

SOCIAL NOTWORKING

A study of “well-being” and social care in
Scotland

June 2017

INTRODUCTION

The debate around how we meet the growing demands being place on our health & social care services continues to be one of the most difficult of our time.

The Scottish Government and the Scottish Parliament, through legislation and numerous strategies; its Committees and Members, has strived to meet the challenges we face by creating the climate to deliver dynamic, flexible and person centred responses.

The Social Care (Self-Directed Support) (Scotland) Act 2013 and the Public Bodies (Joint Working) (Scotland) Act 2014 sought to challenge culture, break down silos, bring together “experts” and find innovative and creative solutions on an individual, case-by-case basis.

But there’s no getting away from the macro-fiscal climate that we are also operating in.

A global financial crisis that left developed economies reeling and struggling to find their equilibrium; a fiscal policy at U.K. Government level aiming to bring down the deficit and all that means for public expenditure; the uncertainty of “Brexit” and what this will mean for our economy, our workforce, our working conditions and how we continue to attract the very best skills to our shores to meet our needs.

It’s a complicated and challenging time.

And yet, too often we focus on the simple dynamics of what is a complicated problem.

How do we meet the needs and demands of today’s communities and the needs and aspirations of the individuals therein with all that’s going on around us.

We debate and discuss the amount of money being invested in our most treasured services; we count the number of nurses and doctors; the number of hours we expend supporting people to remain in their own homes or a homely environment, we even count the number of years people live in relatively good health and seek “transformative change” through channelling available funds to areas of deprivation to break the link between poverty and ill-health.

We count the number of people on each Option available through Self-Directed Support.

We’re good at counting things, that’s not in question.

What the debate never seems to extend to though is the most fundamental of all measures - the “wellbeing” and “quality of life” experienced by our citizens.

This is, after all, the main driver behind our quest for meaningful change.

We count the pounds and pence expended but until we start asking ourselves what this expenditure is achieving (or buying), we don’t actually know whether the investment is making a meaningful difference or achieving what we set out to achieve - a BETTER QUALITY OF LIFE and improved “well-being”.

The lack of qualitative data perplexed me. Are we measuring the right things? Are we measuring what is meaningful or just what is easily measurable?

Can we measure what really matters?

This led to a discussion with Alan Crozier, Managing Director of Q4 Consulting Ltd, a renowned expert in the field of “Employee Engagement”.

Alan has been measuring, consulting and driving “employee engagement” for the past 30 years and has worked with some household names from across the globe, advising them on how to better engage and align their employees to achieve great business results in an environment that has individual employees at its heart.

This is a person centred approach in a context that many would perhaps not expect to see it - the “working environment” and big business.

If you can measure something as abstract as “employee engagement” then surely you can do the same for “well-being”? That was the challenge we set ourselves.

First, it was important to define “well-being”.

The term features in a whole range of articles and contexts. It appears in policies and in practice manuals. It extends to and often includes prefixes such as “mental”, “physical” and “emotional”.

I can confidently say there’s not a single Self-Directed Support themed event I’ve attended in the last Five years that hasn’t, at some stage, made reference to well-being or quality of life - but it’s never measured, never quantified or qualified.

Instead, it is usually assumed that by moving people away from “traditional” care services, it will inevitably improve and so we revert back to counting the number of persons on each of the 4 Options and extrapolating from this point.

DEFINING & MEASURING WELL-BEING:

Often referring to the “*state*” of an individual, the term well-being has, more recently, been used in reference to homogenous groups - “social well-being” and “national well-being” becoming more prominent and frequently referenced in the modern lexicon and social context.

In the end, we had to decide on a definition that suited our purpose, reflected our values and adequately described our mission:

WELLBEING IS DEFINED AS A SERIES OF INTERCONNECTED INDICES WHICH, WHEN TAKEN TOGETHER, GIVE AN APPROXIMATION OF A PERSON'S QUALITY OF LIFE.

Millar, 2017

Academics, experts and others may well suggest that “well-being” and “quality of life” are exclusive and different from the other.

In social care circles, the two are often seen as inter-related or inter-changeable and it is on that basis and against that backdrop that we proceeded.

The purpose of our research activity was not to challenge or to redefine people’s understanding or interpretation of “well-being”, it was the pursuit of a single, consistent and honest measure of what matters to people - to find and measure what matters to them and what impacts on their “well-being” in the broadest sense and then to express this as a quantifiable expression of a person’s “quality of life” at a particular time.

To that end, we were delighted to achieve a baseline in our initial survey.

What we also discovered was, we hope, far more powerful.

Having developed, refined, tested and verified our “well-being” metric using a range of complimentary techniques, we now firmly believe that we can start to drive improved “well-being” using the data the tool expresses.

The challenge now is taking our initial learning and findings and increasing the scale of our activity to cover a much larger group of Self-Directed Support users and to start to gather and evaluate longitudinal scores to quantify the effect that focussed interventions can or do have on an individual’s “well-being”.

What we aspire to achieve is “person centred planning” in it’s truest, purest sense.

And so to the title of this report, **SOCIAL NETWORKING** .

Our introductory report suggests that “social care” is “not working” when measured against the strategic aspirations and stated goals of the “Social Model of Disability”; the United

Nations Convention on the Rights of Persons with Disabilities (UNCRC) and the Self-Directed Support Act.

We seek to be good, constructive and challenging partners to the Scottish Government; the Scottish Parliament; the public bodies and social care agencies grappling with the challenges they face in terms of service delivery; personalisation; value for money and expressing the fruits of their endeavours as “the difference made to someone’s quality of life”.

It seeks to give meaning to the Scottish Government’s strategic priorities for social care and to aid practical application in the shift from measuring “*time and task*” to “*outcomes*” and more, to improving “*quality of life*” for social care users.

The title of this report is intentionally challenging but I also hope that we have made an important start on what will be an exciting and empowering journey for the people we’re privileged and fortunate enough to offer support to and seek to represent.

A handwritten signature in black ink, appearing to read 'C. Millar', with a long horizontal flourish extending to the right.

