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Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales?

REPORT OF A CITIZENS' JURY



The Jury



Measuring the Mountain is an initiative funded by Welsh Government. The Citizens' Jury took place between 24th and 27th September 2018. The report was drafted by Katie Cooke, Measuring the Mountain Project Manager and Rachel Iredale, Reader in Public Engagement at the University of South Wales, on behalf of the Jury and has been approved by all the Jurors. This report was finalised in January 2019 and published by the University of South Wales.

ISBN: 978-1-909838-36-9

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Design: USW Print & Design 01443 482 677



Summary

This is a report of a Citizens' Jury which took place with 14 citizens of Wales in September 2018. Over four days the Jurors explored the question *What really matters in social care to individuals in Wales?* They listened to evidence, asked questions and compiled a series of recommendations. The recommendations highlight important aspects of social care. They are the beginning of a process for Welsh Government, and other organisations working in the sector, to ensure positive experiences for people accessing care and support.

Citizens' Jury Recommendations

The Jury recommends that:

- 1** Each person approaching the social care system and related sectors, whether child, adult or carer, should receive the support of an independent, well-trained and knowledgeable key worker who will advocate and stand alongside them.
- 2** Care and support plans need to respect an individual's desired outcomes, and be more holistic, so that services fit the person and not the other way round.
- 3** Greater consideration must be given to carers so they are recognised, supported and valued, as the vital assets they are.
- 4** The transition between children's and adult services must be made less disruptive and should better prioritise the young person.
- 5** Individuals and service providers should work collaboratively as equal partners, promoting good decision-making and minimising the need to challenge decisions.
- 6** Greater consistency is needed in strategic and operational delivery of social care across Wales with better facilitation of partnerships and collaboration.
- 7** Regional Partnership Boards need to be made more transparent and accountable, and need to be more open to the public.
- 8** Co-production needs to be defined and embedded as a practice which is understood and utilised by all who are involved in the creation, delivery and evaluation of social care services.
- 9** Tendering and commissioning processes need to ensure they focus on delivering high quality services that provide exactly what is needed for people in the short, mid and long term.
- 10** Processes and tools need to be developed and utilised effectively to embed good partnership and collaborative working.
- 11** Statutory bodies should provide clear information about their services and about the Act, ensuring it is easy to access and understand, no matter what someone's circumstances, background or needs.
- 12** Improvements should be made to the overall system so that people's experiences are not complicated, and getting the right support is easy.
- 13** Frontline workers need to be recognised as critical assets within the social care sector and their status, professional development and pay should be enhanced to reflect this.
- 14** All those who are involved in social care should be encouraged to embrace new technology.
- 15** Citizens should be formally involved in greater and deeper scrutiny of the Act to build confidence in the sector and ensure the proper delivery of the Act.

Introduction

The Social Services and Well-being (Wales) Act 2014 puts people at the heart of delivery, enshrining new approaches and ways of working into legislation. To understand if the Act was making a difference where it mattered most, Welsh Government funded this Citizens' Jury. An established research method, a Citizens' Jury enables members of the public to explore a complex topic from a number of perspectives. This approach to public involvement enabled Welsh Government to hear directly from the people of Wales and to learn more about the early implementation of the Act.

The Question

The Jury considered the question **'What really matters in social care to individuals in Wales?'**

This question was derived from experiences of social care that were submitted to the Measuring the Mountain project, between May and July 2018. Those experiences demonstrated the breadth and complexity of people's involvement with social care, and the need to explore the notion of 'what really matters'.

The Jurors

The 14 Jurors were all residents of Wales. Members of the public registered their interest in being a Juror creating an initial pool of 42 people. Following the provision of more detailed information about the process and expectations, this potential pool of Jurors reduced to 21.

These 21 were anonymised leaving only demographic data; those that were the only ones in a demographic category were automatically selected, such as being aged 25 and under. Of the remaining people a random selection method was employed to complete the Jury.

The process of self-selection to register interest in being a Juror, created a pool of Jurors that were older, better educated and more knowledgeable about social care than an equivalent group of randomly selected people.



Jury Profile

Gender	Male	6
	Female	8
Age	18 – 24	1
	25 – 44	3
	45 – 64	8
	65+	2
Residence	North	2
	South west	6
	South east	6
Education level	Below graduate	5
	Graduate	6
	Postgraduate	3
Employment status	Employed	4
	Retired	7
	Unemployed	2
	Student	1
Registered disabled	Disabled	6
	Not disabled	8
Carers	Carer	7
	Not a carer	7



The Witnesses

A total of 22 witnesses agreed to give evidence to the Jury. A copy of the programme is in Annex 1. The witnesses represented a broad range of views and experiences from across the statutory and Third Sectors. They included six service users and carers who shared personal experiences with the Jurors, and one proxy-witness who shared testimony from younger people. In most sessions the witnesses presented information for approximately ten minutes and were then questioned by the Jury. A summary of the presentations is included in Annex 2. Time was set aside each day for the Jurors to discuss the evidence themselves and with the aid of the facilitator to prepare for, or de-brief from, the day's testimonies.

The Organisers

The Jury was organised by Measuring the Mountain's Steering Group (see Annex 3) and drew together experienced practitioners from research, social care, the Third Sector and public sector. The four days of the Jury, as well as an initial half-day preparation session, were facilitated by Dafydd Thomas, an independent facilitator with considerable experience of working with the Third Sector.

Funding

The Citizens' Jury was funded by Welsh Government as part of their one-year funding of the Measuring the Mountain project. The salaries of the organising team, barring that of the Measuring the Mountain Project Manager, were met by their respective employers, or their time was given on a voluntary basis.

The Citizens' Jury

The Programme

The Jury first met on Saturday 15th September in Cardiff for a pre-meeting. The purpose of this was to meet each other for the first time, to introduce the facilitator Dafydd Thomas, and to agree ground rules for how they would operate during the Citizens' Jury process.

