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The Dandelion Employment Program: Longitudinal Findings

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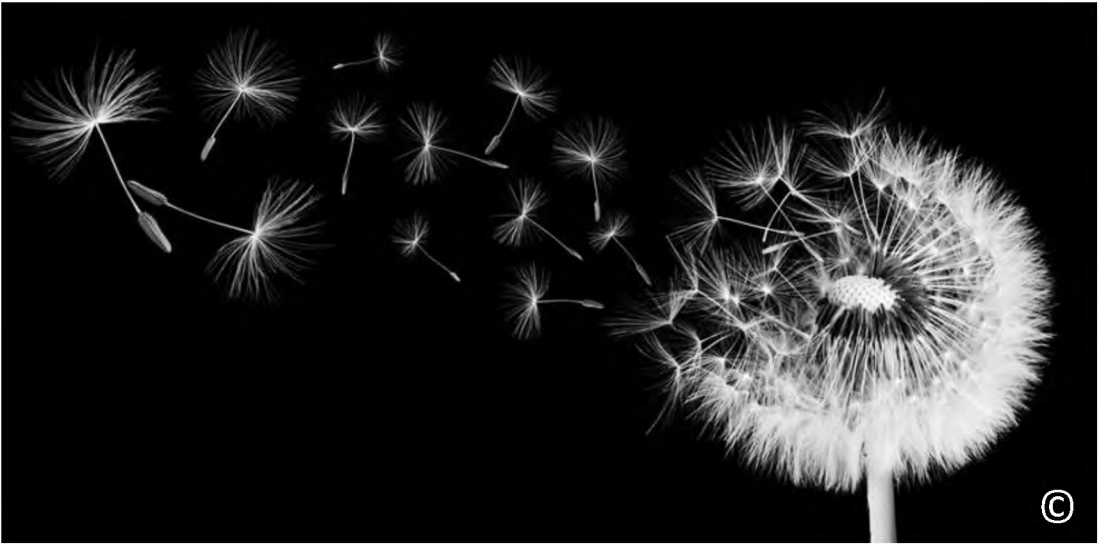
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Directors foreword

The Olga Tennison Autism Research Centre at La Trobe University has been the research partner in an ambitious journey with DXC Technology (formerly HP/HPE) to realize the successful implementation of the Dandelion Program, designed to increase employment opportunities for people with autism. In doing so, DXC Technology have combined social responsibility with building a competitive advantage that will continue to impact the community at large. This important initiative has been undertaken in partnership with the Australian Government Departments of Human Services, Department of Defence and Home Affairs.

The objective in our program of research is to understand the social impact and employment outcomes for employees with autism. This research is critical because although access to employment is recognized as a fundamental human right in the UN Convention on the Rights of Persons with Disabilities, more than 50% of Australian individuals with autism remain unemployed. Thus we are committed to providing a strong evidence-base on how best to enable work opportunities for people with autism so that they may contribute, develop careers, and prosper.

We have previously reported on the benefits of the Dandelion Program. In the current report we describe, for the first time, the longitudinal outcomes of thirty-five Dandelion candidates over the period of one year. Surprisingly, we show that the overall well-being of these candidates remain unchanged over the first year of employment, despite positive qualitative reports and high rates of job retention and satisfaction. We continue to chart outcomes beyond the first year, to determine whether overall well-being will remain stable over the longer term. These latter data will be the subject of a subsequent report.



Cheryl Dissanayake, PhD, MAPS

Professor & Director

Executive summary

Overview

The DXC Technology Dandelion Employment Program is currently in its 4th year. An important research question addressed as part of this program was:

- [What is the impact of the program on participants' health and well-being?](#)

The current report details findings from our ongoing longitudinal research program. We examined change in participants' health and well-being, reporting here on findings following the first year of employment across multiple sites.

This is the first longitudinal study to date that has closely examined the impact of supported employment on employees who are on the autism spectrum. Our findings reiterate the importance of appropriate and meaningful workplace supports in ensuring the sustainability of the program. We continue to chart outcomes beyond the first year, to determine whether findings reported here are consistent over the longer term. This information will be the subject of a subsequent report, as data becomes available across sites.

Key findings

It was predicted that providing meaningful employment to individuals on the autism spectrum would lead to benefits in their health and well-being. However, the majority of individuals surveyed showed little change on our health and well-being measures following one year in the program. Furthermore, while a small number of individuals showed significant improvements, another small group declined. Consistent with other adults on the autism spectrum,^{16,17} Dandelion employees reported difficulties associated with symptoms of depression, anxiety, and sleep. These challenges remained relatively stable over time.

Encouragingly, Dandelion employees returned high levels of job satisfaction comparable to that of new graduate recruits, suggesting job satisfaction may be relatively independent from the challenges associated with mental health.

Most importantly, the efficacy of the program is shown by the high rate of retention, and also the successful transition of a number of participants out of the program and into meaningful, open employment.⁸

The findings indicate that provision of employment does not necessarily lead to broad improvements in health and well-being. However, neither did it result in negative impacts, at least for the majority of participants, with some showing significant improvements.

The Dandelion Program is a supported employment program. It is likely that supports provided have contributed to good retention rates and high levels of job satisfaction.⁸ Our previous research findings, summarised within and reported elsewhere, identified broad satisfaction with the program, with specific benefits including learning of new skills, financial independence, development of friendships, and feelings of contributing meaningfully to society.^{1, 2, 4, 8, 11, 14, 15} The supports provided, and support staff, were consistently identified as crucial to the success of the program.⁴

Nonetheless, for the sustainability of the Dandelion Program it will be important to develop cost effective and targeted programs for supporting mental health challenges, and for promoting positive mental well-being, amongst program participants and in the workplace. Our recommendations focus primarily on this point.

Recommendations

- Development and implementation of a cost effective education and training program to support the mental health and positive well-being of employees with autism.
- Development and implementation of a mental health and autism training program for support staff who may need to manage mental health concerns in the workplace.
- Identification of region specific professional support networks for referral.
- Broad workforce training and awareness concerning mental health and well-being; for example, how to talk to someone and what to do, if a colleague comes to you for help or assistance.
- Increased integration of Dandelion Employees into the wider workforce to encourage development of social networks and professional relationships.

Preface

The research described in this report was funded by DXC Technology, the Australian Government Department of Human Services (DHS), and the Australian Government Department of Defence (DOD).

Data reported herein were collected across two DHS sites (Brisbane, Canberra), and single sites from DOD (Canberra), and the Australian Government Department of Home Affairs (DHA, Canberra). Data were collated across sites to increase sample size, and to improve generalisability and reliability of findings. Longitudinal data from one site (DHS Adelaide) were not included in this report as baseline data at this site were not available.

All sites are structured similarly with up to 14 people with autism working in a supported office environment. Support is provided by one or two professionals (Autism Spectrum Consultants; ASCs) per site who are experienced working with people with autism, and various professional staff and supervisors. Employees within the program are provided with ongoing support and training opportunities, with the goal of transitioning to unsupported, competitive employment at the completion of three years. The program has clear and structured guidelines to achieving this goal.