Colin Millar
Chief Executive Officer

EXECUTIVE SUMMARY

SOCIAL CARE AND WELL-BEING:

This report details the findings of a SPAEN / Q4 Consulting Ltd study into “well-being” across a section of social care service users in Scotland as captured between 1st - 21st May 2017.

The number of persons participating in the survey means that the findings of this report are only indicative and represent a small proportion of social care users in Scotland but nonetheless, the findings of the survey are significant.

WHY UNDERTAKE THIS STUDY?

There’s a simple reason we undertook this study.

“Well-being” is referred to in multiple national and local strategies and is often synonymous with and accompanied by eulogies of the importance of improving the well-being of individuals.

Yet despite the high profile and prominence that well-being has been given in these strategies, it became apparent that there was little or no way of measuring the impact supports and services were having on an individual or group’s well-being and that there lacked a single standard against which we could measure the difference such expenditure was making.

As a result of this study - that’s no longer the case.

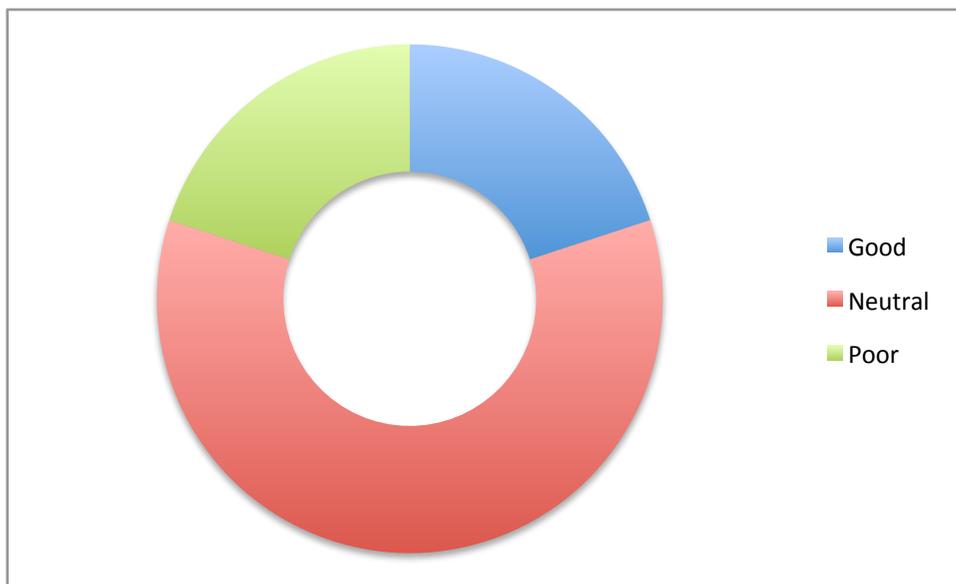
WHO WAS INVOLVED?

A total of 227 SDS recipients participated and either completely or partially completed the well-being survey.

WHAT WERE THE RESULTS?

In short, it was established that only 1 in 5 social care recipients responding to this exercise actually reported “Good” well-being and the same number reported “Poor” well-being.

When comparing the well-being of social care recipients responding to this study against the Office of National Statistics (ONS) surveys on similar indicators and metrics across Scotland, it was ascertained that social care recipients have significantly lower self-reported well-being.



This was an inaugural study and we cannot therefore suggest any kind of pattern or trend and therefore any correlation between the roll-out of Self-Directed Support and well-being however, it is worthy of note that we are 70% through the Self-directed Support strategy, a national strategy which aimed to improve the life experiences and choices of social care recipients in Scotland to increase well-being.

This study suggests that progress toward a more person centred approach to social care and the integration and equality of social care recipients across Scottish communities is still not necessarily having a positive impact on the well-being and quality of life for 8 in every 10 people who responded.

KEY FINDINGS:

The study ascertained that social care recipients score more positively around aspects of their lives in which they have greater choice and / or control; when they have a sense of “*self-worth*” or strong sense of “*purpose*”; are surrounded by supportive informal (community) networks and have a sense of hope or personal aspirations for their future.

These dimensions were measured under and pointed to the “*Intrinsic Well-being*” of an individual or group.

Recipients scored less positively around aspects of their lives in which they had less control such as being able to participate in normal daily / community life; where they felt disempowered, disconnected or ignored; and lacked natural or informal support networks.

Not being encouraged or actively being discouraged to develop a sense of hope or set personal goals and aspirations and a lack of “*choice*” also a significant factor in negatively affecting a person’s well-being.

These areas were measured under “*Extrinsic Well-being*”.

SOCIAL NOTWORKING:

And so to our conclusions and the title of this report, **SOCIAL NOTWORKING**.

Our findings suggest that there are several dynamics within the social aspect that are not working, including:

- general social constructs such as natural networks and community involvement that is an intrinsic part of feeling accepted by peers is either not present or is remote and unachievable;
- There are a lack of meaningful measures and metrics to ascertain whether any progress is being made in seeking to integrate, establish and sustain disabled people / social care recipients in “*normal*” community life;
- Formal supports (such as paid for care) fail to recognise the importance of meaningfully involving and / or deferring to the person in receipt of support about aspects of their daily life as the default rather than the exception; and
- Individual SDS users are not being afforded choice and / or markets not evolving to facilitate choice.

IN ORDER TO DRIVE MEANINGFUL CHANGE, WE NEED TO MEASURE WHAT MATTERS AND TO MEASURE IT CONSISTENTLY AND FREQUENTLY.

CONCLUSIONS:

The precepts of the Self-Directed Support strategy should and, where fully delivered, do appear to create greater self-reported “well-being”.

However there remains significant work to be undertaken in areas including:

- Making meaningful inclusion in care planning and implementation the norm;
- Fully and properly devolving available financial resources to individuals through a Direct Payment (DP) or Individual Service Fund (ISF) to allow them to choose from and direct available supports; utilise creativity and stimulate local care service markets;
- Ensuring that formal supports such as paid care staffs are fully trained on person centred planning and that care provider agencies use a range of tools and techniques to measure this is being done (through 360° appraisals / satisfaction surveys or similar); and
- Assist individuals to identify ways of engaging with and becoming active participants in their communities including through volunteering and / or paid employment as a recognised part of the social care strategy; and
- Regularly and frequently reviewing an individual’s progress; life circumstances; aspirations and needs and adapting and adjusting care plans and resources accordingly and timeously.