The Citizens' Jury took place in the Liberty Stadium in Swansea between 24th and 27th September. The first day was designed to provide context, and background to, the Social Services and Well-being (Wales) Act 2014. Discussions focused on the aspiration and early implementation of the Act. Day two concentrated on services in practice and the realities of delivering and receiving social care services. Much of the discussion centred on transitions between services and the challenges that the sector face. The third day highlighted best practice and innovative approaches; the witnesses included people who shared stories about how transformation might be brought about in a range of ways.

Jurors were asked a series of questions pre- and post-Jury. As would be expected, the Jurors stated that their knowledge and understanding of the Act was higher after the Jury. Their levels of confidence about discussing the Act also improved significantly by the end of the process.

Rate your knowledge and understanding of the Act

	Pre-Jury	Post-Jury
None		
Very little	4	
Know what it is	4	4
Quite a lot	5	8
Know a lot	1	2

Rate your confidence discussing the Act

	Pre-Jury	Post-Jury
None	1	
Not very	3	2
Moderately	7	3
Confident	2	6
Very confident	1	3

Jurors were asked about their hopes and fears in relation to the process, and their feelings about being involved (see Annex 3). Their responses demonstrated the sense of responsibility with which they approached their role and the value they thought it could bring to people's understanding of social care as well as the development of social care policy.



How do you feel about the whole experience?



What do you now hope will happen to the Citizens' Jury recommendations?

- A move forward in breaking the cycle and actually putting people first
- A happier Wales
- To be a spearhead for government action
- That persons responsible take them seriously and act appropriately
- That they will be listened to, understood and put into actual practice
- I hope they go to Welsh Government for consideration and are taken forward to improve practice
- That they are presented to key influencers and decision makers with practical solutions rather than a list of barriers or negatives
- That they will be used as a guidance to service providers to improve services where needed
- That they will be seriously considered and acted upon by Welsh Government
- They provide insight
- That they begin some good conversations
- Formulated into some coherent sense, then seen by the right people and hopefully re-evaluated at some point in time
- That there is accountability to improve social care in Wales – and some commitment not just aspiration
- They bring about real change

Citizens' Jury Recommendations

The Jurors reached a number of conclusions in relation to *what really matters in social care?* These recommendations reflect the breadth of the issues that were explored and the complexity of the task the Jurors were set. They highlight the need for ongoing discussion and for considered action in successfully implementing the Act.

The Jurors expressed an admiration for the aspirations of the Act and its central tenets, but were frustrated at the systems and processes that hindered, rather than helped, practitioners to bring the Act to life. Acknowledging the enormity of the challenge of delivering good care, Jurors were concerned that respect and value for people were being lost from day-to-day experiences of accessing services.

Broadly, their conclusions and recommendations can be grouped under three of the four principles of the Act as defined by Welsh Government. The fourth principle, that of well-being, is achieved when the other principles are met. An additional set of recommendations relating to Scrutiny and Review were also felt to be needed to support the delivery of the Act.

These recommendations emphasise the role of people in Wales in shaping social care delivery, the value of meaningful engagement and the need for the development of social care to be an ongoing and collaborative process.

People

Jurors agreed that the social care system is complicated and difficult to navigate, making it hard for people to have voice and control; for them to get the right support, and for them to feel confident that decisions are being made in their best interest. Additionally, they felt that carers are under-valued and that the language of systems there to provide support does not resonate with them.

The Jury recommends that:

- 1 Each person approaching the social care system and related sectors whether child, adult or carer, should receive the support of an impartial, well-trained and knowledgeable key worker who will advocate and stand alongside them.**
 - It should not be a battle to get the right support: processes should reduce stress instead of produce stress
 - Access to financial resources should be straightforward and easy to understand
 - Whoever is best placed to deliver a service should be the one to do so: 'best' may vary from person to person.
- 2 Care and support plans need to respect an individual's desired outcomes, and be more holistic, so that services fit the person and not the other way round:**
 - Focus on what people can do, and want to do, and not what they cannot do
 - Relationships, whether intimate, familial or community friendships, are paramount to well-being and support. Their importance needs to be embedded in social care delivery at all stages
 - Greater effort needs to be made to engage with people, particularly those with additional needs and those that are housebound, to find ways to better include them in communities.

- 3 Greater consideration must be given to carers so they are recognised, supported and valued, as the vital assets they are:**
- Greater diversity should be employed in the methods, language and imagery used to promote services and support for carers
 - Support for carers should continue to be made available after they have ceased to be a carer as this is a significant and difficult adjustment.
- 4 The transition between children's and adult services must be made less disruptive and should better prioritise the young person:**
- Children in residential care should be able to access transition support to ease their move to live more independently
 - Services should provide greatly flexibility in their offer and approach to young people enabling greater support that promotes 'normality'.
- 5 Individuals and service providers should work collaboratively as equal partners, promoting good decision-making and minimising the need to challenge decisions:**
- Independent legal help should be provided to those who wish to challenge decisions
 - Statutory services must be supported to learn lessons arising from legal challenges and the decisions that result from them.

It seems statutory services think public expectations are unrealistic compared to their concerns. I hope they give up a little of their power to work for the public good. That they reflect on what a public service is, what is a social service? Who do they actually serve?



Partnership and Integration

Jurors were clear that approaches to partnership and integration could be improved and should have a renewed focus on the individual and ensuring the best service for them. They felt that partnerships tend to be limited in scope, and that tendering processes hinder, rather than support, collaboration and creative working. Whilst best practice is recognised across social care, Jurors considered that more needed to be done to share, learn from and emulate it.

Social care should not be a fight between those that need services and those that provide them, nor should it be a fight between service providers. The holistic provision of services that many need, and that the Act aspires to provide, requires sectors across Wales to be supported and guided to look upwards and outwards far more.