Data included in this report represent changes in health and well-being following one year in the program. Data were collected at the start of the program (Baseline, approximately 2-4 weeks following on-boarding) and at 6 and 12 months thereafter (T2, T3). Data for all time points were available for 35 individuals, representing 63% of individuals with autism participating in the Australian government affiliated programs.

*‘The job provides a purpose, you're looking forward to getting up in the morning, to going to work.’
(Dandelion employee)*

We thank Michael Fieldhouse, Cathryn Masters, Adam Easterbrook, Rodney Hocking, and the ASCs and support staff from DXC Technology for assisting in data collection and supporting the research goals. We also thank DHS and DOD staff for their support and participation, and most importantly, all the Dandelion Program participants and their families who so graciously contributed their time to completing surveys and participating in interviews and focus groups.

We appreciate the contributions of the following professional and academic staff from La Trobe University: Associate Professor Amanda Richdale, Ru Cai, Mathilda Wilmot, Alex Aulich, Alex Haschek, Ensu Sahin, Professor Tim Bartram (now at RMIT), Dr Mirko Uljarevic (now at Stanford University), and also David Hedley and Dr Simon Moss (Charles Darwin University).

Structure of the report

The report first provides an overview of our research to date, drawing on previous reports and research findings. Our goal is not to replicate this work here, but to provide a summary and consolidate our work to date.

Next, we present results from our longitudinal study, initiated in August 2015. This study examined health and well-being in Dandelion employees over the course of their involvement in the program. We focus specifically on change over the course of 12 months amongst participants, a period in which we currently have the maximum number of sites where the Dandelion Program has been implemented. Subsequent reports will examine longer time periods, as data across sites become available.

Throughout this report we present our research in a format that can be understood by people without a scientific or academic background. Nonetheless, we also believe it is important to provide data and, in some cases, statistics to support our conclusions and interpretations. To ensure that our results are interpretable to the lay reader, we provide a ‘plain language’ interpretation of our findings at strategic points in the report.

Last, a brief word on terminology. To be consistent with the wishes of Dandelion employees, and where labels are required for clarity, we use the term “on the autism spectrum” or “person with autism” to describe those whose individual uniqueness places them somewhere “on the spectrum”. We also refer to individuals on the spectrum who are employed within the Dandelion Program as “Dandelion employees”.

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The Dandelion Program

The Dandelion Program is an initiative of DXC Technology undertaken in partnership with the Australian Government Department of Human Services, Department of Defence, Department of Home Affairs, and, more recently, the ANZ bank. As of July, 2018, 58 Dandelion Program employees are employed within the program, across four Australian States. Individuals are placed within teams of 9-14 individuals. Organisational level training is provided by local autism professionals and DXC Technology staff to facilitate program implementation.

The program is aimed at increasing employment opportunities for people on the autism spectrum by providing workplace accommodations and supports, as well as a modified recruitment process that provides an opportunity for candidates to demonstrate their skills over four weeks. The program has a 3-year structure that focuses on job awareness and training (year 1), self-advocacy and increasing autonomy (year 2), and transition to an unsupported work environment and career (year 3).

Job retention is high in the Dandelion Program (89% as of July, 2018), with at least three of seven individuals who have formally left the program moving to competitive, open employment.

Employment provides opportunities for social inclusion, economic independence, and improved health and well-being. Perhaps most importantly, employment provides individuals an opportunity to contribute to society, and to develop a sense of meaning and purpose concerning their own lives.

‘What is important isn’t the money, it’s giving something back to society that’s important. I can get by on a little bit of money, I’m ok, that’s not important. Without a job, I feel like I’m a drain on society. I feel like I’m not giving anything back, I feel it’s my duty – it’s the right thing to do. We have an understanding of how society works, even if we don’t fit in. Logically we understand how it works, this is something we do understand, even if we don’t understand people’s emotions we do understand how society functions’
(Candidate)

Research review

The research strategy for the Dandelion Program focused on key areas of employment: recruitment, on-boarding, employee experience and performance, and organisational outcomes.

First, a review of employment programs and interventions that target adults with autism was conducted in order to position the Dandelion Program within the broader autism employment literature, and to provide context and direction for the research going forward.¹⁰ We reviewed over 60 research articles in detail. The review identified specific factors that lead to better outcomes, including workplace supports to both find a job and assist within the workplace, and individual level factors such as education level, presence of mental health difficulties, and age.

Adults with autism were more likely to be denied services compared to other disability groups, were over-represented in low-paid or entry level positions, and expressed a lack of support and understanding in the workplace. We also identified high economic costs of this employment crisis on individuals, their family members, and the broader economy; costs that can be mitigated through improving opportunities for adults on the autism spectrum and reducing the unemployment gap.

Finally, we identified a need for better quality research in this field, encompassing both qualitative and quantitative methodology.

With the results of the review in mind, we conducted extensive interviews with DHS Adelaide-based employees, their support staff and co-workers, and their families.⁴ We aimed to gain a better understanding of Dandelion employees' history concerning employment, and their experiences and perspectives concerning the recruitment and on-boarding process.

With few exceptions, Dandelion employees, like many people with autism, experienced difficulties obtaining reasonable employment, attributing their challenges to recruitment practices (e.g., interviews) and lack of support concerning challenges associated with their autism. Employees and families were very supportive of the skills based selection process employed in the Dandelion Program. Co-workers and support staff found autism awareness training to be an important component to support the successful integration of individuals on the autism spectrum into the workplace.

'He has always been an outstanding student - Dux of both Primary and High School, all the top prizes for every subject, OP1, University scholarship - which is the "positive" side. He got his Physics Degree but then hit the wall in a big way in his final year. It was looking very bleak - not just for him, but me also as a parent who had been struggling to deal with all the challenges it brings. It was clear that he wasn't able to continue with his University studies, but the problem was he was unable to job search effectively, even with me having 16 years as an Employment Consultant assisting him. It once took him 4 hours to pick up the phone and talk to a prospective employer, even with me having made a Resume for him and having written a script of what he should say. That's precisely why I believe this program is excellent.' (Family member)

Some of the challenges identified by Dandelion employees included difficulties with tasks, work related stress, managing distractions, and the manner in which social and communication difficulties associated with autism affected integration into the workplace.⁴

Enablers to successful transition into employment, and to success in the workplace, included: the level of support from the organisation, co-workers, and support people; environmental modifications; and the availability of autism spectrum consultants (ASC).

‘He has now realized he’s more capable of going places, getting himself to places, jumping on the transport and just going to town, and going to wherever he wants.’ (Family member)

Overall, employees, co-workers, support staff, and families, were positive about the Dandelion Program, and the benefits of being involved in it.⁴

These benefits included improved independence and opportunities for developing social relationships and friendships, a sense of purpose, pride and contribution to society, and greater self-esteem and financial independence:

'You're sort of like, let's see what today brings, it's not "Oh, got to get to work", it is challenging yes, sometimes stressful, but now I've been able to cope with a lot larger work load with minimal stress but in the end I know that I've done good.'

(Dandelion employee)

With the support of an RFA grant from La Trobe University, we subsequently conducted interviews with a large number of co-workers from DHS, roughly 2 years following commencement of the program. While a summary of this information can be found elsewhere,¹¹ it is important to note that co-workers from the broader organisation were particularly impressed with the high quality of work completed by the Dandelion employees, and how proud they felt to be involved in the program.

