org/cq_live/resources_a_z/inclusive_communication/overview

https://www.rcslt.org/members/docs/5_good_comms_standards_easy_read

How might we share evidence between assessments, including between Employment and Support Allowance/Universal Credit and Personal Independence Payments to help the Department for Work and Pensions benefit decision makers and reduce burdens on claimants? What benefits and challenges would this bring?

We would recommend the adaptation of an information sharing agreements between organisations, this would alleviate the burden upon claimants with potentially severe conditions to provide evidence.

For claimants, we would recommend simple printed summaries (see communication access standards above) but also the option for people to specify their preferred methods of communication (email, phone, letter, braille, audio file etc.).

Greater accessibility of information across organisations as well as to claimants, in a format that they would be able to fully understand and appreciate; invariably would reduce anxiety and depression amongst claimants whilst encouraging engagement.

There is however potential for a cost implication as well as the need for training amongst administrators.

Building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing financial support for this group?

As often reports can be misunderstood, the seriousness of the situation be underestimated and the specific impact not fully taken into account, we would encourage the provision of specialist assessors and assessments with appropriate support to this particular group, rather than traditional (catch-all) assessors would ensure greater understanding and support to their individual conditions and the provision of a bespoke support system.

We would also encourage the involvement of health professionals such as speech and language therapists to accommodate the potential communication needs of an individual; this support may not be directly to individuals but may be delivered in consultation with traditional assessors.

Chapter 4: Supporting employers to recruit with confidence and create healthy workplaces

Embedding good practices and supportive cultures

What are the key barriers preventing employers of all sizes and sectors recruiting and retaining the talent of disabled people and people with health conditions?

What expectation should there be on employers to recruit or retain disabled people and people with health conditions?

There is an understandable reticence on the part of the (potential) employee about sharing information which s/he might perceive could make him/her less employable, more needy of support, more "expensive" to the employer. This runs counter to the tide of disability legislation, which prioritises "reasonable adaptation" (e.g. with communication approaches) as a legal right. Greater openness about how to help employees with communication difficulties and a boosting of the national conversation about this- would help employers understand some of the issues that underlie the difficulties that their employees with a disability experience.

Although we do feel that an employer may take a number of practical steps to recruit and retain talent from amongst individuals with communication difficulties, we feel that there should be a system of support put in place for employers to recruit, mentor and retain people with a communication difficulty to the labour force. There should be particular emphasis placed on support provided to employers in smaller businesses and services.

The practical steps employers may take:

The encouragement of phased returns to work

Occupational health departments often have a very limited understanding of communication impairment. Individuals seeking to return to work may be expected to make a phased return after significant head injury or brain tumour or encephalitis at the same rate as someone who has had a physical injury (and who may just need the support of crutches). Phased returns need to be less rigid, much less litigious and accommodating to individual needs.

We would encourage use of the Allied Health Professionals Advisory Fitness to Work Report which can identify specific adjustments to enable a person to make a phased return to work following illness or to access work as part of a supported internship. For some cases with communication disability this might include an independent employment advocate to offer a "bridge" between the person, the employer and the work and health agencies.

Flexible working arrangements through the use of technology

Flexible working arrangements such as the ability to work remotely through readily accessible IT adaptions; this may include systems enabled or adapted by assistive technology experts working in the NHS catered to individuals. IT systems would need to be enabled so that they can be adapted by Assistive technology experts working in the NHS for use with individuals.

To provide you with an illustration of such difficulty through an example; here barriers from IT department of companies not allowing remote access to systems for a client with MND who was not able to attend work on a daily basis but at the stage where she was still able to work but could not physically, but only through assistive communication technologies. She could have been able to access her computer but due to lack of adaptation of IT systems prevented her from doing so.

We would therefore encourage DWP to aid in the facilitation of such adaptation; whether it is through direct encouragement to companies or to support companies with financial provision to enable such adaptions.

Greater awareness and knowledge of disabilities and vocal load in workplaces

We feel that there should be greater support to employees to build up an 'understanding me' profile which they are willing to share with the employer; this would include background of health issues, challenges and crucially how they manage them. This may lead to an open conversation about the level of support required. Open conversations instigated by employees are rare for fear of reprisal - reticence on the part of the (potential) employee about sharing information which s/he might perceive could make him/her less employable, more needy of support, more "expensive" to the employer; workplace culture of this nature is harmful and may prevent employees receiving appropriate levels of support. How a potential employee may initiate such discussions if supported to do so might come from health professionals or as part of the job centre work coach role.