METHODOLOGY

DEVELOPING A WELL-BEING TOOL:

The methodology for our “well-being” study was premised on a tried, tested and proven model used by Q4 Consulting Ltd (*Precis*®) for measuring “Employee Engagement” combined with SPAEN’s “YOUR Plan”, a tool and technique developed around the Social Model of Disability and used by the charity for person-centred planning.

In developing a “well-being” tool, we considered and drew from the Organisation for Economic Development and Co-operation (OECD) and the Office for National Statistics (ONS) indicators used for measuring “*well-being*” nationally and internationally.

However, it was important to us that the final tool gave due cognisance to our target audience -people in receipt of social care supports - and that questions were tailored to acknowledge and reflect their circumstances.

The tool also took into consideration Government strategies such as Self-Directed Support, where the primary aim was to achieve meaningful inclusion and equality for disabled people.

A “Development Group” comprising a range of stakeholders was formed and met on 3 separate occasions.

The Development Group considered the important factors associated with “*well-being*” and “*quality of life*” and finally agreed 5 key “Dimensions” and 2 key “Outcomes” that, when measured together, would provide an approximation of someone’s overall “well-being”.

Under each of the 5 key Dimensions, a question set was developed.

The questions were devised and refined using a range of key stakeholder groups including Health & Social Care professionals; SDS users; disabled persons; expert consultants and social care service providers.

The group invited feedback and comment from persons with considerable practical and academic experience in the field of “well-being” and “social care”.

A consultative group representing a range of stakeholders agreed the final questions to be included in the tool before we entering into a closed testing phase.

The tool presented a series of 33 statements inviting respondents to grade their response using a Likert scale ranging from “Strongly Disagree” to “Strongly Agree”.

TESTING THE TOOL:

Once agreed, the Tool was exposed to a period of “closed testing” and a number of SDS users known to SPAEN were invited to complete the Tool and provide feedback.

Independently of their participation and use of the web based tool, SPAEN completed “YOUR Plan” for the same sample users.

The completion of “YOUR Plan” included face-to-face interviews with the test group.

The social care assessors completing “YOUR Plan” interviews were not privy to the data collected through the well-being tool.

VALIDATING THE TOOL:

The social care assessors were then invited to place indicative scoring against each of the “Dimensions” contained in the well-being tool based on their in-depth, person centred interviews with the trialists.

The social care assessor undertook to co-produce “YOUR Plan” with the trialists, identifying personal goals, aspirations, interventions and supports that were considered beneficial to the individual’s well-being and the trialists were invited to enact their personal plans over the intervening period.

The indicative scoring given by the social care assessor based on the person centred interviews was then compared and contrasted on an individual basis with the data collected through the closed testing of the well-being tool

This ascertained and confirmed that the tool and assessor’s scorings were closely matched and highly consistent.

The activity was repeated after a period of the trialist following their co-produced personal plan using both “YOUR Plan” and the “well-being” tool independently.

The trailists showed improved scores across the well-being tool in the areas the co-produced personal plan had focussed and the positive impact of these interventions and actions was also evidenced in the follow-up one-to-one interviews conducted by the assessor independently of the well-being scores being known or shared.

It was concluded that the well-being tool had accurately identified a person’s overall “*well-being*” and was able to express this as a number on a scale of 1-5 not only at the outset of

their personal journey but also as their well-being improved or declined as a result of focussed interventions and activities or a lack thereof.

TIME REQUIRED:

The detailed one-to-one interviews required a total of 6-7 hours to complete (exclusive of travel time). This included an initial interview using SPAEN's "YOUR Plan"; co-developing a personal outcomes plan; matching the personal outcomes to the stated and agreed outcomes in an individual's "Care Plan" (the plan developed and agreed by the Health & Social Care Partnership as part of the SDS assessment - this may be referred to as something different in each HSCP) and then the follow-up interview.

The time taken to complete the well-being tool was approximately 10 minutes of the individual user's time with a further 30 minutes of the assessor's time required to interpret the data.

The interpretation of individual data can be done from a remote location and some preparatory work was found to be beneficial prior to the assessor and the individual meeting to discuss the results of the well-being survey.

It was ascertained that the well-being tool accurately identified areas of greatest need or concern in the trialist's life as validated by the independent one-to-one interviews.

It is important to state that the well-being tool did not negate the need for in-depth interviews and the co-production of a personal outcomes plan and that around 2-3 hours of input time was still required to achieve this.

However, in using the well-being tool, it was estimated that the time required of Health & Social Care professionals and / or other professionals working with individuals to develop effective "Care Plans" could be reduced by around 50-75% whilst still yielding highly effective results for the supported person without compromising the quality of the intervention or support provided.

Indeed, it is considered that the well-being tool was highly effective in highlighting areas that a person-centred conversation should focus around and that its use could yield consistent and effective results nationally.

Using the well-being tool also allowed the individual to complete a self-appraisal of the Dimensions independent of any external influence and / or bias (such as "leading questions") leading to a much more accurate assessment of the individual's quality of life.

The well-being tool successfully identified the areas where interventions should be keenly focussed to maximise benefit to each individual.

It should be noted and is stressed that the potential time saving benefits of the well-being tool are a "by-product" and the intention behind developing and utilising the tool was and remains

the measuring of an individual's "*well-being*" and the identification of focussed interventions and supports that can and do have a positive impact on same.

OPEN DATA COLLECTION:

Having tested and validated the efficacy and accuracy of the well-being tool in a closed testing phase, the tool was then hosted on a secure web URL with an open invitation to participate shared with a number of SPAEN members and other SDS users through social media channels and a number of other social care organisations.

We gratefully acknowledge the support provided to us by a large number of individuals and groups who shared the link to the tool, without their support and assistance, we would not have been able to reach such a wide audience.

The well-being survey was open from 1st May 2017 until 21st May 2017.

Initially, to assist in the validation of completed responses, participants were required to provide a range of nominal and demographic data.