‘I’m always proud to say that I work in an organisation that accepts diversity and in fact looks at it as an advantage.’ (DHS Co-worker)

Our findings from a large survey with DHS staff we found that the impact of the program on workload (18% reported an increase in their own workload) and responsibilities (15% reported additional responsibilities) was small.¹¹ DHS employees stated that the program serves an important purpose (87%), is valuable (90%), and is a good organisational strategy (83%). Overall, 91% of co-workers surveyed were positive about the program, summarised in the word map in *Figure 1*.

Finally, in our interviews with co-workers, one of the few critiques of the program was that co-workers would have liked to have seen greater integration of Dandelion employees into the broader workforce, both socially and in work.



Figure 1. Word map of DHS employee perceptions of the Dandelion Program; larger font size represents greater word frequency

Longitudinal study

Background

To determine potential impacts of the Dandelion Program on its participants, we undertook a broad and comprehensive self-report survey of health and well-being, and job satisfaction. Surveys were distributed electronically to all participants, who were permitted time at work to complete them. In accordance with La Trobe University (No. 14-101) and DOD (ADHREC; No. 825-16) ethical requirements, participation was voluntary, all participants provided informed consent, and were free to withdraw from the study at any time.

Participants completed their first survey approximately 4-weeks after on-boarding (the time point used as the baseline measure), representing the point when the usual work routine began and on-boarding activities had concluded.

To ensure that the 4-week time point was representative of participants' general health and well-being prior to any potential program effects, we compared data from this time point with data from a small group (n = 12) of individuals who had completed surveys prior to any involvement with the program (other than submitting an application); i.e., representing a 'clean' baseline. We did not identify any statistical differences between their scores from this point and the 4-week following work commencement, suggesting that health and well-being at 4-weeks was representative of health and well-being when participants first applied for the program, and thereby a reasonable proxy for a baseline measure. For job satisfaction, we include comparison data from a sample of new graduate level hires from DHS in Canberra.

Structure

We first present the overall survey results following 12 months involvement in the program for the primary health and well-being measures. We then provide a more detailed, individual level analysis of change on mental well-being, anxiety, depression, and sleep, concluding with a closer look at job satisfaction.

Main findings

Results

Thirty-five (31 male - 88.6%) employees from 4 sites provided completed surveys during the first 12 months of the program.

Health and well-being

Figure 2 provides a summary of scores on the primary health and well-being measures at program commencement, 6 and 12 month follow-up points. The constructs assessed were:

- Sleep (Pittsburgh Sleep Quality Index)
- Quality of life (World Health Organization Quality of Life-BREF)
- Mental well-being (Warwick-Edinburgh Mental Well-being Scale)
- Social support (Interpersonal Support Evaluation List-12)
- Loneliness (University of California Los Angeles Loneliness Scale)
- Depression (Patient Health Questionnaire-9)
- Anxiety (DSM-5 Dimensional Anxiety Scale, Cross-D).

Overall, average scores were the same across all time points for all of the measures, indicating no significant change over time.



Figure 2. Average scores for measures of health and well-being at program commencement, 6 and 12 month follow-ups

Plain language interpretation of findings

In designing this study, our main aim was to identify positive benefits to participants in terms of their health and well-being. Through being engaged in appropriate employment with reasonable supports, it was expected that participants would report an overall improvement in their well-being, and a reduction in mental health symptoms such as depression and anxiety, and better sleep.

However, overall, Dandelion employees did not show any real change over time on the measures included in the study from when they started the program to when they were re-assessed with the same measures 6 and 12 months later.

It is important to note, at the same time, we did not identify an overall worsening of health and well-being based on the measures used. That most people's health and well-being was stable over time is somewhat encouraging, as it suggests that employment did not adversely affect them.

One possibility for our findings is that the instruments we selected were not sensitive to detecting change in people on the autism spectrum. However, this is unlikely as the instruments have been previously used in a variety of different groups, including with people with autism.

It may be that some individuals did show significant change over time but, if the number of these people was small, or if some showed improvements and others worsened on the measures, then any effects may not have been detected. To address this possibility, we need to look at change over time at an individual level, instead of only looking at the group averages. We do this in subsequent sections.

Mental well-being

Mental well-being

Mental well-being refers to positive states of being, thinking, behaving, and feeling. Positive mental well-being is regarded by the World Health Organization as foundational to functioning, allowing individuals to realise their abilities and potential, work productively, cope with stress, develop satisfying relationships, and contribute to their community. Whereas mental health focuses on psychological dysfunction, mental well-being describes the positive aspects of psychological functioning and emotions (e.g., happiness).

Measuring mental well-being is an important indicator of change when evaluating the psychosocial impact of programs such as the Dandelion Program, which we expected (and furthermore was reported in our qualitative research findings^{2, 4, 8, 11}) to have a positive impact on those involved in the program.

Measure

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) is a measure of positive mental health (e.g., 'feeling optimistic about the future'). It differs from disorder specific measures which tend to focus on the negative aspects of mental health, rather than on positive mental health outcomes. It was designed for use in the general population, as well as to assess outcomes of mental health promotion initiatives. The scale consists of 14 positively worded items completed using a 5-point scale ('none of the time' to 'all of the time'). Scores range from 14-70, with a higher score indicating greater mental well-being.

To evaluate change over time, we calculated a Reliable Change Index (RCI). The RCI is a statistical measure which can be used to evaluate how much change has occurred in scores over time. Significant RCI change suggest that changes in scores reflect a real change, rather than normal variance due to assessments being completed at two different time points.

Change in mental well-being over time

To examine change, we calculated Reliable Change Indexes (RCIs) to indicate potential statistical improvements (or otherwise) over time. We first examined the RCI on the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) for reported scores at commencement and at 12 months. Three (9%) individuals showed a significant improvement ($RCI > 1.96$) in mental well-being over the 12 months, and 4 (11%) showed a significant decline in mental well-being over the same timeframe, based on the RCI. The remainder (80%) showed no significant change in mental well-being, as presented in *Figure 3*.

Overall change in WEMWBS scores ranged from 0 to 22 points. Three individuals showed improvement of 8 points (suggested as a potential cut-off for meaningful change on the WEMWBS) or more (range 11-12 points), and six individuals whose scores indicated a decrease in mental well-being showed reductions of 8 points or more (range 8-22 points).