This would also enable employers to gain a greater awareness of vocal load (voice use) in a work environment would enable greater recognition when employees may be at risk; this may mitigate voice loss and long term sickness particularly in vulnerable professions such as teaching, call centre workers, sport coaches etc.

Which measures would best support employers to recruit and retain the talent of disabled people and people with health conditions? Please consider:

- the information it would be reasonable for employers to be aware of to address the health needs of their employees;
- the barriers to employers using the support currently available;
- the role a 'one stop shop' could play to overcome the barriers;
- how government can support the development of effective networks between employers, employees and charities;
- the role of information campaigns to highlight good practices and what they should cover;
- the role for government in ensuring that disabled people and people with health conditions can progress in work, including securing senior roles;
- the impact previous financial, or other, incentives have had and the type of incentive that would influence employer behaviour, particularly to create new jobs for disabled people; and
- any other measures you think would increase the recruitment and retention of disabled people and people with health conditions.

We feel that there should be practical support for the employers – perhaps a three way conversation between employer, employee and communication advocate (this could be speech and language therapist, or other person in role of advocate). This may for example be a "one stop shop" or an information campaign might sign-post employers, employees and employment support workers to evidence based advice leaflets on vocal hygiene (voice care) in the workplace, with emphasis placed on ease of access of information.

Employers have many different work cultures which may vary across sectors (public and private) and also organisational size (a corporate environment to a small high street business). As such, we feel that there should be engagement from DWP across the various sectors and category of employer, in order to inform a practical approach to accommodate the various cultures which may invariably present a challenge to the encouragement of change, adaption and accommodation.

Additionally, alongside our previous recommendation of a bespoke support system for employers, we feel that employers must be made aware of existing funding structures and assessments that are available from the NHS for example in relation to communication aid and computer access. The current Access to Work scheme which can assist with physical computer access is an example of this; although available to potential employees, employers may encourage potential employees to seek assistance through the scheme.

In terms of the information available to employers in in relation to the health of employees, we would once again encourage the provision of support to employees to advocate openly for themselves the support that they feel that they require without consequence, to enable an open discussion with employers to address as to whether they feel would be able to provide support fully or even partially (such as periodic release from work to attend timely employment targeted health interventions, such as voice therapy during the early stages of Parkinson Disease). This may take place in the form of a supported interview to share information with the assistance of an expert such as a speech and language therapists. This may also be in the formal of a statement of communication access needs would be routinely provided to employers, with an expectation of routine submission.

Employers must be continuously diligent and conscious of individuals with disabilities who may sometimes be at increased risk of bullying and harassment. This makes it very hard for them to persevere when returning to a former job role. Enshrining further safeguards in law may be necessary to avoid constructive dismissal or lack of promotion.

Should there be a different approach for different sized organisations and different sectors?

As this is a broader social issue, there should be an expectation of the same ethos from all employers (as enshrined in law); however smaller businesses may require ongoing mentoring or support (perhaps from experts such as speech and language therapists) as there are clear cost implications.

It should however be noted that vocal hygiene has a minimal a cost burden and should be available in all work places.

How can we best strengthen the business case for employer action?

The investment in employee health with the loss of profit from avoidable worker absence or excess payment for locum workers in the public sector is a clear practical implication, as is sickness. Increased productivity owing to improved employee well-being are factors which may help the business case.

Additionally, we would recommend further development of the evidence base of the unmet potential of those with disability such as stroke. From the research of Vyas et al:

'Stroke survivors are less likely to be employed and they earn a lower hourly wage than the general population. Interventions such as dedicated vocational rehabilitation and policies targeting return to work could be considered to address this lost productivity among stroke survivors.'

Key evidence:

• Vyas, Manav V., et al. "Lost Productivity in Stroke Survivors: An Econometrics Analysis." *Neuroepidemiology* 47.3-4 (2016): 164-170.

Staying in or returning to work

What good practice is already in place to support inclusive recruitment, promote health and wellbeing, prevent ill health and support people to return to work after periods of sickness absence?

There are examples of multidisciplinary community Acquired Brain Injury teams that liaise with HR departments to support tailored return to work packages. They play a crucial part in ensuring information is communicated effective while facilitating conversations about the disability. However these are not geographically standard and most do not contain speech and language therapists and therefore rely on the local community speech and language therapists.

Often graded returns to work as a joint project with the health team involved have proven successful (in ABI) but the financial support does not always facilitate this approach and requires much more flexibility.

Should Statutory Sick Pay be reformed to encourage a phased return to work? If so, how?