After a period of operation, it became apparent that a number of participants were unwilling to or uncomfortable with share their personal data and, in the latter stages, these fields became optional rather than mandatory.

During the Open Data Collection period, a total of 227 individuals entered and partially completed the survey.

Of these, 67 responses were discounted from the final results as these participants failed to provide a sufficient number of responses to the questions and as such, were categorised as "tourists" (persons visiting the data tool to explore it but not intending to complete or participate in the overall exercise).

A further 97 respondents failed to complete the nominal and demographic data sections during the period this data was mandatory and these responses were therefore discounted from the final result.

This left 63 completed and validated responses on which to base the final findings and gives the inaugural survey a Confidence Interval of 11%.

It is recognised the Confidence Interval is high and any future mass data collection exercises would need to consider a range of factors found to be prohibitive in this instance such as the requirement of nominal and demographic data whilst balancing the absence of such information against the integrity of the final data collected.

SCORING:

The final results were arrived at using “Weighted Mean Scoring”.

Scores of 3.5 or above indicate “acceptable” levels of well-being and scores of 3.75 and above indicate “Good” levels..

Scores of below 3.5 indicate “Poor” levels of well-being and the lower the score, the poorer the individual’s or group’s overall well-being.

Weighted Mean Scores were available for individuals who completed the well-being survey as well as an overall score being arrived at for all participants.

This report only refers to grouped scores.

Scoring was broken down into a range of 5 key dimensions and 2 key outcomes as previously indicated and these are further described later in this report.

FINAL VALIDATION:

A final validation undertaken was the comparison of the well-being tool’s findings against other comparable studies, reports and findings from other bodies looking at the progress and roll-out of health & social care strategies in Scotland including those conducted by Self-Directed Support Scotland (2016) and the Health & Social Care Alliance (2017) amongst others.

These studies did not look at or consider “*well-being*” but did highlight areas for improvement in the current deployment of the Self-Directed Support strategy and professional practice in areas covered by the survey and it was therefore considered this was an appropriate way to further compare and validate the findings in comparable areas.

SURVEY FINDINGS

The survey and Tool measured a number of key areas affecting a person's overall well-being and impacting (positively or negatively) on their "quality of life".

The Tool measured responses against 5 "*dimensions*", namely:

- Purpose
- Autonomy
- Involvement
- Development
- Support

The Tool then measured responses against 2 "*outcomes*":

- Intrinsic Well-being
- Extrinsic Well-being

Of all the dimensions measured, "*Purpose*" scored highest with respondents reporting a high level of "*self-awareness*" including the positive or negative effect "*self-management*" of their personal situation and / or any health conditions may have on an their overall sense of well-being and their ability to participate in their community.

Respondents were generally clear on what they expected of and for themselves and a majority of respondents indicated they had considered their future and what they wished to achieve over a period of time.

Purpose also links to a person's sense of "*self-worth*" and "*self-respect*" and it was encouraging to see people scoring higher in this area, suggesting that SDS users view themselves as an intrinsic part of their community and having a real sense that they have something to offer which is of value.

The Weighted Mean Score for Purpose was in the "Average" range at 3.52 (with a score of 3.5 - 3.75 being within the "Average" range and anything over 3.75 being "Good").

Scoring for “*Involvement*” and “*Support*” were “Poor” with both measuring 3.46.

Around 50% of respondents stated they felt they were provided with sufficient information with which they could make an “informed” decision about their care and support and 59% felt that they had a good social circle but when asked to describe how connected they felt to their local community, the scores dropped significantly.

Fewer than half of all respondents felt they were offered sufficient opportunity to engage with their local community and / or community activities and 66% of respondents stated they did not have the opportunity to contribute to their communities in a meaningful way.

Community disconnect was a theme that came through very strongly and it serves as a timely reminder that people can and do feel isolated and excluded from their community despite receiving supports and services within a community setting.

THE RESULTS REMIND US THAT COMMUNITY IS ABOUT FAR MORE THAN JUST WHERE YOU LIVE OR WHERE YOU ARE AT THE TIME OF RECEIVING SUPPORT, ITS ABOUT BEING ABLE TO MEANINGFULLY ENGAGE AND CONTRIBUTE; TO BE ABLE TO PARTICIPATE AND FOR SUCH INCLUSION TO BECOME THE ESTABLISHED NORM.

We need to make a distinction between “*community based*” activities - activities that are undertaken in a community setting but are not actually advancing community engagement and participation, and activities that aim to develop community activism and inclusion.

The former is care in the community and the latter is, in its truest sense, lived equality.

Until the distinction is made clear and the front line social care workforce are developed and encouraged to recognise the difference, it is likely that SDS users’ well-being and quality of life will continue to suffer to some extent.

A lack of available support in respondents’ areas was recorded as a further barrier to people feeling involved or enabled to become involved in community life.

Despite being 7 years into a 10 year strategy, it would appear that normal market forces have failed to properly stimulate and generate adequate provision of a range of social care services to choose from.

It is only speculation and supposition at this point, but it may well be that the continued financial squeeze placed on and subsequently passed down from local authorities and now Health & Social Care Partnerships has had a negative impact on the availability and sustainability of localised support services and what remains is a pseudo-representation of Darwinian evolution where only the “*wealthiest*” have survived.

Whilst this would be expected of normal market economics, it should be considered whether leaving such commercial forces are good for the overall well-being of the people we seek to support and serve in communities.

“*Wealthy*” organisations may be those who have significant financial resources to deploy at times of uncertainty or to who are able to “*undercut*” smaller competitors based on cost of services being procured rather than based on “quality” of service being provided and “value to the end user”.

(We make a distinction between “*rich*” organisations and “*wealthy*” organisations. “Rich” organisations may be so considered because they have a deep pool of resources; experience; high quality staffing and are able to add value through the services and products they provide.

“*Wealthy*” organisations tend to dominate their preferred market or sector through the deployment of financial resources and this does not necessarily correlate or influence “*quality*” of product or service but may, instead, suppress competition.)

