

## **GUIDANCE ON WRITING A GOOD LETTER OF SUPPORT FOR PIP OR ESA APPLICATIONS BY CLIENTS WITH MENTAL HEALTH DIFFICULTIES OR DISABILITIES**

### **WHO WROTE THESE GUIDELINES?**

The **Westcountry Community Psychology Group (WCP)** is a collective of Health and Social Care professionals, namely psychologists and benefits workers in Devon, who collectively work in active ways to address issues of social inequalities which significantly contribute to psychological distress within our communities.

The project delivers educational workshops for benefits workers, professionals and families on understanding disabilities and mental health difficulties, lobbies the government on these issues, and offers direct support for people struggling to navigate the benefits system in partnership with Citizens Advice.

The project has produced these guidelines to support health and social care professionals, including psychologists, to write good letters of support for their clients with disabilities and/or mental health difficulties to help communicate the extent of how an individual's difficulties impact their daily activities.

### **WHY IS IT IMPORTANT? THE FACTS**

Recent changes to the way the government assess people for disability related benefits have meant it is increasingly difficult for vulnerable people to access the support they need, with a 42% drop seen in people claiming ESA in just 3 months after the changes were introduced, and 200,000 people removed from PIP in the last year. Research from Scotland (Marks, 2017) reports that the ESA Work Capability Assessments (WCA) for people with mental health problems lead directly to a deterioration in mental health and increased suicidal ideation, backed up by reports from the Mental Health Foundation (2015) indicating that 43.2% of people applying for ESA have made a suicide attempt following a WCA. When 65% of PIP appeals and 68% of ESA appeals are overturned at Tribunal, it is clear that the distress caused by the benefits process is unnecessary and avoidable.

We believe professionals can reduce this distress by supporting their clients to ensure they get the correct benefits they are entitled to first time around.

### **HOW CAN A LETTER HELP?**

Although medical professionals are under no statutory obligation to provide medical evidence unless requested by the DWP, supporting letters can often be the deciding factor in an individual's application. Assessors rarely have sufficient experience of disability or mental health to conduct accessible and detailed assessments, and benefits workers report that good quality letters of support from professionals are the most powerful tool in overturning an outcome at appeal.

Such letters can help provide evidence of the extent of an individual's difficulties, particularly where individuals may have difficulties acknowledging and communicating the extent of their difficulties accurately within the assessment process. This could be for a number of reasons including:

- Lack of awareness of the severity of their difficulties, due to adapting in order to cope
- Anxiety within assessments causing difficulty asserting or expressing themselves
- Distress and shame associated with focussing on weaknesses and impact of disabilities or mental health difficulties

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- The time-pressured nature of assessments and lack of mental health/disability training of the assessors making it a difficult space to address the level of depth required to fully understand an individual's difficulties
- Attending or paying for necessary medical appointments to get the supporting evidence
- Difficulties accessing/engaging with services required which would provide supporting evidence.

## **Here is some guidance on writing good letters of support:**

### **General tips**

- **Language** - Despite the refreshing movement towards a formulation-driven way of communicating an individual's difficulties instead of using diagnostic labels, unfortunately the reality is that often access to services and benefits relies on diagnostic labels. Therefore, if you feel strongly about not saying '*X has a diagnosis of X*', it can be helpful to use terminology in such formulations as:
  - o *The difficulties this individual experiences are consistent with a diagnosis of ....*
  - o *The individual is presenting with some symptoms that would be indicative of ....*
  - o *The difficulties regarding ..... are characteristic/in line with difficulties associated with ....*
- **Jargon** - Decision makers within the DWP are not medical professionals, so whilst it is helpful to include formal terms, be aware of any acronyms or medical language will need explanation. It is important to communicate the impact of any diagnosis or condition on the client and their ability to do tasks. For example '*X has a diagnosis of ASC (Autism Spectrum Condition) which means that...*'
- **Support required** - Consider detailing what "support/aids" may be required to complete activities. "Support or aids" could come in the form of BOTH physical mobility aids AND medication, people, use of safety behaviours/objects to get things done.
- **Compensatory behaviours** - Sometimes clients aren't aware of how many compensatory behaviours they have adopted which means although they are able to do an activity it may not be in the way expected. Being curious as to *how* they might complete certain tasks, or even asking them to re-enact in the room, can help make the individual aware of their compensatory behaviours. Explain in your letter how the client may lack insight into the adaptations they have made, as they may minimise these.
- **Timing and frequency** – Be aware that if someone cannot do an activity REPEATEDLY, SAFELY and in a TIMELY MANNER (which means in less than double the amount of time it would take someone with no difficulty to complete) for MORE THAN 50% of the time – then they CANNOT do the activity – be sure to break down the time taken, the safety and the repeatability of activities.