The Jury recommends that:

6 Greater consistency is needed in strategic and operational delivery of social care across Wales with better facilitation of partnerships and collaboration:

- Portable services that travel with the individual across localities if required
- Services, such as foster care and specialised schools, should not be different if someone moves across the invisible boundaries of Local Authorities.

7 Regional Partnership Boards need to be made more transparent and accountable, and need to be more open to the public:

- Increased, and more meaningful, citizen representation and engagement
- Mandated, and consistent role across Wales, publicising their function, activity and how to get involved.



8 Co-production needs to be defined and embedded as a practice which is understood and utilised by all who are involved in the creation, delivery and evaluation of social care services:

- It must be easy for service users and carers to understand how they can contribute and the value of their contribution
- It must be accepted that all statutory and voluntary bodies have to share power for the well-being of users
- Service providers must regard citizens as stakeholders and provide accessible approaches to engagement by looking at transport, the location of meetings and covering all costs for service users and carers.

9 Tendering and commissioning processes need to ensure they focus on delivering high quality services that provide exactly what is needed for people in the short, mid and long term:

- 'Races to the bottom' where low cost triumphs, no matter the longer term consequences to people, need to be stopped
- Very short service delivery contracts need to be avoided as they create uncertainty, and lead to people reinventing the wheel for the sake of securing further funding
- As innovation requires risk, pilot projects need to be given some leeway to demonstrate their achievements
- The administration of 'saving' money should not be more expensive than the savings made.

10 Processes and tools need to be developed and utilised effectively to embed good partnership and collaborative working:

- Develop platforms to share best practice and to demonstrate how that practice is achieved
- Share learning and understanding from other sources, including from co-operatives, social enterprises, failed schemes, the corporate world and other countries
- Identifying strengths and weaknesses around collaboration and sourcing complementary organisations will enable productive partnership and consortium working.



Prevention

Jurors agreed that greater priority should be given to preventative services and measures. Accessible information, a motivated and supportive workforce and a focus on supporting people's independence were considered vital to early intervention, minimising the risk of issues escalating and promoting trust of, and within, social care.

Jurors considered that too many aspects of social care created a need for people to fight for services or information, and that simplified systems would promote ease of access as well as transparency, trust and accountability.

The Jury recommends that:

11 Statutory bodies should provide clear information about their services and about the Act, ensuring it is easy to access and understand, no matter what someone's circumstances, background or needs:

- Pride should be taken in creating clarity for people and the onus for understanding what a person is entitled to is removed from individuals and returned to services
- Common sense should be applied, and communication needs stated once (and only once), for example, those that are registered blind receive information in a format appropriate for their screen-reader technology
- The Act must respond to the diverse, and multi-cultural, communities of Wales and facilitate diverse ways of communicating, for example teaching British Sign Language in primary schools.

12 Improvements should be made to the overall system so that people's experiences are not complicated, and getting the right support is easy:

- Complex processes and large quantities of information need to be made simple and easy to understand
- People's mental health should not be adversely affected by their interactions with social care.



13 Frontline workers need to be recognised as critical assets within the social care sector and their status, professional development and pay should be enhanced to reflect this:

- Training, and the opportunity to attend it, needs to be provided properly to support professional development
- Trust should be encouraged amongst workers in the sector, motivating them and allowing them to challenge the status quo
- Better marketing of social care professions that reflects the diversity of roles within the sector and appeals to more people
- Better remuneration and terms and conditions for frontline social care workers.

14 All those who are involved in social care should be encouraged to embrace new technology:

- Many innovations could enhance care and promote independence, supporting people to live longer with less intense service provision
- Providers may need to be creative in cultivating multiple sources of expertise in relation to their understanding of technology and its applications.



Scrutiny and Review

Throughout their discussions, Jurors identified that scrutiny and review processes needed to be enhanced and that they required more meaningful citizen involvement. They were concerned that reports from Commissioners in Wales on aspects of social care, as well as treaties that inform the Social Services and Well-being (Wales) Act 2014, including the UN Convention on the Rights of Persons with Disabilities, were ignored or not well understood, and that it was difficult to see their impact in service delivery.

They agreed that scrutiny and review processes needed to result in tangible outcomes, and that robust and transparent approaches would support effective implementation and delivery of the Act.

The Jury recommends that:

15 Citizens should be formally involved in greater and deeper scrutiny of the Act to build confidence in the sector and ensure the proper delivery of the Act:

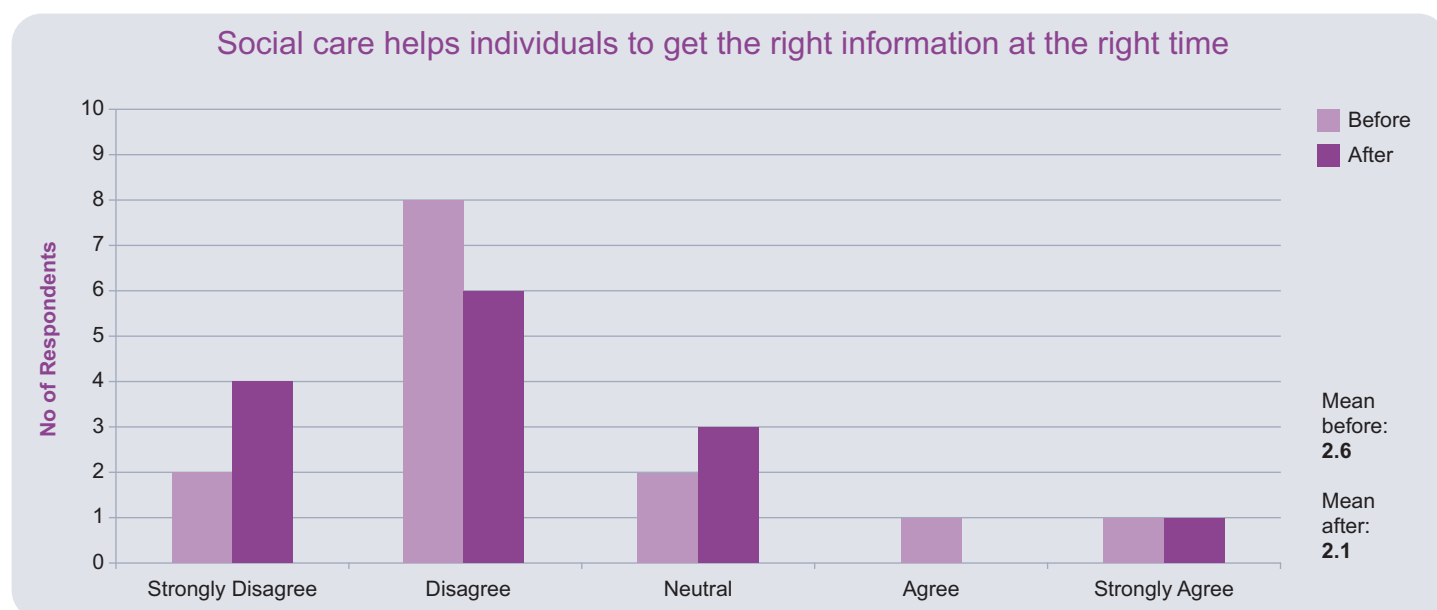
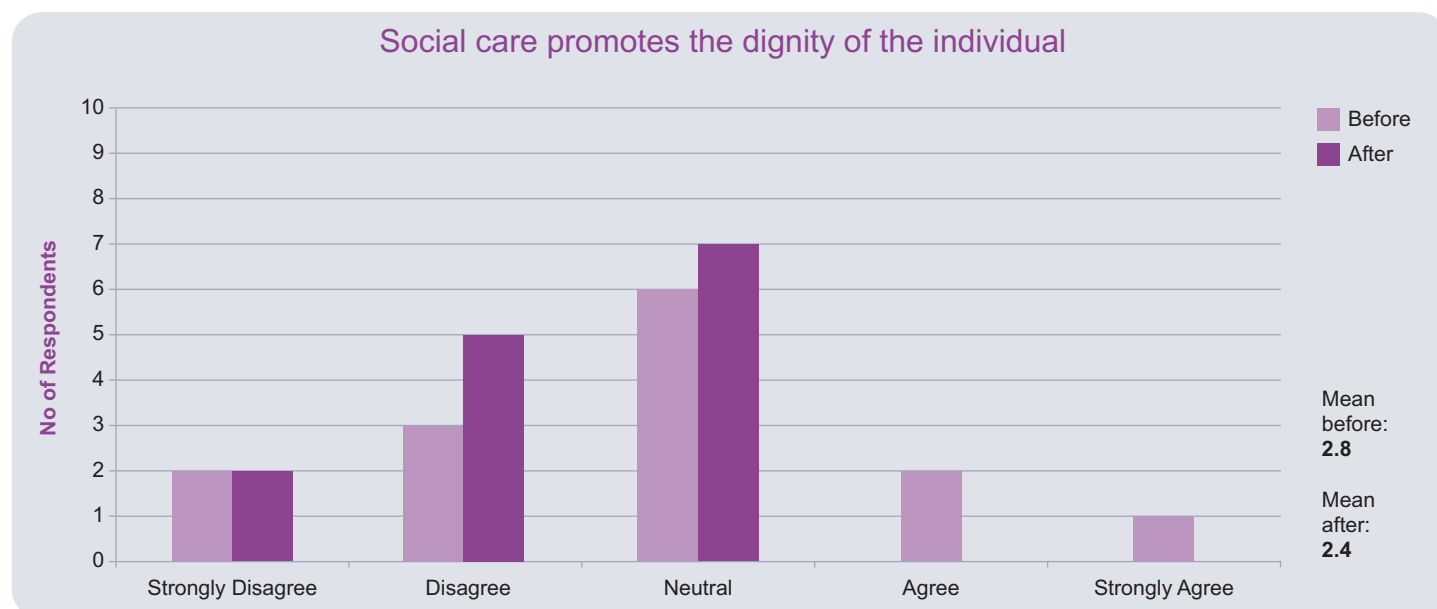
- A 'You Said, We Did' process in social care
- An annual Citizens' Jury to be broadcast live to the public across Wales
- All levels of governance to develop local, citizen-based critical friendships, strengthening their relationships with communities and formalising their approach to citizen input and public engagement.



Juror Attitudes

Jurors were asked to plot on a scale of 1 to 5, where 1 is 'strongly disagree' and 5 is 'strongly agree', the extent to which they disagreed or agreed with a set of statements. These statements included 'social care improves the well-being of adults who need care and support', '...of children who need care and support' and '...of carers who need care'. They also included 'social care enables people to have control over their day to day lives' and that 'social care allows people to have a say in their own care'.

Jurors became slightly less optimistic about social care by the end of the Citizens' Jury, with responses clustering towards the middle, and slightly lower, parts of the scale more than they had before the Jury. The mean score before the Jury across all seven statements was 2.9, and the mean after was 2.6. The results from the two statements that saw the greatest shift in feeling are below and underscore the motivation for a number of the recommendations that have been made.