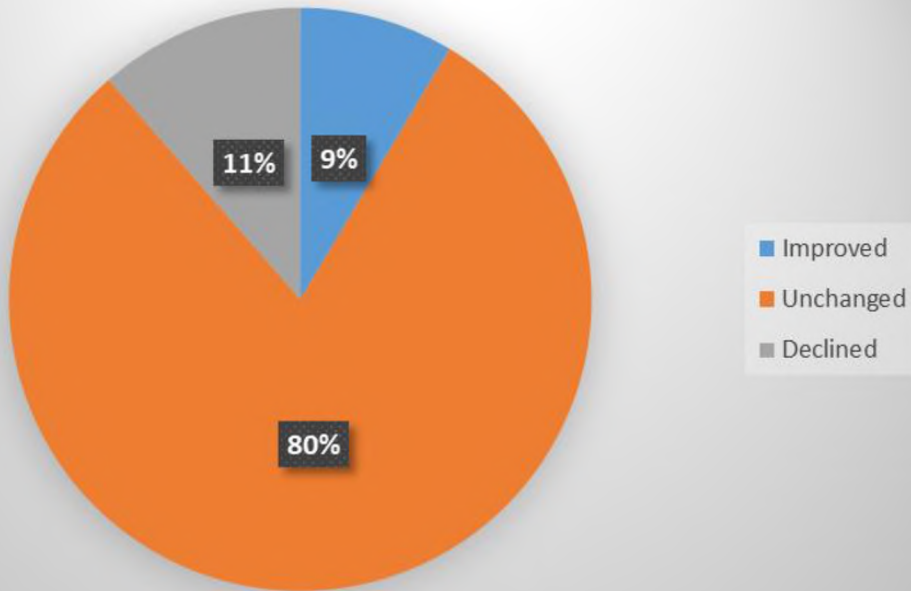


Figure 3. Change (RCI > 1.96) in mental well-being from commencement of employment to 12 months in program

Plain language interpretation of findings

Although a small number of participants showed some improvement in terms of mental well-being, the vast majority of participants showed no meaningful change, and a further small number reported decrease in their mental well-being at 12 months compared to their scores when starting the program.

Summary and recommendations

These findings suggest that working within a supported environment did not lead to significant improvements in mental well-being for the majority of individuals over the course of approximately one year. These results emphasise the importance of developing strategies to support and encourage mental well-being, and indeed health and well-being more generally. This is especially true amongst people employed within the Dandelion Program who may be at particular risk of poor mental well-being.

In the next sections we review and discuss aspects of mental health (depression, anxiety) and sleep, which are all likely to be associated with mental well-being. However, improving mental well-being amongst employees may involve different strategies that focus on the positive aspects of well-being, rather than on strategies aimed specifically at reducing mental health problems (i.e., depression, anxiety).

Anxiety

Anxiety in autism

Anxiety is characterised by anticipation of a future threat. It can influence thoughts, behaviours and physiological responses (e.g., fast heart rate, increased perspiration). Although some anxiety is both normal and common in everyday life, excessive and persistent anxiety can interfere with well-being and daily functioning. In Australia, 14% of individuals experience clinical levels of anxiety throughout the year. This figure is higher for adults with autism. Our recent research estimated 46-64% of Australian adults with autism experience clinically high levels of anxiety.¹⁶

The higher rates of anxiety amongst people with autism may be associated with the difficulties they often face navigating their environment. Behaviours common to autism, for example a preference for sameness, could represent an attempt to regulate anxiety by constraining the uncertainty and unpredictability of the environment. The unique presentation of anxiety amongst individuals with autism may result, for example, in retreat into specific interests or hobbies, or an increase in repetitive behaviours.

Measure

The DSM-5 Dimensional Anxiety Scale (Cross-D) was used to assess anxiety symptoms, and is designed to apply to any anxiety disorders (i.e., is not specific to particular disorders, such as social anxiety). Participants completed 10 questions, answered on a 5-point scale (never to all of the time), with total scores ranging from 0 to 40. Higher scores indicate a greater degree of anxiety symptoms. Scores over 16 have been found to be reliable indicators of clinically significant anxiety disorders.

In addition to the cut-off score, to evaluate change over time in anxiety scores, we again calculated the RCI.

Change in anxiety symptoms over time

Of the 35 participants, 7 (20%) reported very high symptoms on the anxiety scale at commencement of the program, and 9 (26%) did so at 12 months. Overall, 12 individuals reported very high anxiety symptoms at either time point, indicating that anxiety was a significant challenge for around one third of Dandelion employees at some point during the first 12 months of the program. Sub-threshold anxiety symptoms (i.e., showing symptoms but below a score of 16) were also present in many individuals, suggesting significant anxiety symptoms are prevalent amongst Dandelion employees.

To determine change in symptoms over time, we examined the RCI for reported scores at commencement and at 12 months. Two (6%) individuals showed a significant improvement (RCI > 1.96) in anxiety symptoms over the 12 months, and 3 (8%) showed a worsening of anxiety symptoms in the same timeframe. The remainder (86%) showed no significant change in symptoms over time, as presented in *Figure 4*.

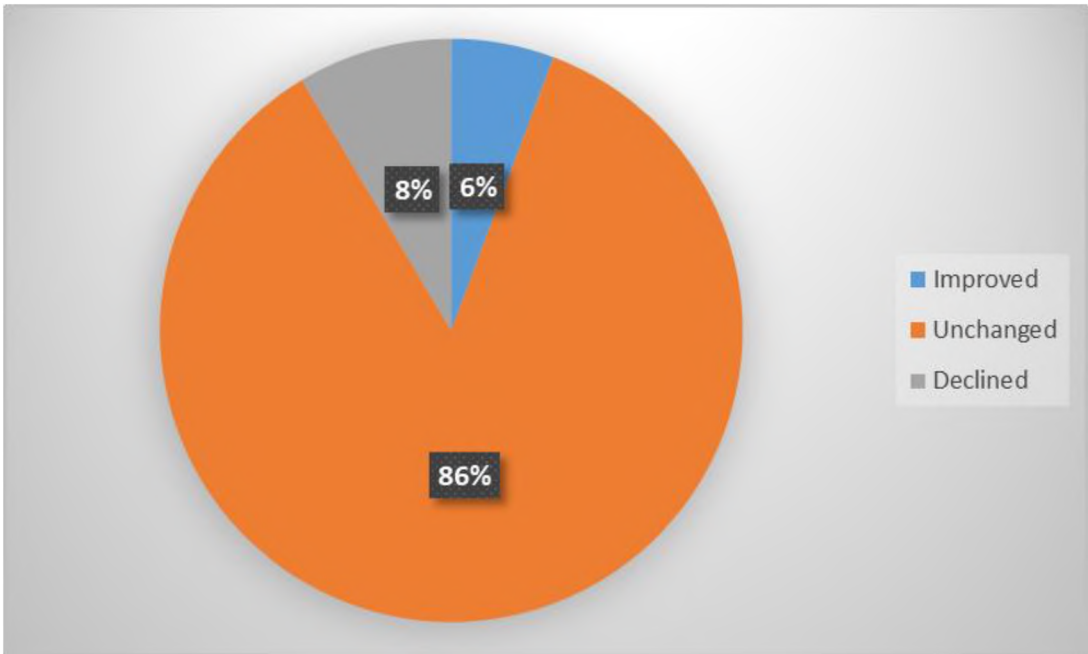


Figure 4. Change (RCI > 1.96) in anxiety symptoms from commencement of employment to 12 months in program

Plain language interpretation of findings

Overall, around one third of participants showed significantly high anxiety symptoms in the first 12 months of the program.