For the SSP assessment to be linked to an assessment of work capacity, specifically noting invisible deficits, such as fatigue and the extra cognitive load produced by a communication deficit.

The assessment needs to be tailored to the specific needs of the person with clear descriptions of the impact of the communication difficulties and practical planning which involves the person or the person and an advocate.

What role should the insurance sector play in supporting the recruitment and retention of disabled people and people with health conditions?

Insurance policies often cover physical aspects of injury or disability but not psychological or communication needs and we would therefore encourage an expansion of scope.

Additionally, whether business insurance may cover costs involved in locum pay for a support worker during an employee's phased return to work is an area for potential review.

Chapter 5: Supporting employment through health and high quality care for all

Improving discussions about fitness to work and sickness certification

How can we bring about better work-focussed conversations between an individual, healthcare professional, employer and Jobcentre Plus work coach, which focus on what work an individual can do, particularly during the early stages of an illness/developing condition?

For individuals in the early stages of illness/developing conditions, separate assessments should be conducted to enable periodic access to SSP to accommodate phased returns to work.

We would encourage the development of a standard questionnaire/assessment that would place the client at the centre with a focus on ability rather than disability; this may address employer expectations and address specific needs in details and potential for provision of support. As part of which, there should be ring-fenced health time for liaison between the health professional and the work coach, which may require a protocol facilitating the individual's consent for information-sharing between the two.

The outcomes of which may feed into a work profile for each client detailing ambitions for returning to employment, gaining employment and progression against the support structures required and those available, that they would require to do so.

We would strongly encourage the use of RCSLTs inclusive communication principles for communication (verbal and written) across Jobcentres to promote engagement for those who may have communication disability as this may not be wholly apparent or obvious to an observer due to a lack of diagnosis and the nature of such condition.

How can we ensure that all healthcare professionals recognise the value of work and consider work during consultations with working age patients? How can we encourage doctors in hospitals to consider fitness for work and, where appropriate, issue a fit note?

We feel that this may be addressed through envisaging a dialogue between work and health, where flexible approaches and a genuine understanding of the challenges for those with an "invisible" communication disability are held throughout the DWP and where health workers look for practical ways to build a work "mosaic" (an individual approach to how this person could best be employed) for and with the person.

While there are reports of inconsistent assessments and a limited attention given to specialist reporting, these may act as a deterring factor for health care professionals, negating confidence that individual long term needs are being adequately understood.

We would recommend a demonstration of engagement with work issues and the consideration of return to work as a health outcome to be reported locally and nationally.

Are doctors best placed to provide work and health information, make a judgement on fitness for work and provide sickness certification? If not, which other healthcare professionals do you think should play a role in this process to ensure that individuals who are sick understand the positive role that work can play in their recovery and that the right level of information is provided?

Although this may be beneficial for an individual with communication disability to be supported into work, it is also important that healthcare professionals are seen as independent.

The relationship between a speech and language therapist (for example) and the person with an intellectual/language disability is built on trust and a belief that the SLT has the best interests of the person at heart. In this way, the speech and language therapist (or other health professional) can represent the needs and strengths of the person to labour force and similarly the benefits of belonging to a labour force to the person.

However, if this is a proposal that is to be taken forward, we would encourage that such assessment or decisions are not completed in isolation; there should be appropriate health care professional input (such as a speech and language therapists) into this decision as to avoid the medical model of sickness eclipsing language cognitive and social needs.

It is important to take the person's impairment along with their subjective perspective and their work / home environment into consideration. This bio psycho social model requires a multidisciplinary input. This approach is advised by Occupational Health Professionals, who can be accessed via HR and will make an independent assessment and onward referrals to appropriate professionals.

There are resource implications in this profession; development of this strand might be a good investment to speed up the process of appropriate rehabilitation and return to work, thus reducing the SSP costs.

Regarding the fit note certificate, what information should be captured to best help the individual, work coaches and employers better support a return to work or job retention?

We would encourage the capture of language cognitive and social needs as well as medical diagnosis and prognosis.

Additionally, it should highlight potential solution or support that be available such as assistive technologies that and individual may require, to motivate use these and to help identify what equipment is needed by healthcare to provide.

Is the current fit note the right vehicle to capture this information, or should we consider other ways to capture fitness for work and health information? Does the fit note meet the needs of employers, patients and healthcare professionals?

We would recommend that the "fit note" could trigger subsequent use of the allied health profession advisory fitness to work report which details professional advice to be agreed with the patient's manager for facilitating an individualised return to work.