Annex 1 - Jury Programme

	Monday 24th September	Tuesday 25th September	Wednesday 26th September
9.45am	<p>Neil Wooding, Chair of Measuring the Mountain's Steering Group</p> <p>Albert Heaney, Director of Social Services and Integration, Welsh Government</p> <p>Mark Llewellyn, Professor of Health and Care Policy, University of South Wales</p>	<p>Geraint Jenkins, Assistant Director, Cartrefi Cymru Co-operative</p> <p>Julie Boothroyd, Chief Officer for Social Care, Safeguarding and Health, Monmouthshire County Council</p>	<p>Adele Gilmour, Information and Support Manager, MS Society Cymru</p> <p>Nick French, Chief Executive, Innovate Trust</p> <p>Sally Jenkins, NCC and Marisa Moon, Assistant Director, Barnardo's Cymru</p>
11.00am	BREAK	BREAK	BREAK
11.15am	<p>Sheila Lyons, Improvement and Development Manager, Social Care Wales</p> <p>Jenny Williams, Strategic Director of Social Care and Education, Conwy and President of Association of Directors of Social Services</p>	<p>Changing needs, changing services – a panel of service users and carers share their perspectives</p>	<p>Meilys Smith, Senior Transformation Manager, Gwynedd County Council</p> <p>Joanne Bartlett, Cooperative Development Advisor, Wales Co-operative Centre</p> <p>Tim Williams, Manager, Hengoed Park Care</p>
12.30pm	Jury discussion and deliberation	Jury discussion and deliberation	Jury discussion and deliberation
1pm	LUNCH	LUNCH	LUNCH
1.30pm	<p>Finance, integration and accessibility – a panel of service users and carers share their perspectives</p>	<p>Sally Jenkins, Head of Children's and Young People Services, Newport City Council</p> <p>Alex Williams, Head of Adult Services, Swansea Council</p> <p>Dave Street, Corporate Director Social Services & Housing, Caerphilly County Borough Council</p>	<p>Networks, support and independent living – a panel of service users and carers share their perspectives</p>
2.30pm	Jury discussion and deliberation	Jury discussion and deliberation	Jury discussion and deliberation



Annex 2 - Witness Statements

Day 1 | Monday 24th September



Albert Heaney

Director for Social Services and Integration, Welsh Government

Our intention as Welsh Government is that the Social Services and Well-being (Wales) Act will fundamentally change the approach to social care across the whole of Wales.

The Act sets out an ambitious and sustainable approach to social care in Wales and a long term vision where voice and control, prevention and early intervention, well-being and co-production are at the heart of social care. A number of new approaches, services and activities have been introduced to facilitate and strengthen the principles that underpin the Act and move social care closer to the long term vision.

These include new approaches to the role of social enterprises, co-operatives, user-led services and the third sector in social care; the introduction of Regional Partnerships to support collaboration and integration; the establishment of Information, Advice and Assistance Services to support people to access the support they need; services to support families and young people in foster care; and enhanced professional development opportunities for many that work in the sector.

The aims and the ambitions set out in the Act are extensive and there is much to consider but we must remember that these are still early days. The sector remains in a state of transition. What is most important is for us to be able to see, at this early stage, what has happened so far, what is going well, where further work is needed and how we can continue to support the changes in the social care system that the Act is driving forward.



Mark Llewellyn

Professor of Health and Care Policy & Director, Welsh Institute for Health and Social Care, University of South Wales

This Jury in many ways is asking a ‘what matters’ question – what matters to the citizens of Wales in respect of their social care services? The reason that is significant is that it signals one of the crucial changes at the heart of the Social Services and Well-being (Wales) Act – that ‘what matters’ to people has a legal basis for the first time ever.

There are five principles that underpin the Act – co-production, prevention and early intervention, well-being, multi-agency, and voice and control – which should be driving the changes that the Act intends to implement. These principles are important and rare to see embodied in legislation – which is to the credit of the policymakers and politicians that pioneered this approach in Wales.

However, there is a huge challenge here, which is to try and understand what it means to measure and evaluate social care and its impact on individuals. Measuring the Mountain has made a significant contribution to this. But there are some difficulties in the way we think about what ‘impact’ and ‘what matters’ actually means for people in the real and messy circumstances of their lives. None of this is easy, but I will try and provide some ways in which the Jurors should think about the evidence that they will be hearing over the coming days.

Jenny Williams

Strategic Director of Social Services, Conwy County Borough Council & current President of ADSSC (Association of Directors of Social Services Cymru)

Fundamentally the Social Services and Well-being (Wales) Act has transformed our traditional thinking and approach to providing a ‘nudge in the right direction’ at the time people most need it. Conwy started to think about this change in 2014 and undertook some research to help us think about how and what we needed to do differently. I will give a snapshot of that research, and show how our community well-being service was developed. I will show how the approach has offered more advice and assistance to adults than we ever have; how we reconfigured core funding to shape a more community-based response working with the third sector locally; and used different fun engagement techniques which traditionally, as Social Services, we would not have provided.

I will also show our journey for children and families, and the development of our ‘funding flexibility’ opportunity. This has been given pathfinder status, enabling us to show how a range of grants supporting those in poverty can be used differently. The development of integrated family support across agencies in five key areas of the council has had a positive impact on children and their families, as well as providing quality and cost effective services at an earlier stage which has led to a reduction in children needing more costly provision at later stages in life. This will also show the benefits of big corporate areas in councils coming together such as Education and Social care.

Sheila Lyons

Improvement and Development Manager, Social Care Wales

Social Care Wales regulates the social care and social work workforce in Wales. As well as supporting the workforce, we have responsibilities for service improvement and research. We were created in April 2017 bringing together the Care Council for Wales and the Social Services Improvement Agency into one organisation.

As Care Council, we were asked to develop a national learning plan for the Act and create a website to hold all resources about the Act. The aim was to have a consistent approach to learning across Wales and all parts of the workforce. The scale of the task was huge: 8,000 workers attended awareness raising sessions and 12,000 core training modules were completed in 2016-17 alone.

We evaluated our work and know we made an impact: the average score for a worker having the knowledge to deliver services in line with the Act increased by 40%. Partnership working on the training plan was very strong.

