Appendix 1

Response from PWSAA for cognitively impaired people with Prader-Willi Syndrome to

DSS ‘New Disability Employment Services from 2018: Discussion Paper’

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|  | **DSS DES Question** | **PWSAA response** |
| 1 | Should people who take part in DES be required to go to face-to-face meetings? | Yes. Otherwise, the provider won’t get to know them properly |
| 2 | Should DES have a minimum number of available:  • contacts  • hours of support? | Yes to both. This should be specific to the individual (see Q3) |
| 3 | Is this something that should as part of the Job Plan and agreed between:  • the DES provider  • the person taking part? | Separate to job plan and documented in a Service Level Agreement so the provider can be held accountable. |
| 4 | How can we make sure people are involved in the development of their Job Plans? | Include the client’s advocate, family supporter or nominee in the service |
| 5 | What information would you like to know about DES providers in your area if it was available:  • online  • through a smartphone app? | * Are they registered DES provider? * Are all staff trained to minimum of …. For the recruitment officer and the onsite ‘skills building coach’ * All staff have passed a Police Check and not on the The Disability Worker Exclusion Scheme register or similar * Any complaints against the provider * Ratings by service users (like Trip Advisor) * Success rates at each time interval as a percentage of all their clients * Success rates in comparison with all other providers offering the same services in the scheme * Area they cover * Credentials of the assigned individual provider * Any employers the provider referred to which have a pattern of ‘revolving door’ with employee placements turning over |
| 6 | If you were given more say in how money is spent on you, would you know what to spend it on? | No. People with PWS do not have the capability to make use of a competitive provider environment to their own advantage. They need major support to understand money, service objectives and manage a contract with a service provider |
| 7 | If not, what information or support would you need to help with this? | Jobs service provider must work with the client’s advocate. Service descriptions, hours recommended for outcome goals, cost per hour of individual assistance, group sessions, and on site in workplace. |
| 8 | Would you like DES providers to focus on getting you:  • a long-term job?  • short-term jobs? | Long term. Constant changes do not suit this disability |
| 9 | Did you find it easy or difficult to access DES, such as the registration and assessment process? | Difficult. |
| 10 | If you found it difficult:  • what didn’t you like?  • how could it be improved? | Information too vague. Provider did not try to understand the disability. Must be much more specific, about the minimum services on offer, and client-specific service package especially after signing on |
| 11 | If a participant chooses not to tell their employer about their disability, how should DES providers assist them in the workplace? | That would be close to impossible with PWS. The behaviours need a supportive employer or the placement will quickly break down. |
| 12 | What should the provider do to assist if a person’s job is a risk due to their:  • disability?  • injury?  • health condition? | Don’t place a person with PWS in a job where the risk is too great. Educate the person with PWS and their advocate about other options |
| Other | PWS clients have had bad experiences with providers:  Client must not be penalized for failure.  Client must not be threatened with financial loss or loss of job support access for non-attendance. A clear ‘separation’ process must be transparent to the client up front.  Client must be treated with patience and as an individual | |