Mental health and musculoskeletal services

How should access to services, assessment, treatment and employment support change for people with mental health or musculoskeletal conditions so that their health and employment needs are met in the best possible way?

As communication issues in adults are often present alongside physical issues (from the same aetiology) and carry with them an increased risk of mental health issues (e.g. depression research in aphasia) they are co-morbidities and for these people standard intervention such as talking therapies are by nature not always appropriate.

There is an artificial distinction between physical and mental health conditions; investment in good community rehabilitation using person centred holistic interventions, delivered in the

patient's own environment may prevent unnecessary long term unemployment with associated negative health implications. This may present an additional saving in acute health care.

How can we help individuals to easily find information about the mental health and musculoskeletal services they can access?

We would recommend the development of universally accessible Work and Health materials (websites etc.) developed through input from multidisciplinary healthcare professionals.

The World Report on Disability as a blueprint for international. National and local aphasia services outlines key recommendations that may aid in the development of accessible material(s).

Key Evidence:

International Journal of Speech-Language Pathology, 2013; 15(1): 106–112 The World Report on Disability as a blueprint for international, national, and local aphasia services LINDA E. WORRALL 1, TAMI HOWE 2, ANNA O'CALLAGHAN 1, ANNE J. HILL 1, MIRANDA ROSE 3, SARAH J. WALLACE 1, TANYA ROSE 1, KYLA BROWN 1, EMMA POWER 4, ROBYN O' HALLORAN 3 & ALEXIA ROHDE 1

Transforming the landscape of work and health support

What kind of service design would deliver a position in which everyone who needs occupational health assessment and advice is referred as matter of course?

We would encourage greater consideration of cognitive disability. These clients may also require speech and language therapists input and would require a tailored approach distinct from the 'return to work'. This may include individuals with adult learning disability and dementia (for example).

Creating the right environment to join up work and health

How can we best encourage innovation through local networks, including promoting models of joint working such as co-location, to improve health and work outcomes?

Speech and language therapist services however commissioned must be able to provide communication support as well as swallowing support.

How can we encourage the recording of occupational status in all clinical settings and good use of these data?

What should we include in a basket of health and work indicators covering both labour market and health outcomes at local level?

We would recommend a review of a number of outcomes, including quality of life measures, modifications made in the workplace, retention, promotion and progression, as well as reward and recognition.

How can government and local partners best encourage improved sharing of health and employment data?

We would recommend routine records of employment information with health records which are held securely while return to work is considered as a health outcome.

The integrity and security of information governance around individual health data must be protected in any arrangement.

What is the best way to encourage clinicians, allied health professionals and commissioners of health and other services to promote work as a health outcome?

We would encourage the government to support best employment practice to move towards continued work and employment becoming a good health outcome.

At a local level, there is a need for good relationships between employers and healthcare staff, where allied health staff can be accessible to employers, for training and awareness raising about the implications for long term communication difficulties in the workplace and how these might be supported. There needs to be practical forums for employers to be able to access to help them support those with long term communication needs and flexibility amongst allied health staff to look at ways in which real, viable work could be envisaged for individuals.

Although work should be considered a work outcome, we would caution the government not consider this as a simple black and white outcome. We would encourage the development of a grading structure for phased working, part time working, volunteering and internships.

Chapter 6: Building a movement for change: taking action together

How can we bring about a shift in society's wider attitudes to make progress and achieve long-lasting change?

We would encourage the promotion of work champions; individuals that have been able to return to work following a life changing illness or condition. Greater awareness of their conditions alongside the treatment or provision of support that has enabled individual return to work easing the burden on the welfare state would change invariably change perceptions.

The RCSLTs "My Journey My Voice" is an excellent example of such an initiative that has enabled individuals that have experienced life changing conditions demonstrate how speech and language therapy has made a difference to them and society, enabling them to live their lives with greater independence and also return to employment.

Key Evidence:

http://www.myjourneymyvoice.org/

What is the role of government in bringing about positive change to our attitudes to disabled people and people with health conditions?

The government has a significant contribution to make in setting the national conversation about the social as well as economic function of work within our society. As we have previously mentioned, we would encourage the government to support best employment practice to move towards continued work and employment becoming a good health outcome.

Could any of the proposals within the green paper potentially have an adverse effect on people with a protected characteristic? If so, which proposal, and which protected group/s are affected? And how might the group/s be affected?

Our greatest would be the acknowledgement that there are individuals living with profound disability that may never be able to consider work. There cannot be a "catch all" approach to disability and there needs to be a parallel focus on achieving potential and quality of life so that those severely impaired are not further marginalised and starved of funding.