We know we have more to do to support the workforce. This year we are working with partners on clear priorities: care and support at home, dementia, children in care and family carers. We are also working on improvements which cut across these areas. For example, we have a programme of work to support social services with how they work with people to achieve their personal outcomes. We are working with Qualifications Wales to make sure new qualifications for social care workers are fit for purpose. Recruiting and retaining good staff in social care can be difficult and we have launched a major recruitment campaign.

As the workforce regulator, we use our powers to support improvement. We set standards for social work qualifying and post qualifying courses. We publish Codes of Practice and guidance for social workers, social care workers and their employers. We act if practice is poor, for example, we can remove a worker from our register so they are not able to work in the sector. We use what we learn to support improvements. For example, we publish guidance on 'professional boundaries' and 'openness and honesty when things go wrong' because we know these can be challenging topics.

We set research priorities informed by evidence of what needs to be improved.



The future to be that little bit easier for generations to come.

Day 2 | Tuesday 25th September

Geraint Jenkins

Assistant Director, Cartrefi Cymru Co-operative

Cartrefi Cymru Co-operative supports people with learning disabilities in Wales, to lead fulfilled lives, at home and in the community. We support people with autism, challenging behaviour, older people, and provide breaks and support for carers.

We are always looking for ways to improve our services, and ways to reduce inefficiency. In Carmarthen, having identified a group of people who were frustrated with the current system, we decided to pilot a new way of working.

In the area, demand for sessional and community services was going up, and the existing 'time and task' approach wasn't flexible or responsive enough to meet people's needs. This was resulting in over-provision in some cases and waste within the system.

We took a different approach that enabled support workers to focus on the specific needs of an individual. Their remit was to deliver what mattered to people and to do this regardless of the timings or frequencies prescribed in the care plan.

By giving more control to the individual and the support worker, support can be provided when it's needed rather than when it's prescribed to happen. This has enabled more preventative work, work that is more important to the person being supported, staff feel more empowered, trusted and valued, and more people are being supported with the same money.

Julie Boothroyd

Chief Officer for Social Care, Safeguarding and Health, Monmouthshire County Council

In Monmouthshire we started a transformation approach, as we knew we were not serving people well. Our assessment process was mechanistic, our services focussed on time and task and we were regularly getting a lot of traffic /noise from disgruntled people.

We had to look long and hard at ourselves and unlearn and begin to listen, a process that required buy in and sign up from everyone and a recognition that we could do a lot better.

Essentially, it is all about relationships, with each other and the people we support. It is about removing barriers and refocussing what we do *with* people not *for* the people we are supporting.

To get to a better place people have to find this out for themselves, so a large part of the change process has been winning hearts and minds and facilitating the workforce to move to a different practice approach. This may sound easy but it is not; the last 20 plus years of community care legislation and practice is hard to undo. By taking a systems approach and really focussing on what matters to people, using a defined purpose: helping people to live their own lives; and a set of key operating principles we have been able to re purpose how we support people.

The journey to date has been bumpy at times but the results are coming. Services have transformed the way support is delivered. By way of example, the well-established Care @home service across the county concentrates on personal and emotional well-being before addressing personal care needs: connection to community and purposefulness are key features of the support offered.

This approach will be adopted in the rest of the sector as part of a large transformation project known as 'turning the world upside down'.

This concentration on relationships and community has been key to the development of many place-based approaches, which look to support people to be less socially isolated and more connected to their lives and communities, so increasing their well-being.

My Mates, supports people with learning disabilities to find friendships and connections and lead active lives independently. This is growing from strength to strength and has recently won a social care accolade.

Sally Jenkins

Head of Children's and Young People Services, Newport City Council

Alex Williams

Head of Adult Services, Swansea Council

Dave Street

Corporate Director Social Services & Housing, Caerphilly County Borough Council

During this panel session Sally, Alex and Dave talked about significant changes that the Social Services and Well-being (Wales) Act 2014 has inspired and necessitated. They highlighted challenges that they, and their service are facing, now and into the future, as they discussed the realities and feasibilities of service delivery.



Day 3 | Wednesday 26th September

Adele Gilmour

Information and Support Manager, MS Society Cymru

My MS, My Rights, My Choices is an MS Society Cymru project that delivers a comprehensive information and support service for people with MS and their carers across Wales.

There are 4 staff working on the project and we have recruited 27 Information and Support Volunteers who help to deliver the project. We aim to reach 1100 people with MS and their carers over the 3 years of the project, April 2017-2020.

We run a series of condition management events each year. These are unique to the project and not run anywhere else in the UK. We run Newly Diagnosed Days, in conjunction with the specialist MS health teams, for people who have had a diagnosis of MS in the last 6 to 12 months.

These days focus on understanding what MS is and what help is there to support people as they journey with their condition.

We also run information days and Living Well with MS days for those people who have been diagnosed for some time, and these days focus on well-being and coping with living with the condition.

A great deal of our work though, is one-to-one: each of the 4 staff have a caseload of over 70 people who we support with issues such as access to social care, benefits and grants advice, employment or housing issues or support to have their voice heard.

In the first 18 months of the project we have supported almost 300 people on a one-to-one basis, and the project is highlighting the importance of people having individual support, and the opportunity that can present for someone to open up more, and ultimately, have more of their needs met.

Nick French

Chief Executive, Innovate Trust

In late 2016 Innovate Trust began to explore the possibilities afforded by voice activated devices such as the Amazon Echo. It appeared that the opportunities provided by the expanding IOT (Internet of Things) could, combined with verbal prompts and reminders, improve the prospects of many people supported by the charity.

These devices and associated applications have provided some of the individuals we support with increased independence: moving on to greater independence and less reliance on staff support or an ability to simply interact and control things within their own environment, such as turning on a light or controlling the television. We have sourced, explored and researched the possibilities of many freely available consumer devices, in some cases creating our own compatible links through the use of Raspberry Pi (tiny and cheap computers).