Almost 60% of Dandelion employees returned anxiety scores that were high enough to suggest at least some difficulties with anxiety. This rate is consistent with our own research which examined anxiety in Australian adults who are on the autism spectrum.¹⁶

Over time, a few individuals showed improvement in their anxiety symptoms relative to their initial reported symptom severity, and a few reported an increase in their anxiety symptoms from entering the Dandelion program and following 12 months.

For the majority of individuals, the levels of reported anxiety symptoms, although high, remained relatively constant over the 12 month period.

Summary and recommendations

It is important to acknowledge that many individuals with autism experience high levels of anxiety, and it can be difficult to manage or reduce these symptoms without specialised intervention, such as group or individual therapy. The work environment can provide additional stressors, such as noise, open plan office environments, unpredictable social situations, and both social and task related demands that can all potentially contribute to anxious feelings. However, these symptoms can be managed at work with understanding, awareness, and flexibility.

It can be useful to raise awareness in the workplace about anxiety, and to work with individuals to develop management strategies and enact workplace supports. Environmental provisions (e.g., space to remove oneself when anxiety is overwhelming, social banter restricted to non-working areas) and management strategies (e.g., flexible work hours, work location, and extra time off when needed) may help to reduce the impact of anxiety on the individual at work and ensure individuals challenged by anxiety can fulfil their potential at work.

Depression

Depression in autism

Depression is typically characterised by feeling sad, empty, or irritable. These feelings are often accompanied by physiological (e.g., tiredness, lethargy) changes, and can also affect a person's thinking. While everybody feels sad or low from time to time, when such feelings persist and significantly affect an individual's capacity to function, they could be considered to have a depressive disorder. In Australia, 9% of the population are thought to experience clinical levels of depression at some time in the year. Our own research indicates this figure may be as high as 28-38% for Australian adults with autism.^{16,17}

Higher rates of depression in autism could arise due to an awareness of being different from others, or from being bullied. It is associated with higher levels of loneliness and isolation. It is not unusual for people with high levels of depression to also experience high levels of anxiety. Much like individuals without autism, depression could present as low mood, difficulties concentrating, or worsening self-care. Depression may also lead to increases in autism characteristics, such as increased insistence on sameness.

Measure

Dandelion employees completed the Patient Health Questionnaire (PHQ-9), a nine-item questionnaire which measures major and subthreshold depressive symptoms. Higher scores indicate a greater degree of depressive symptoms, and a cut-off ≥ 10 can be used to indicate clinically significant symptoms, reflecting people showing moderate to severe levels of depressive symptoms.

In addition to the cut-off score, to evaluate change over time, we again calculated the RCI.

Change in depressive symptoms over time

Of the 35 participants, 11 (31%) were in the significant range for depressive symptoms on the PHQ-9 at program commencement, and 13 (37%) were at this range at the 12 month mark. Overall, 17 individuals returned significantly high depression scores at either time point, indicating that depression was a significant challenge for around half of the Dandelion employees during the first 12 months of the program.

In terms of change in symptoms over time, we examined the RCI for reported scores at commencement and at 12 months. Five (14%) individuals showed a significant improvement ($RCI > 1.96$) in depressive symptoms following 12 months in the program, and 12 (34%) showed a worsening in depressive symptoms in the same timeframe. The remainder (52%) showed no significant change in symptoms over time, as apparent from *Figure 5*.

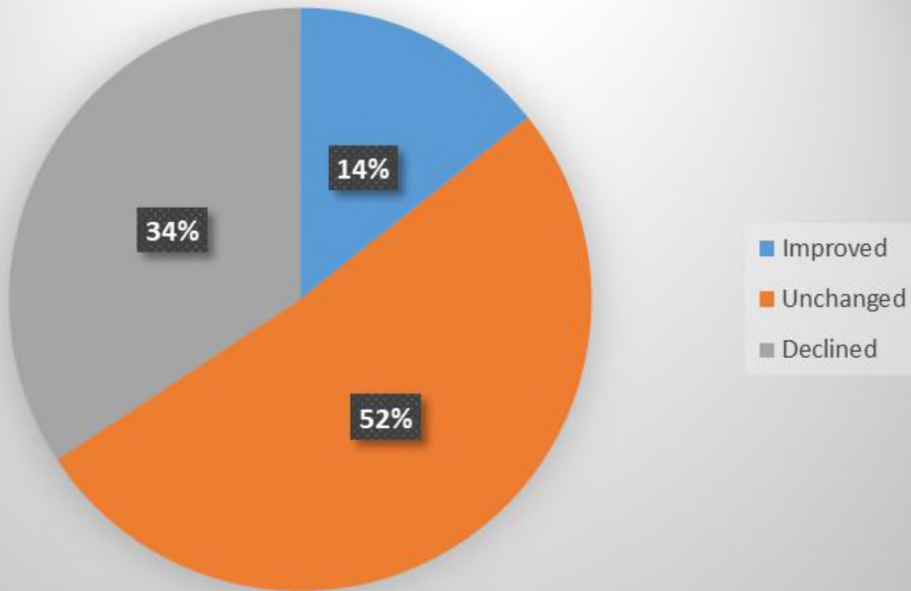


Figure 5. Change (RCI > 1.96) in depressive symptoms from commencement of employment to 12 months in program

Plain language interpretation of findings

In terms of severity or prevalence of depressive symptoms, 23-37% (8-13 individuals) of Dandelion employees reported particularly high depressive symptoms, depending on when they were assessed. This is not unexpected given the high prevalence of depressive symptoms in individuals with autism.

We were interested to know whether involvement in the Dandelion Program might result in a reduction in depressive symptoms over time. We expected this because employment can lead to positive personal outcomes such as increased financial independence, and opportunities to develop friendships and other social relationships, potentially reducing feelings of loneliness.

However, overall, the Dandelion employees appeared to show minimal change in depressive symptoms over time.

We then derived a measure of significant change which revealed that 52% of this group were unchanged following 1 year in the program, 14% improved, and 34% showed an increase in terms of depressive symptoms. Therefore, different people reported different patterns of change (i.e., profiles) in terms of their depressive symptoms following one year of involvement in the program.

An important question is why some people improved, some declined, and some were unchanged. In addition to the potential positive outcomes, employment can also be stressful. Even in a supportive environment, difficulties managing stress, and coping with the challenges of work life, may contribute to an increase in depressive symptoms observed in approximately one-third of the Dandelion participants.

An important consideration is that depression, if left untreated, can be particularly hard to overcome. While many people experience feelings of sadness as a normal part of life, it can be difficult to know when it might be useful or even necessary to talk to someone about these feelings. People may also think that no-one can really help them, particularly if they have had these feelings for a long period of time. Nonetheless, there are many effective treatments for feelings of depression, for example talking to a professional experienced in treating depression and other mental health concerns.

Medications can also be helpful, particularly if combined with therapy and behavioural or lifestyle changes. It is therefore very important to seek help or talk to someone to develop a strategy to combat these feelings.

In the case of Dandelion employees, managing work stress or challenges may make it difficult to find the time to seek assistance. They may also be concerned that their chances of keeping their job or of promotion may be affected if they seek assistance for their symptoms.

Summary and recommendations

Most workplaces now acknowledge the importance of supporting the mental health and well-being of their employees, and many will provide employees access to support services that are free of charge to the employee.