GIVING TRUE AND MEANINGFUL EFFECT TO OPTION TWO AND ENABLING ALL SDS USERS TO BECOME COMMISSIONERS OF SERVICES WILL CREATE MORE EFFECTIVE MARKET CONDITIONS AND DRIVE UP QUALITY.

As stated, this is supposition and it may be that in reviewing how we improve the “*well-being*” and “*quality of life*” of social care recipients in Scotland, a full and comprehensive review is undertaken to consider how new entrants or smaller providers in the social care market are incentivised and / or supported to constructively challenge monopolies where such are found to exist and these are considered to be to the detriment of the community’s “*well-being*”.

(Note: procurement legislation does allow Health & Social Care services to be procured outside the normal procedures and it may be that any future review considers the prevalence of this exemption being used).

Health & Social Care Partnerships and other public bodies have started to include “*value*” proposition and social return on investment in their weighted assessment of tender bids but this is relatively new and may take some time to feed through to tangible results.

Restrictions being placed on the use of available funds through pre-paid cards or Individual Service Funds being held by the funding authority or service provider and the continued existence of “*approved provider lists*” for social care will continue to restrict normal, healthy market growth.

The benefit of such practices should be considered and reviewed against the dis-benefits experienced by social care users where markets are restricted; “*choice*” is therefore limited or non-existent and the impact this has on users’ well-being.

In relation to “*personal development*”, the split was again 50/50 at best.

Respondents suggested that “*personal development*” was not a consideration in the SDS process and that it was instead about maintaining their existing condition / situation or slowing deterioration and any associated increased need.

6 out of 10 respondents did not know where to source support or advice on seeking suitable volunteering and / or paid employment opportunities and the same number of respondents felt they could not engage in such activities even if they wanted to.

Financial security and personal identity are intrinsically linked to an individual’s overall sense of well-being and their quality of life and both volunteering and paid employment are critical factors in these areas.

It is well documented that disabled people are more likely to live in relative poverty and, as a result, they are less able to withstand even short or small financial shocks. The current social care delivery model does not appear to be bettering peoples’ opportunities to break this link.

Social care faces a dichotomy in this regard.

It is the stated aim of the Scottish Government’s Self-directed Support strategy to empower people to exercise choice and control to “*meet their personal outcomes in participating fully in economic and social life*” and to “*create vibrant communities where everyone can learn, work and socialise together.*”

Source: Social Care (Self-directed Support)(Scotland) Act 2013

Yet simultaneously, Health & Social Care Partnerships are, in the main, only providing social care support and funds to persons assessed as having “*critical*” needs, with social, cultural and economic participation being considered superfluous or “*nice to have*” and therefore outside the range of support eligible for funding.

It would therefore appear that the existing system contrives to maintain a vicious cycle of social, cultural and economic exclusion which, in turn, leads to poorer well-being, reduced quality of life and increased risk of further poor health, social exclusion and isolation.

Around half of respondents felt they had sufficient financial resource to meet their basic needs adequately and the same number also felt they had sufficient financial assets to maintain a “*reasonable quality of life*”.

When asked about the level of “*autonomy*” they were able to exercise, respondents generally felt they were involved in the main aspects of their life such as deciding how their personal goals should be achieved but this level of “*involvement*” did not carry through to the practical aspects of the “*care and support*” that was being delivered.

This discrepancy suggests that some respondents were generally positive and felt listened to and involved in the assessment and person centred planning aspects and, where this is the case, this is a credit to the shift in culture at Health & Social Care Partnerships without doubt.

Other studies, such as those undertaken by Self-Directed Support Scotland, suggest the culture change required to ensure person-centred planning and meaningful involvement in this process is inconsistent resulting in a “*postcode lottery*” for social care recipients.

The findings of this study suggest that such a haphazard and inconsistent approach will have a detrimental impact on an individual’s quality of life and overall self-reported wellbeing.

What was equally interesting was that the same level of “*involvement*” and “*control*” did not continue into the delivery of the person-centred plan and respondents scored much lower when asked whether they had a “*good input*” into how their personal goals were delivered and achieved.

These findings suggest there remains a shift still to happen in the “front line service delivery” of social care support whether that’s through Personal Assistants; care agencies or support provided through statutory bodies.

The Tool did not seek to ascertain which Option respondents were using under the Social Care (Self-directed Support)(Scotland) Act and we cannot therefore draw further conclusions about whether this lack of shift in culture is across all front line care services or isolated to care and support delivered through a particular Option.

Future exercises could include this data and may provide an insight into the extent to which this change in practice has failed to materialise and has left SDS users feeling less involved than is intended or optimal for good well-being.

Around three quarters of respondents stated that their current accommodation was suitable to meeting their lifestyle and needs.

Another key factor assessed as having a significant bearing on a person’s well-being was change and life changing events.

This is a very broad area and could include changes such as a deterioration in health or mobility; a loss of key supports or services; changing environmental factors or welfare and policy changes.

Only one third of respondents stated they felt they had access to sufficient or indeed any level support for “*life changing*” events such as those detailed above (although the above list is not exhaustive, merely illustrative).

This may link back to indications that SDS users and disabled people living in the community continue to feel disconnected from those around them and that sources of support are limited

with an over-emphasis on formal or paid support workers and / or Health & Social Care professionals rather than natural support networks.

When looking at “*independent support and advice*”, less than half of respondents stated they were able to access such.

This again points to a lack of natural support networks developing around and including people drawn from the local community and an over-dependency on formal supports such as Health & Social Care professionals and paid support workers.

The overall picture was of people receiving social care support feeling restricted and limited in how they are supported and by whom; isolated from their surroundings and communities; limited in their ability to positively influence and / or change these dynamics and unsure of where or how to access independent support or advice that could assist them make affirmative changes.