We are installing an Amazon Echo Plus device in all 72 of the Supported Living Settings we manage in Cardiff & the Vale of Glamorgan, and have partnered with two housing associations to support them to develop 'smart homes'.

We have also established a partnership with Cardiff & the Vale's smart house in Llanishen (JES), where we have installed several voice activated devices and are currently engaged in altering existing products, at present a stair lift, to respond to voice activation. The OT's we are working with are particularly excited about the potential to maintain people in their own homes through the further expansion of voice and motion control.

Our Charity has initiated a partnership with the Psychology School at Cardiff University and together we are going to be creating further research projects focusing on well-being. We also hope to include eye tracking technologies and brainwave devices that we have already sourced to assist us in potentially reaching those with the most profound impairments.

It is our hope that our ideas and continued research will be disseminated, adapted and further developed both across the social care sector and further afield. We will continue to explore, develop and harness such freely available consumer technologies over the coming years to best meet the needs of the people we support.

Sally Jenkins

Head of Children's and Young People Services, Newport City Council

Marisa Moon

Assistant Director, Barnardo's Cymru

Newport City Council (NCC) and Barnardos Cymru formed a collaborative partnership to deliver family support services via the Integrated Family Support Services (IFSS). The service co-locates a team of workers that are dually managed by NCC and Barnardos. Both parties are committed to collaborative working with a multi-agency approach.

The aims of the collaboration are to provide evidence-based and intensive support to families with complex social care needs. The team work intensively to stabilise family situations so that children can remain at home with their parents safely or return home quickly with support. The focus of the intervention is to enable parents to improve their parenting capacity, build on existing strengths and increase their resilience whilst decreasing risks factors to the children.

The Partnership arrangement between Newport City Council and Barnardo's includes a long term commitment to developing family support services jointly and a high degree of core funding commitment on both sides. The benefit of the partnership has been the ability to grow a highly evidence-based service as we are able to flex, negotiate and develop together to improve outcomes for children.

The Social Services and Well-being (Wales) Act 2014 reminds us that it is best practice to use multi-agency approaches and to form strong partnerships between all agencies and organisations, with integration being the key driver for change. The collaborative partnership between Newport City Council and Barnardos embodies the vision of the Act and practices this coproduction approach to deliver effective and integrated family support.

To be a carer you don't have to have a degree; you don't have to have an apprenticeship. You don't even have an interview.

Meilys Heulfryn Smith

Senior Transformation Manager, Gwynedd County Council

Within Gwynedd, we've faced shortage of home care capacity, increasing demand, tensions between commissioners and providers and many issues relating to workforce terms and conditions.

We decided to redesign our entire home care system. We wanted each person needing support to be given the help they needed to live life as they wanted to live it.

The Local Authority, Health Board and Cartrefi Cymru Co-operative (a provider in Gwynedd) mapped out the home care system from end to end. We learnt that we were slotting people into time slots where carers could undertake specific tasks, that we were spending a lot of money on wasteful activity and that, ultimately, what mattered to people was largely being ignored.

We set up a pilot in one town in Gwynedd where we brought together home carers, social workers and community health workers to jointly work out 'what mattered'. Carers weren't given a rota. Their brief was to understand what mattered to people, help them achieve that and work out if they could step back and let personal and community networks offer support.

By taking more time on the 'assessment' stage, involving a wide range of people in it, and co-producing solutions with people, we saw a reduction in demand (over 50% overall). We also found that job satisfaction was greater and that, by reducing waste in the system, we could aim to divert costs related to bureaucracy into better pay and terms and conditions for staff.

An isolated elderly gentleman wasn't allowed visits by his son who has learning difficulties, due to the state of his house. The team cleaned the house, helped the gentleman to regain his self-pride and enabled reconnection between him and his son. This is one example that shows how the service addressed what mattered (as opposed to delivering personal care and seeing everything else as someone else's problem).

We are now implementing this new model of home care across Gwynedd. Provider agreements will be in place by summer 2019, with a programme of cultural change continuing beyond then.

Joanne Bartlett

Cooperative Development Advisor, Wales Co-operative Centre

Care to Co-operate is a project delivered by the Wales Co-operative Centre. The project supports the implementation of the Social Services and Well-being Act 2014

It was established to lead the way in making the policy drivers of "co-design and co-delivery" a local reality in social care in Wales. Our vision is to "enable citizens and service providers to come together to develop a co-operative approach to the delivery of local social care and well-being services."

We achieve this by providing bespoke business support using appropriate methods including workshops, presentations, our Road to Co-operation board game and other tools which can be found on our website: <https://care.wales.coop>

We are a small team of four staff: one north and one south Wales business advisor, an administrator and a manager. We reach out across Wales to wherever we are needed. Care to Co-operate is funded through the Welsh Government Sustainable Social Services Third Sector Grant. Currently in the third year of a three year funded programme it is hoped that this is just the beginning of our journey and further funding is secured.

During the presentation you will be given two examples of when and how citizens in receipt of support have come together to co-design and co-deliver a service.

The first will be 'Cwtch Together'; a group of parents and volunteers who have been supporting Cardiff Local Authority to co-deliver an inclusive play provision for children with learning difficulties and disabilities, their siblings, parents and carers. There is a risk that the Local Authority will not have the funds to continue this provision in the future therefore Cwtch Together have been supported to register as a Charitable Incorporated Organisation with an aim to develop a membership who can continue delivery themselves.

The second is Conwy Deaf Translation Support Service – an unincorporated citizen led service that has found a way to deliver translation and support sessions to the deaf community on behalf of the local authority and privately at affordable prices.

Tim Williams

Training and Development Manager & Director of Hengoed Care

Hengoed Court and Hengoed Park are family run care homes based in Swansea providing care and support for older people. Many of the people supported have a diagnosis of dementia or require nursing care. A small number of clients require minimal personal care and support. We work in partnership with different County Councils in and around Swansea to accept placements, as well as various Health Boards. We also accept private clients. The overarching vision of Hengoed Care is to consistently be looking at ways of improving quality of life for the residents we support, as well as the staff and families who we work alongside.