It is possible that work may exacerbate the difficulties people with autism have with their mental health. We recommend vigilance in terms of the challenges faced by Dandelion Program employees, and suggest targeted mental health training and awareness for support staff, co-workers, and the employees themselves. Developing a distribution list of service providers with experience working with mental health concerns in people on the autism spectrum would be beneficial.

Dandelion employees should be encouraged to talk to their support staff, supervisors or managers if they are experiencing significant feelings or other symptoms that might be associated with depression or other problems, so that they can be appropriately referred for services if needed.

Sleep

Sleep in autism

Sleep is important for maintaining physical and mental well-being, as well as daily functioning. Difficulties obtaining or maintaining sleep have been associated with decreased concentration and functioning during the day. Other outcomes of reduced or troubled sleep can include low mood, difficulties with emotional regulation, as well as poor mental health. Individuals with autism have been found to have more sleep disturbances, take a longer time to fall asleep and have poorer quality sleep than people without autism.

Measure

The Pittsburgh Sleep Quality Index (PSQI) was used to assess sleep quality. Participants completed 19 items concerning subjective sleep quality, time it takes to fall asleep, sleep duration, percentage of time in bed when asleep, daytime functioning, and sleep disturbances. The PSQI provides a global score ranging from 0-21, with lower scores indicating better sleep quality. Scores of 5 or greater indicate poor sleep quality.

To analyse sleep data we focused on the overall number of people reporting poor sleep quality using PSQI guidelines at 6 months and then again at 12 months. Data were available for 24 people at 6 months, and for all individuals at 12 months.

Finally, we also examined the relationships between sleep quality and health and well-being measures, as well as job satisfaction (job satisfaction is discussed more fully in the next section).

Sleep quality

At 6 months, sleep information was available for 24 individuals. Four individuals (17%) reported sleep quality in the normal range, and 20 (83%) reported poor sleep quality (*Figure 6*). At 12 months, sleep information was available for all 35 individuals. Five individuals (14%) reported sleep quality in the normal range, and 30 (86%) reported poor sleep quality (*Figure 7*).

Relationships between sleep quality and health and well-being

We further explored the relationship between reported sleep quality and the health and well-being measures. Poorer sleep quality was associated with higher anxiety and depressive symptoms, and better sleep quality was associated with better overall mental well-being. Interestingly, sleep quality was not related to job satisfaction.

Change over time

Overall, the frequency of poor sleepers to good sleepers remained stable over time. As shown earlier, no significant differences on the PSQI were identified for different time periods, suggesting participant sleep habits are relatively stable. Moreover, the high ratio of poor sleepers overall suggests that sleep remains a concern irrespective of whether or not individuals are working, with few employees overall reporting good quality sleep.

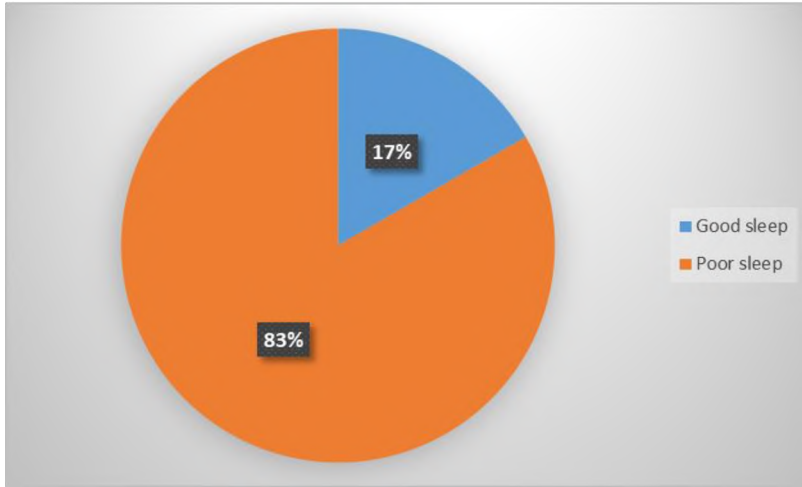


Figure 6. Reported sleep quality at 6 months

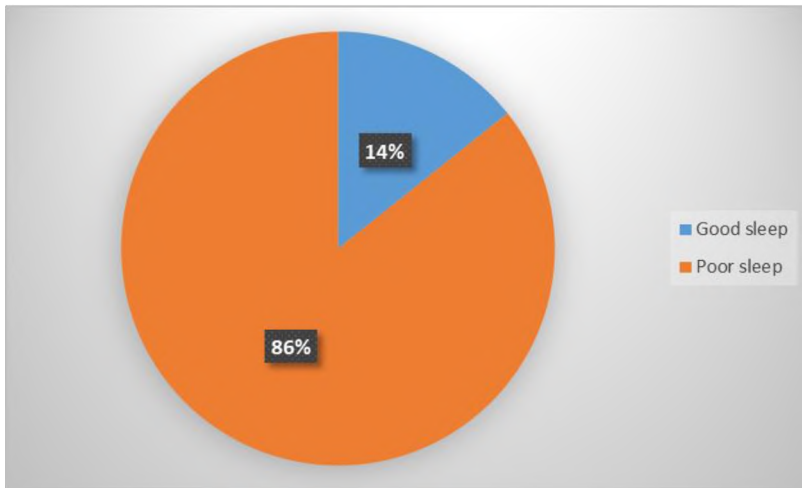


Figure 7. Reported sleep quality at 12 months

Plain language interpretation of findings

In this analysis of sleep quality we identified both a high prevalence of poor sleep quality amongst Dandelion Program employees, and also relationships between sleep quality and health and well-being outcomes. More specifically, we found that poor sleep quality was associated with poor outcomes in terms of depression and anxiety and, conversely, better sleep quality was associated with perceived better mental well-being. Job satisfaction was, however, not found to be related to sleep quality. Finally, the prevalence of poor sleep quality was relatively stable over time.

Along with depression and anxiety, poor sleep can be a significant challenge for people on the autism spectrum. As we identified here, sleep is interwoven with poorer mental health outcomes. This makes sense as symptoms of both depression and anxiety include poor sleep.

Summary and recommendations

It is important to acknowledge that many individuals on the autism spectrum experience poor quality sleep, and this can have flow-on repercussions for work, as well as other aspects of their lives. Sleep can generally be improved by ensuring good sleep hygiene (a term used for good sleep practices), but for more persistent sleep problems, sleep focused cognitive behavioural therapy, and some medications prescribed by a medical professional may help stabilise an individual's sleep cycle.

It is unclear how habits such as late-night gaming or other screen based activities affect people on the autism spectrum. However, avoiding stimulants (e.g., caffeine) and stimulating activities (e.g., gaming) before bed can be important factors in healthy sleep. Additionally, limiting exposure to bright light just before bed aids sleep, while early morning exposure to light, such as the sun or even artificial light, can help to reset the sleep-wake cycle. However, this may depend to a large extent on the underlying cause of the sleep problem, thus it is important to discuss sleep (and any other health concerns) with a medical professional to determine the appropriate treatment for the individual.