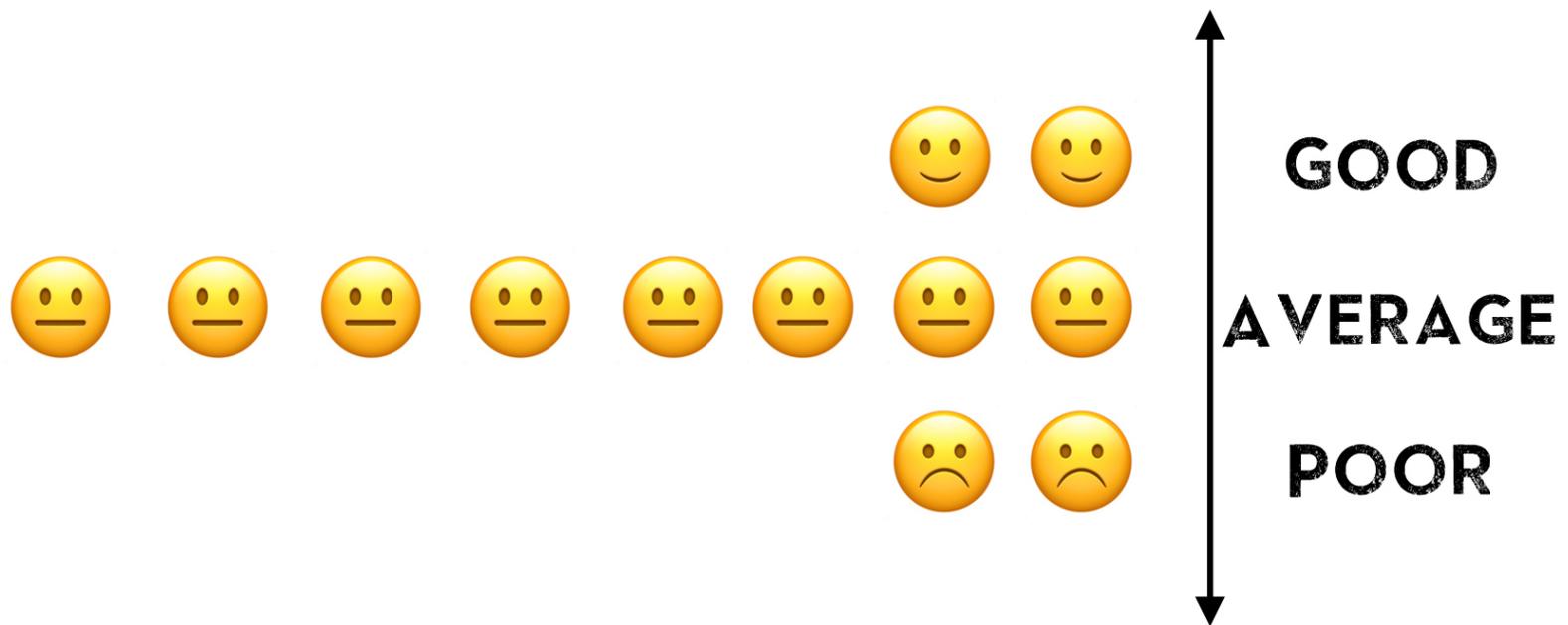
WELL-BEING SCORES / OUTCOMES

Not surprisingly based on the foregoing, the overall picture was that respondents “*intrinsic well-being*” (3.46) was higher than their “*extrinsic well-being*” (3.21) giving an overall “well-being” score of 3.34 (“Poor”).

Respondents had a stronger sense of well-being within themselves, their abilities, their self-identity and self-worth than they got from their external environment such as their formal supports and their community.

Overall, 1 in 5 respondents were assessed as having “Good” well-being (a score of 3.75 or above) with the same number of persons assessed as having “Poor” well-being (a score of less than 3) and 3 in 5 respondents meeting an “Average” level (3 - 3.5).

Within the group identified as having “Average” well-being, greater scoring in relation to the extrinsic factors affecting well-being would significantly improve their overall score going forward.



SIGNIFICANT DRIVERS OF WELL-BEING:

The following areas were recorded as significant in improving well-being and recorded high scores for persons who had an overall well-being score that was higher than average:

- 😊 Having clarity on personal goals;
- 😊 Knowing what you can do to improve your own well-being;
- 😊 Having a clear sense of what you want to achieve on a day-to-day basis;
- 😊 Being fully involved and empowered in making decisions about your life, how your needs are met and how your support is arranged / organised and delivered;
- 😊 Having suitable accommodation to meet needs and aspirations;
- 😊 Having good relationships with a support network (beyond formal supports);
- 😊 Being able to access independent and impartial support, advice and guidance in relation to “care issues”;
- 😊 Having a good relationship with formal supports such as the Health & Social Care practitioner(s) and carer(s) / support worker(s).

SIGNIFICANT BARRIERS TO GOOD WELL-BEING:

Similarly, the following areas were highlighted as having a negative impact on the respondents’ well-being and featured in those reporting “low” or “poor” levels of overall well-being:

- ☹️ Not having a clear personal plan for the future or not feeling positive about your future and what you hope to achieve over a period of time;
- ☹️ Not being comfortable with your personal situation, feeling disempowered; uninvolved; disconnected and ignored;
- ☹️ Not having suitable influence and input into the care and support being provided to help the individual meet their personal goals or achieve the things that are important to them;
- ☹️ Not having adequate finance to meet basic needs and provide financial stability to overcome short / sudden changes in a personal financial situation;
- ☹️ Not being able to influence their personal development or not being encouraged or enabled to aspire to and achieve a normal level of personal development and growth;
- ☹️ Not having adequate information to make plans for the future (e.g. uncertainty over SDS packages being reviewed with the potential of available financial and / or care supports being reduced / removed) leaving people feeling uncertain;
- ☹️ Not feeling included, involved or valued by their local community;
- ☹️ Not being involved in the community and community activities that included or were open to non-disabled peers;
- ☹️ Not being able to contribute to their community and community activities;
- ☹️ Not feeling valued by the wider community, being seen as “disabled” rather than viewed as a person with assets and abilities and having something of significant value to offer to their community;
- ☹️ Not having adequate supports and services available in their area and therefore having to “make do” with what’s available rather than being able to exercise choice;
- ☹️ Not having access to independent support and advice and instead having to rely on formal networks such as Health & Social Care practitioners and / or paid support workers;
- ☹️ Not having support available during “life changing” events;
- ☹️ Not being encouraged (or being actively discouraged) to think about personal development and viewing their abilities and assets as something that could be cultivated, grown and / or effectively utilised for themselves and / or others / the community;
- ☹️ Not being able to (or being discouraged in) engage in social activities; volunteering activities and / or seeking / accessing paid employment;

- 🙄 Not knowing where to go to get independent, affirmative support and guidance to consider and potentially access social activities; volunteering and / or paid employment.