Hengoed Care believes health and well-being is paramount to improving a person's quality of life.

Two areas of focus for us that make a positive difference to the lives of our residents are:

- Outdoor engagement
- Community engagement

Spending time outdoors has proven health and well-being benefits, enjoying green spaces and wildlife, going for a walk and breathing in the fresh air, gardening, a quiet space to reminisce, etc.

Our outdoor nature project was developed 3 years ago and in the past few months we have also introduced an accessible, animal petting sanctuary within the green space. We have rescue ponies, sheep, ducks, rabbits and a bird aviary. Resident involvement with the animal sanctuary has created excitement, fun, purpose, a sense of ownership and a feeling of 'home and family', positively impacting one's health and well-being.

We have observed families and grandchildren wanting to spend longer lengths of time with their loved ones enjoying the outdoors, gardening together and having fun. Residents with dementia have improved sleep patterns, less challenging behaviour and are calmer and more content as a result of feeding and stroking the animals, as well as increasing positive mood, raised self-esteem and confidence resulting from interactions with the wider community.

People living in the local area regularly visit the nature park which has created opportunities for residents to meet and forge friendships with the wider community, feeling part of 'the bigger picture'. School groups visit which has created intergenerational partnership working opportunities such as pen pal projects, fetes, parent and toddler groups and seasonal events.

The outdoor space has provided opportunities for families to remember a loved one who has passed away at the care home making a difference to their well-being. Many relatives have bought their own remembrance trees and benches which are located around the nature park so they can continue to feel a part of Hengoed Care as they visit and remember their loved one.

Annex 3 - Juror Surveys

What do you hope to gain from the Citizens' Jury?

- That our and future generations benefit from all services they need
- That the Act is implemented and understood from professional people to the public
- To be part of something that has potential to be very positive and make a difference
- Sense of going forward, making a difference
- Being able to make a valued difference to the way social care is commissioned and delivered
- Knowledge and experience
- To help develop new attitudes to social care in Wales
- Involvement in identifying positives and negatives to bring about long-term improvement for service users and carers
- Sense of achievement

Describe how you are feeling about being involved

- | | |
|-----------------|----------------|
| • Privileged | • Passionate |
| • Nervous | • Expectant |
| • Hopeful | • Interested |
| • Compassionate | • Emotional |
| • Thoughtful | • Frustrated |
| • Excited | • Optimistic |
| • Open-minded | • Pleased |
| • Happy | • Enthusiastic |
| • Honoured | • Intrigued |
| • Curious | • Positive |
| • Inquisitive | • Proud |



I hope that people are finally listened to, that they are seen as co-producers rather than a drain on resources, and an acknowledgement that sometimes the best knowledge and ideas can come from service users/carers.

Hopes and Fears

Jurors, overwhelmingly, hoped that the Act would be a force for good, and that the aspirations it embodies will become the core of social care delivery. For all though, this was a distant hope.

More immediately, they hoped that people could be better included in existing structures of sharing, review and service development; that more meaningful partnerships could be developed across sectors and services; and that providers could focus on people in need of support.

The fears of the Jurors centred on finance, inaction and the disconnect between layers of the social care system, and more critically between the social care system and the people it is there to support. Common responses included:

- That positive change is too difficult for the system to achieve and so it will, to a large extent, be ignored
- There is a focus on conversation and review and not nearly enough action. There were two years to prepare for the Act and yet the clear delivery processes, resources and guides that are needed for the Act to become realised for the frontline and for users are not there
- Due consideration was not given to how austerity and other pressures would squeeze social care and now people, and the systems they have found themselves a part of, are stuck: they do not know how to change and are not being supported to learn
- Money is being wasted: those that deliver services are more focused on money than on people. This is diverting attention from the areas it is really needed
- The spirit of the Act is its most vital component so that has to be turned into meaningful service delivery.

What has been the most significant thing you have learned from being involved?

- There are cycles that need to be broken
- The act is attempting to get a more person-centred approach
- The amount of common problems and experiences we all have
- Promising instances of good work by a number of persons
- It is a very human way of connecting with data – reflecting the spirit of the Act
- Consistent and recurring themes across all areas of social care
- The two sides of a very complex picture are often far apart
- Many challenges being faced by all and being tackled individually
- Fight is a word that is used too much
- The complexity of implementing positive change within social care even when it could save money and prevent crisis.

Being offered support should not be contingent upon failure.

Annex 4: Measuring the Mountain

The Steering Group includes representatives from the following organisations:

- Interlink
- Office for National Statistics
- Welsh Government
- Tempo
- University of South Wales
- Cartrefi Cymru Co-operative
- Social Care Wales
- Co-production Wales
- Disability Wales
- Wales Audit Office
- Children in Wales
- NHS Wales
- Greater Gwent Health, Social Care and Well-being Partnership
- Wales School for Social Care Research
- North Wales Social Care and Well-being Improvement Collaboration



“For true personal outcomes to be achieved in line with the Act there needs to be better alignment between processes and legislation – increased freedom to focus on the individual and their choices.”

Acknowledgements

The Measuring the Mountain Steering Group would like to express their enormous gratitude to all those who helped with the project in any way. In particular, the facilitator, witnesses and everyone who shared their stories of social care that helped inform how the project took shape.

Finally, huge thanks to the Jurors: Annie Galt, Bill Fawcett, Charlotte Whitney, Chris Kemp-Philp, Craig Lloyd, David Hawker, Grahame Nelmes, Jacqui Caldwell, Janet Morgan, Karen Berrell, Leighton Morris, Philip Westcott, Sara Flay and Tegwen Knox, without whom, none of this would have been possible.