Job satisfaction

Job satisfaction

Dandelion employees' job satisfaction was compared with graduate level employees (without autism) who were starting work at the Canberra DHS site at approximately the same time as the commencement of the Dandelion Program. This latter group were selected because they were employed under similar conditions and at the same site, and were entering similar job roles to Dandelion employees. Graduates were not, however, matched to Dandelion employees on other factors including age or gender.

We assessed job satisfaction in both groups following on-boarding, and at 6 and 12 months of employment. Fifteen graduates completed the survey at commencement; unfortunately only 10 completed the survey at 6 months, and only 5 remained after 12 months. Although we compared job satisfaction between groups at all time-points the reduced participation rates in the graduate group needs to be considered when interpreting these results.

Measure

The Minnesota Satisfaction Questionnaire (MSQ) is a 20 item job satisfaction questionnaire. Questions relate to satisfaction with, for example, praise, getting along with co-workers, pay, and opportunities for advancement, which are rated on a 5-point scale. The MSQ provides three scales: Intrinsic Satisfaction--satisfaction with the content of the job or job itself (score range 12-60), Extrinsic Satisfaction--satisfaction with the work environment(e.g., supervision, working conditions; score range 6-30), and General Satisfaction (score range 20-100). Higher scores indicate greater job satisfaction.

Job satisfaction

Although we are somewhat limited by the small sample size in the comparison graduate group, we found that intrinsic and overall job satisfaction was significantly higher in Dandelion employees compared to the graduate cohort at program commencement. However, these differences ameliorated at the 6 and 12 month time points, with Dandelion employees and graduates reporting almost identical levels of job satisfaction. This result is presented in *Figure 8*.

Change over time

Overall, neither group showed a significant change in job satisfaction over 12 months, remaining relatively high on intrinsic, extrinsic, and overall job satisfaction across all time points.

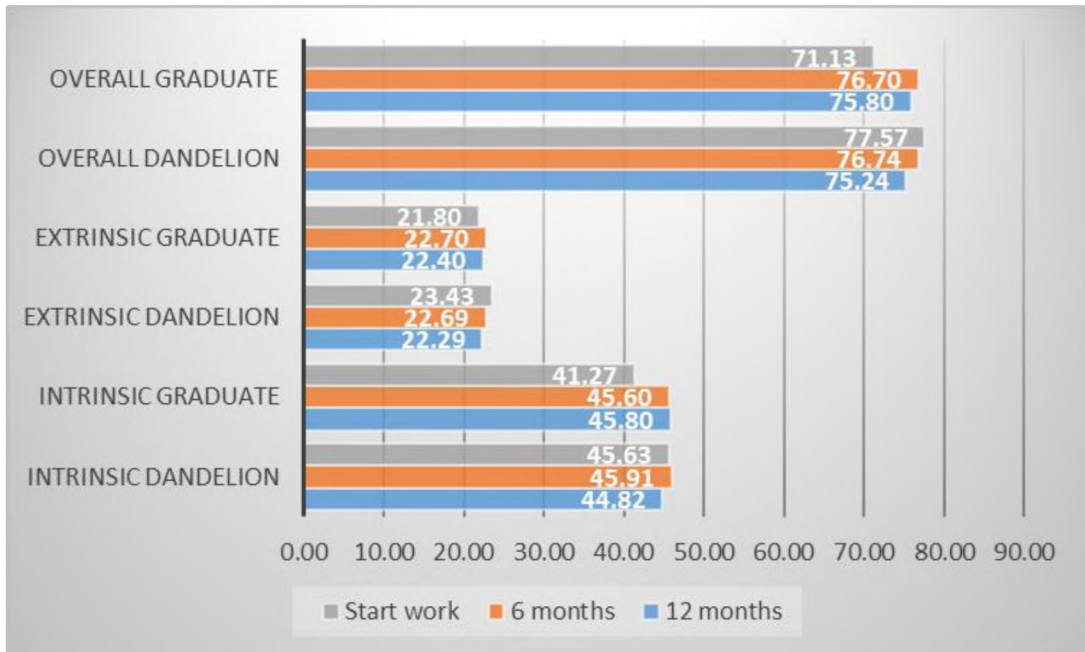


Figure 8. Overall, extrinsic, and intrinsic job satisfaction at commencement, 6 and 12 months for Dandelion Program employees and DHS graduate cohort

Plain language interpretation of findings

Compared to the graduate control group, Dandelion employees reported overall similar levels of job satisfaction across the 12 month period. This is encouraging for several reasons. First, despite the personal challenges faced by employees on the autism spectrum, they generally appeared to both remain positive about their work, and were satisfied with it. These findings suggests that, when provided with reasonable supports, Dandelion employees are able to navigate and overcome barriers to employment.

Second, as we have noted previously, although integration into the broader workforce was challenging and employees within the Dandelion Program remained somewhat separated from the broader workforce,¹¹ particularly in the first year, this factor did not seem to affect their satisfaction at work.

Third, it is encouraging that job satisfaction remained relatively high during the course of the program, suggesting a resilience in terms of overcoming personal barriers to work.

Summary and recommendations

The inclusion of job satisfaction levels for both entry level graduates and Dandelion employees provides a baseline for understanding satisfaction at work for employees with autism. With sufficient supports in place, employees with autism do enjoy their work. This is important, because being satisfied at work is critical for being productive, and reducing turnover. This is also relevant for sustainability, as investment in employees who are new to their job requires time to fully manifest. In other words, in return for investing in training and support, the longer the employee stays at the company, the better the rate of return as the employee's productivity will improve overtime as they become more skilled at their job over time.

Job satisfaction has been relatively overlooked in the autism employment literature up until now. Our results suggest that, not only is job satisfaction in employees with autism comparable to a similar cohort of employees without autism, but also job satisfaction can be sustained, at least in a supported work environment. This is likely to contribute to factors such as retention and productivity, and the sustainability of supported employment programs, such as the Dandelion Program.

Conclusions

This research found that overall, most participants in the Dandelion Program showed stability in health and well-being following one year of involvement in the program. In addition, this research found that some people also showed improvements across the measures used, and some also reported decline, or increase in symptoms. This highlights the importance of focusing on the individual, rather than overall scores when evaluating the impact of programs such as the Dandelion Program.

The Dandelion Program reports excellent retention rates and successful transitioning into open, competitive employment.⁸ Our qualitative research (summarised here and reported in detail previously; please refer to references for links) based on extensive interviews with participants found that most were positive about their involvement in the program and would encourage others to do it.^{1, 2, 4, 11} However, they also discussed many challenges, and the importance of having quality supports to assist them to manage and overcome these challenges.

Thus, although the Dandelion Program offers many benefits for program participants, our research suggests that underlying difficulties with co-occurring conditions including depression, anxiety, and sleep difficulties, continue to challenge employees who are on the autism spectrum. This highlights the importance of providing quality workplace supports to those who need them. Further, it highlights the significance of program retention, and also job related factors such as productivity and satisfaction, as useful outcome markers for employment programs that are aimed at people with autism, one of the most disadvantaged groups in terms of employment, and also other (e.g., health and well-being) outcomes.