In presenting these findings, it is hoped this will aid person-centred conversations and outcomes planning and that Health & Social Care professionals and social care service providers actively seek to ensure they construct and deliver social care services in a way that enhances the positives and mitigates the negatives outlined.

PEOPLE CHANGE

Whether you're a Health & Social Care Professional or a social care support provider, it is important to recognise that not all "*change*" is negative or adversely impacts on a person's well-being - unless the change isn't recognised and reflected.

In moving toward a system that aims to improve and measure people's well-being, we should expect that people "outgrow" their Personal Support Plan.

It is imperative that the Personal Support Plan reflects this growth and that it may be required to change how support is delivered; who it's delivered by; when it's delivered or that it's increased or reduced to reflect a person's contemporary situation.

Whilst building a reduction in paid support provision can and will be difficult for social care support providers (including Personal Assistants), it is important we recognise the over-provision of care and services is equally as detrimental to a person's well-being and quality of life as under-provision.

We need to recognise and accept that people change - the formal support and business model should and must too.

SDS NEEDS TO SHIFT TO A MODEL WHERE WE HAVE THOUSANDS OF INDIVIDUAL SERVICE COMMISSIONERS, EACH WITH THE ABILITY TO COMMIT AVAILABLE RESOURCES AS THEY SEE FIT WITHIN A FLEXIBLE, AGREED FRAMEWORK.

CONCLUSIONS & RECOMMENDATIONS

The Office for National Statistics (ONS) previously released [findings of a U.K. wide survey of “well-being”](#) with average ratings across 4 measures.

Whilst these measures were slightly different from those measured by SPAEN’s well-being survey and were scored out of 10, as a crude guide and moving ONS scores to a 5 point scoring system (therefore halving the scores recorded in the ONS survey), the average “life satisfaction” rating was 3.85 and 3.9 for feeling what they do in life is “worthwhile”.

Aggregating these 2 scores gives a comparative “*well-being*” score for the U.K. as a whole of around 3.87 some 1.67 points higher than the weighted mean average score recorded in SPAEN’s well-being survey and indicating the national population has a high level of “well-being” and “quality of life” (>3.74).

Average ratings in response to “feeling worthwhile” for Scotland were recorded at 7.82 (3.91 on a 5 point scale), again significantly higher than comparative scores recorded in this study.

Based on the findings of SPAEN’s well-being survey, it seems appropriate and proportionate to suggest that we still have, in 21st century Scotland, an “ability apartheid”; a disability deficit and endemic “**SOCIAL NETWORKING**” leading to social care recipients feeling less valued and less included in normal daily life.

It is the extrinsic factors measured by this Tool and that are inextricably linked to “well-being” that are, in the main, suppressing the quality of life experienced by disabled people in Scotland and causing detriment to their overall self-reported well-being.

And so, it would seem an obvious place to start. But that, in itself, is a huge challenge.

HOW DO YOU RECONFIGURE COMMUNITIES TO MAKE THEM A VIBRANT, WELCOMING AND SUPPORTIVE ENVIRONMENT IN WHICH DISABLED PEOPLE CAN FULLY PARTICIPATE, ENGAGE, FLOURISH, GROW AND CONTRIBUTE?

It’s not that our communities are bad places filled with biased, prejudiced individuals intent on excluding disabled people, quite the opposite. Often the individuals in our communities are the very fabric that holds society together when state support doesn’t stretch far enough.

It's often the individuals in our communities that visit elderly neighbours; drop in groceries when people are unable to get out of their homes and are first responders when our neighbours need us.

It's about taking this approach, this very rich vein of goodness and goodwill that runs through our communities and recognising it; replicating it; supporting it and cultivating it in a structured, meaningful way.

We need to start from where we are now.

Social care services are being delivered in community settings. This is and has been a good and positive shift. It is working - to an extent.

We now need to take the bold and positive steps to break down the barriers and boundaries that have organically grown up around social care and that appear to continue to divide people based on their "*disability*" rather than including them as a result of their tacit "*ability*".

We need to develop strategies and programmes that seek to properly and fully encourage and facilitate the integration of disabled people into established and emerging communities.

**WE NEED A DREAM , ONE THAT SEES DISABLED PEOPLE
LIVING TRUE EQUALITY ACROSS THE SOCIAL AND ECONOMIC
SPECTRUM.**

An important first step in achieving this will be the freeing up of financial and non-financial resources to aid and encourage social inclusion and participation and for this to become the established norm.

To achieve such a shift, we need to move from a "*deficit*" based assessment model to an "*asset*" based one, recognising that people have something to offer rather than something they're lacking.

And we need to move away from assessing "*basic needs*" to encouraging full, meaningful participation and inclusion in society as part of our social care strategy.

We need to channel available resources into enabling people to exercise their rights to full, active citizenship.

WHAT FOR THE FUTURE?

The Scottish Government's Self-Directed Support Strategy was rightly ambitious and set out real transformation based on the principles of dignity; respect and equality.

That transformational change has been backed by significant financial and non-financial resources but one of the things still missing are the meaningful metrics that will indicate

whether we're achieving real, meaningful change across society and in the delivery of social care supports and services.

We need a common language, a common set of metrics by which we can measure individual and group progress and we need data that can help us focus finite resources to the areas where we can make the biggest impact on people's well-being and quality of life.

WE HOPE THAT IN DEVisING, TESTING AND PUBLISHING FINDINGS FROM A WELL-BEING TOOL AIMED AT DISABLED PEOPLE IN SCOTLAND, WE HAVE TAKEN AN AFFIRMATIVE AND WELCOME FIRST STEP.

Our well-being tool gives us a common platform on which to start reconfiguring aspects that will make a real difference to disabled people's quality of life and overall well-being.