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- **Problem focus of letters** - Letters of support for benefits are NOT therapeutic letters, and spending time detailing the person's strengths and progress is not relevant for the purpose of this letter. It can be helpful to highlight this to your client to help maintain your therapeutic relationship.
- **Highlighting barriers** - Highlight what difficulties the individual might face which could impact on their ability to communicate the extent of their difficulties (eg. aim to please / ashamed of difficulties / interpretation of words).
- **Distress/risk associated** - Detail the risks or consequences associated with activities (eg. fatigue, distress, pain, accidents).
- **Clearly linking the individual's history/formulation with current difficulties** - ensure formulation is clear and to the point. Remember, most letters are read by administrative staff.
- **Use professional titles** - Being transparent about your professional role and title adds to the perceived credibility of the letter. If you use language such as "in my professional opinion ...", ensure that your position is backed up with evidence.
- **Co-writing letters** - Think about writing the letter together with other health professionals, or co-signing.
- **Consider attending the assessments** in person with your client, so you can advocate for them.

### **Suggested sub-headings**

We have spent some time looking at the assessment questions used in the PIP and ESA interviews. We recommend using these questions curiously to gain information about exactly if/how an individual is able to engage with such activities. Individuals' ability to adapt means they often don't report on the support, compensatory behaviours, distress/risks and time associated with completing a particular task.

Below is a list of sub-headings you could use when asking the individual about themselves and then detailing in your letter:

- **Mobility:** use of aids, distance, dexterity, standing/sitting, coordination, getting to locations, reaching/ using objects, safe movement
- **Daily living:** washing and bathing, preparing food, eating, dressing, undressing and toileting/incontinence.
- **Communication:** verbal, written, communicating danger, engaging with other people face to face, reading and understanding verbal information, signs and symbols
- **Cognition:** making budgeting decisions, managing therapy or monitoring a health condition, planning journeys, learning new skills, consciousness/dissociation, awareness of danger, coping with change
- **Direct risks:** aggression to/from others, disinhibited behaviours, levels of distress.

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## **Templates**

As time is often a barrier to writing lengthy letters, and to help with clarity for both the assessor and the client, we have found that a helpful way to structure letters is to provide an example of a typical “day in the life of the individual”. This is designed to log all activities within an average day. You could do this over a few days if you and the individual feel this would be more representative.

Things to consider:

- o What time wake/ sleep
- o Routines/rituals/difficulties in any routine
- o How take medication (reminders/need people)
- o Interactions with others (socially, in community, employment)
- o Meal times – preparation, eating, safety
- o Leaving the house and returning home - what support is needed?

## **Points systems**

Eligibility for both ESA and PIP is decided on a points based system, so a person will get a certain amount of points based on their ability to complete certain activities. The 2017 **PIP and ESA descriptors and points** are attached (or can be accessed online). It can be helpful to refer to these descriptors when thinking about a client, marking which points you think they will get, and describing why.

You will note that the PIP Mobility Descriptors now (since March 2017), award points ‘for reasons *other than psychological distress*’. It is therefore important to explain using other language the nature of how a person’s distress manifests itself, thus making the task difficult. For example ‘*X’s Autism means they are hypersensitive to some sensory information which means journeys to new places without adequate support and planning are overwhelming, as they are unable to process sensory information adequately.*’

**WE HOPE YOU HAVE FOUND THIS GUIDANCE USEFUL. PLEASE CONTACT US TO OFFER FEEDBACK.**

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