The workplace itself may present additional challenges to employees on the autism spectrum. However, productivity levels suggest a certain resilience in managing work related stresses. What appears essential is that the best quality of supports are provided where necessary to assist the person in overcoming work-related stresses and challenges. The provision of quality supports further enables individuals to be successful in maintaining their employment, and in developing their skills and technical abilities, to further their career development.

The results of this research, for the first time, allowed us to examine potential impacts of the Dandelion Program on the employees, in terms of health and well-being. The research revealed both challenges and also the efficacy of the supports put in place, which have led to many positive outcomes for the individuals involved in the program. These positive outcomes include high retention rates and movement into open employment, along with strong levels of job satisfaction. These findings complement our qualitative research, which highlighted the impact and value of the Dandelion Program to individuals on the autism spectrum, their families, and also to the organisations and co-workers. We will continue to chart longer term outcomes as more data become available across sites.

It is extremely important to acknowledge the personal struggle that many individuals on the autism spectrum face finding and maintaining meaningful and appropriate employment. At the same time, we must also acknowledge the significant contribution these employees can make to the workplace. Much of this is achieved irrespective of their mental health and well-being which was largely stable over time.



Recommendations

Although only a small number of individuals showed decreases in their mental health and well-being over 12 months of their involvement in the Dandelion Program, it is also important to note that, overall, Dandelion employees reported high incidences of mental health concerns.

In conversations with support staff and program directors, this factor has been identified as an ongoing matter of concern that affects the sustainability of the Dandelion Program. Furthermore, support staff and supervisors are often the ones required to provide support for Dandelion employees while they are coping with sometimes overwhelming mental health difficulties and challenges at work, or in their personal lives.

For these reasons, our recommendations focus on the development of specific programs and educational material to increase the level of workplace support for employees on the autism spectrum. We suggest that this material can be beneficial not only to people in the Dandelion Program, but to other organisations that employ people on the autism spectrum. These recommendations may also prove helpful to employees who are not on the autism spectrum, but who also experience significant mental health challenges.

- Development and implementation of a cost effective education and training program to support the mental health and well-being of employees with autism within the workforce.
- Implement a general positive well-being program that targets positive and healthy living.
- Given the weight of support is often placed on ACSs and supervisors, we suggest developing a mental health and autism training program for staff who may be required to manage a mental health crisis in the workplace.
- Identify region specific professional support networks that can be accessed for referral purposes.
- We support the implementation of broader workforce training and awareness concerning mental health and well-being programs.
- We continue to encourage integration of Dandelion Program employees into the broader workforce to increase their access to social networks and development of professional relationships.

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Appendix: Instrument summary

Autism Spectrum Quotient (AQ). The adult AQ is a self-administered instrument that was designed to assess the degree to which adults with normal intelligence exhibit traits associated with the autism spectrum. Scores range from 0-50 with a higher score suggesting a higher degree of autistic traits. Two cut-off scores are reported in the literature (26, 32), with a score of 32 out of 50 on the AQ predicting a clinical diagnosis of ASD.

Warwick-Edinburgh Mental Well-being Scale (WEMWBS). WEMWBS is described as a 14-item scale of mental well-being (thoughts and feelings) including subjective well-being and psychological functioning in the previous 2-weeks. Items are scored on a 1-5 Likert scale ranging from 'none of the time' to 'all of the time'. Items are summed to provide a total score (score range 14-70) with higher scores indicating more positive mental health. A provisional population mean score is provided in the manual of 50.7, 95% CI [50.3, 51.1] from a Scottish sample (n = 1749). The manual reports reasonable construct validity, internal consistency (Cronbach's alpha .89) and test-retest reliability (intra-class correlation coefficient after one week = .83).

World Health Organization Quality of Life-BREF (WHOQOL-BREF). WHOQOL-BREF is a 26 item assessment of quality of life. The short form is an abbreviated version of the WHOQOL-100. Quality of life is defined as "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". The WHOQOL-BREF is based on a four domain structure which includes: Physical health (activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity); Psychological (bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality, religion, personal beliefs, thinking, learning, memory and concentration); Social relationships (personal relationships, social support, sexual activity); Environment (financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment, transport). Two items which assess Overall Quality of Life and General Health are also included. Higher scores denote a higher perception of quality of life. Raw scores are transformed to a 0-100 scale.

Minnesota Satisfaction Questionnaire, short-form (MSQ). The short-form MSQ is a 20 item self-report measure of job satisfaction based on the theory that work fit is dependent on the relationship between the individual skills and the reinforcement in the work environment. Items are rated on a 5-point Likert scale (1 "very dissatisfied with this aspect of my job", 2 "dissatisfied with this aspect of my job", 3 "can't decide if I'm satisfied or dissatisfied with this aspect of my job", 4 "satisfied with this aspect of my job" and 5 "very satisfied with this aspect of my job"). Item responses are summed or averaged to create a total score – the lower the score, the lower the level of job satisfaction. The short-form MSQ provides three scales: Intrinsic Satisfaction (score range 12-60), Extrinsic Satisfaction (score range 6-30), and General Satisfaction (score range 20-100). Percentiles are available based on normative data for different occupations (professional, technical, managerial; clerical and sales; service; mechanical trades; bench work).

Patient Health Questionnaire-9 (PHQ-9). PHQ-9 is a 9 item, self-report measure of depression. Items are rated on a 4-point scale from 0 (not at all) to 3 (nearly every day), with higher scores indicating increased depression severity. Total Scores can also be rated as: Minimal depression (1-4); Mild depression (5-9); Moderate depression (10-14); Moderately severe depression (15-19); Severe depression (20-27). It has been widely used across both general and different clinical populations with high internal consistency (Cronbach's alpha .86 - .89), good construct validity, and high discriminant validity.

DSM-5 Dimensional Anxiety Scale: Cross-D (DSM-5 DAS: Cross-D). DSM-5 DAS Cross-D is a self-report measures of overall anxiety (cross-cutting dimensional scale utilised here), as well as the severity of DSM-5 anxiety disorders. It has good validity, sensitivity, and specificity and high internal consistency (Cronbach's alpha .90 - .97).

Interpersonal Support Evaluation List-12 (ISEL-12). ISEL-12 is a self-report questionnaire designed to measure perceived social support. It contains 12 items that assess the perceived availability of social support on a 4-point scale ranging from 0 (definitely false) to 3 (definitely true). Items are summed to create an overall social support score (score range 0-36) and three subscale scores representing appraisal, belonging, and tangible social support (score range 0-12). It has good construct validity and reliability in the general population (Cronbach's alpha .88 - .90).

University of California Los Angeles Loneliness Scale (UCLA-LS). UCLA-LS is a 20-item scale designed to measure one's subjective feelings of loneliness as well as feelings of social isolation. Each item is rated using a 4 point Likert scale ranging from "never" to "often". The scale provides a total score (range 20-80) with a higher score indicating increased loneliness. It has been shown to have good to excellent psychometric properties with internal consistency $\geq .84$.

Pittsburgh Sleep Quality Index (PSQI). PSQI is a self-report questionnaire that assesses sleep quality over 1 month. It contains 19 items creating 7 components and a composite sleep quality score. Lower scores signify better sleep quality. Cronbach's alpha is at least .70.



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