And we know that it's this type of common language; shared goal and meaningful and consistent metric that's needed to drive the change we want to see.

One of the recommendations from the Health & Social Care Alliance's Research Report from May 2017 tells us just that:

"While we recognise the importance of recording statistical and expenditure data on SDS, we do not believe this fully tells us whether SDS is being implemented as the national law and strategy envisage; nor the extent to which people are enjoying their human rights to co-production, choice and control."

Source: (Health & Social Care Alliance Scotland (the ALLIANCE), Personal Experiences of Self-directed Support, Research Report May 2017)

The measure of success for SDS in Scotland at present appears to be based around the number of persons accessing each of the 4 Options.

This may be one facet, one indicator of whether people are able to exercise some level of choice and control but it does not and should not be conflated or confused with any level of measure on the "quality of life" people using SDS are experiencing or how social care support is affecting or impacting on someone's "well-being".

IN ORDER TO DRIVE MEANINGFUL CHANGE, WE NEED TO MEASURE WHAT MATTERS AND TO MEASURE IT CONSISTENTLY AND FREQUENTLY. THE SDS OPTIONS ARE AN ENABLER NOT AN OUTCOME OR A RESULT. MEASURING THEM IN ISOLATION IS MEANINGLESS IN TERMS OF WELL-BEING.

Another significant facet in increasing a person's well-being is their sense of "purpose" and of feeling they are making a valuable and valued contribution to the community.

SPAEN has already called for the creative use of new powers devolved to the Scottish Parliament over welfare and work to cultivate a culture that encourages and supports but does not penalise disabled people in accessing paid work (Opening the Glass Door: A Discussion Paper on Disability, Employment & the Economy, October 2016).

The Scottish Council for Voluntary Organisations (SCVO) recently stated that the devolved work programme will fail those needing the greatest amount of support to realise their ability as the new programme "*does not guarantee enough personalised support for people.*"

SCVO cite a number of barriers including the procurement of such contracts being unobtainable for the organisations best placed to deliver these programmes successfully.

It echoes concerns raised earlier in this paper around the failure to adequately support and cultivate smaller, independent organisations to deliver programmes based on their ability to provide quality rather than compete on price.

And there are the issues around the high threshold set by Health & Social Care Partnerships for accessing support, currently set at "critical" (with some HSCP's considering or supporting "substantial" but this being the exception rather than the rule).

The provision of social care support continues to be responsive rather than pro-active.

This has the secondary effect of people falling out of employment and / or becoming disengaged from their community prior to them being able to access statutory supports and their well-being having been detrimentally affected to a significant degree before any action, intervention or support is offered.

When interventions and supports are offered, they rarely focus on re-integrating people into their community; setting achievable goals and aspirations and encouraging people to look at and sharing their "*assets*" and "*abilities*".

It is our opinion that small amounts of focussed, timely intervention will have an exponential impact on an individual's overall well-being and that such actions, if properly delivered, supported and measured, will increase the quality of life experienced by disabled people in Scotland.

There are indications of progress being made at practitioner level but these advances are being stifled and offset against restrictions in the level and kinds of support social care is extending to (e.g. personal development to aid full integration and participation in civic society being outside the scope of social care and only basic needs being met through funding and resource allocation).

WHAT CAN WE DO?:

Based on the findings of this report, SPAEN puts forward the following recommendations and next steps:

1. That this “well-being” tool is adopted and deployed across Scotland to allow consistent and meaningful measurement of the impact of social care expenditure (whether direct or indirect expenditure);
2. That “well-being” is measured on a regular and meaningful basis (possibly quarterly) to ensure progress is being made toward agreed strategic and personal goals and that this is having the desired affect on people’s well-being;
3. That the Scottish Government in partnership with CoSLA and other representative bodies; the National Health Service and other stakeholders develop a strategic plan and a consistent understanding of “*social prescribing*” as a means of increasing “well-being” and improving “quality of life” and that the plan gives cognisance to and addresses the limitations being placed on people receiving support as a result of strict criterion being applied (“critical” and “substantial” and that this fails to prevent “Poor” well-being);
4. That a national study be conducted, taking into account social and demographic data to ascertain other factors that impact on “*Intrinsic*” and “*Extrinsic*” well-being (such as which of the 4 Options each individual is using) leading to the identification of areas of “*good or best practice*” with the aim of learning why social care recipients in these areas are enjoying better self-reported well-being; and
5. The integrating of the findings of a national survey into the final stages of the Self-directed Support Strategy (2018 - 2020) to give the best possible opportunity for improving well-being and quality of life across Scotland.

WHAT SPAEN WILL DO:

Often, research and analysis reports make wide ranging recommendations aimed at improving or changing the “*status quo*” and this is always a vital part of such activity.

We are, perhaps, in a much more fortunate position in that SPAEN has, to a limited extent, the ability to start making real, meaningful changes to the “*status quo*” through the modification and evolution of the supports and services we already provide to our Members.

With that, comes the responsibility that we not only undertake the research and make recommendations but that we also learn from the findings and we make positive, affirmative changes where and when we can.

For that reason, SPAEN will make the following amendments to its own policies; practices; supports and services:

-  Roll out “YOUR Plan” and the “Well-being” Tool as part of our standard support services to all Full SPAEN members;
-  Incorporate the “Well-being” Tool into all our Support Services (including Individual Service Funds; local Independent Support Services and the Journey2Employment Programme);
-  Incorporate the “Well-being” Tool into the **Peace of Mind** Programme both in existing areas and as the programme extends to other parts of Scotland allowing us to capture and measure the impact “social connectivity” is having on the programme user’s overall well-being;
-  Offer to deploy the “Well-being” Tool for all and any independent or statutory support services; public bodies and the Scottish Government;
-  Repeat our “Well-being” survey of social care recipients throughout Scotland on an annual basis;
-  Develop and offer a range of training courses for Personal Assistant Employers and their Personal Assistants using the findings of the “Well-being” Tool with a focus on how they can work together to increase the well-being of social care recipients in Scotland; and
-  Offer consultative support to businesses, employers, community groups and organisations across Scotland on how they can enable greater participation from disabled persons excluded from or struggling to access them and their services.



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