The ABUHB Niwrostiwt Recovery College

Theory Manual

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Introduction / Rhagymadrodd

"The organism is a unitary system, but what is a system to a real living thing? Neuropsychology speaks of 'inner images', 'schemata', 'programmes' etc: but patients speak of 'experiencing', 'feeling', 'willing' and 'acting'. Neuropsychology is dynamic, but it is still schematic; whereas living creatures, first and last, have selves – and are free. This is not to deny that systems are involved, but to say that systems are embedded in, and transcended by, selves."

The above quote is from Oliver Sachs' book *A Leg to Stand On*, published by Duckworth & Co Ltd in 1984. It can be found on P 164. This book records his reflections on the personal learning from the experience of what would be described today as a functional neurological disorder arising from a traumatic injury. Key to these reflections and his subsequent work was the recognition of the need to develop an approach to neurorehabilitation that focuses on people's experience. In his outstanding body of work, Oliver Sacks accomplishes this aim by giving voice to these experiences as stories. He acknowledges the influence of another great neurologist Alexander Luria who refers to these stories as *neurological biographies* or *novels*.

The neurological biographies reported by Luria, Sacks and others not only provide invaluable insights into the impacts of these conditions, their personal meanings, and the impacts on what matters at an individual level, they also highlight the incredible resilience and ingenuity of the human spirit. In doing so they are empowering, humanising, and help to repair the broken dignity of the people he is writing about. These hidden powers of storytelling are highlighted in the quote from Chimamanda Ngozi Adichie below.

"*Many stories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower, and to humanize. Stories can break the dignity of a people. But stories can also repair that broken dignity*."

Stories can also inform us about what is important to us as a collective and help us to use this information to guide our actions and collaborations. This aspect of storytelling is well articulated in the following quote from Lisa Cron, taken from her book Wired for Story.

"*Story, as it turns out, was crucial to our evolution -- more so than opposable thumbs. Opposable thumbs let us hang on; story told us what to hang on to*."

Finally, the deep meaning in stories helps us to remember ideas and concepts in a way that lists and figures do not. This may be a personal shortcoming, but the quote below from Shane Snow was experienced as reassuring.

> "*Good stories surprise us. They make us think and feel. They stick in our minds and help us remember ideas and concepts in a way that a PowerPoint crammed with bar graphs never can*." - Joe Lazauskas and Shane Snow, The Storytelling Edge

A rich history of storytelling is one of the many things that we are lucky to possess in Wales. Welsh literature incorporates a body of writings in the Welsh language, and more recently English, with a rich and unbroken history stretching from the 6th century to the present. These works include the Mabanogi thought by some academics to be the earliest prose stories from the island we now call Britain.

With the above in mind, the Niwrostiwt relies heavily on storytelling as an aid to learning about how to live and work well. In keeping with this insight into the power of narrative, this report is divided into four parts (Rhanau). Each part contains at least one story and other information presented in narrative rather than a more academic style. Rhan Un (part 1) presents stories linked with the origins of the college. Rhan Dau speaks to the Niwrostiwt's underpinning theory, principles, and values. Rhan Tri outlines the shape of Stiwt provision. The last section, Rhan Pedwar, summarises information from the evaluation.

The places and spaces for recovery and discovery co-created as part of the Niwrostiwt's activities draw on the literature on personal recovery and mental health recovery colleges, resilience, community psychology, community development, as well as psychological, culture, organisational, and cognitive self-change. The narrative approach adopted in this report does not include detailed references or a formal literature review. For readers with an academic interest the appendix contains tables of academic research, articles, and books that have informed the development of the Niwrostiwt.

Rhan Un – Cefndir / Background

"…we had become invalids, in-valid. We had resided in sickness too long. And we had not only harboured it but become sick ourselves – developed the attitude of inmates and invalids. Now we needed a double recovery – a physical recovery, and a spiritual movement to health. It was not enough to be physically well if we still felt the fear and the care of the ill. We had all, in our ways, been undermined by sickness – had lost the careless boldness, the freedom of the well. We could not be thrown back into the world straightaway. We had to have an in-between – existential as well as medical, a place where we could live a limited existence – limited and protected, not too demanding – a limited but steadily enlarging existence – until we were ready to re-enter the great world. The acute hospital was scarcely a world at all, as acute injury or illness was scarcely a life. Now we were improved, and needed world and life, but would not face, would be destroyed by the full demands of life, and the bustling, callous, careless hugeness of the world; we needed a quiet place, a haven, a shelter, where we could gradually regain our confidence and health, our confidence no less than our health - a peaceful interlude, a Sabbath world, something like a college, where we could grow morally and physically strong."

The above quote is also lifted from P126-127 Oliver Sacks book *A Leg to Stand On*. It highlights one of the discrepancies between the way practitioners and the people they work with see and talk about health. Whereas health boards often divide provision between mental and physical health services, these aspects of wellbeing are typically intricately linked in the lives of the people they serve. This seems to be one of those things that as practitioners we learn, forget, and need to relearn again.

In his 1621 book *The Anatomy of Melancholy,* Richard Burton (no relation to the famous son of Pontrhydyfen) explains how in his view the body and mind interact in producing the symptoms of melancholy. "*For as the Body works upon the Mind, by his bad humors, disturbing the Spirits, sending grosse fumes into the Braine, and so per consequens disturbing the Soule, and all the faculties of it, with feare, sorrow etc. which are ordinary symptoms of this Disease: so on the other side, the Minde most effectually works upon the Body, producing by his passions and pertubations, miraculous alterations, as Melancholy, Despaire, cruell diseases, and sometimes death it selfe".*

The quote from Richard Burton may sound somewhat laughable with its reference to 'humors' and 'grosse fumes' but I wonder whether people in 400 years will be equally amused and

flabbergasted by our stubborn reluctance to let go of the mind body divide. Integration of these two realms of personhood is a key objective of the Niwrostiwt.

Stori Un (Story 1) – Yr enw / The name

Croeso i Dredegar / Welcome to Tredegar. 1948, the year of the birth of the National Health Service. Croeso hefyd / welcome also to the Tredegar born giant Aneurin Bevan the Welshman who was the architect of the NHS.

Tredegar is a small industrial community in the heart of the South-East Wales coal fields. The miners and steelworkers of the town, including my grandfather, voluntarily paid a proportion of their meagre wages into a community fund that ensured free healthcare at the point of need. They also understood that health was more than the opposite of illness. They paid additional money and volunteered time to support the various welfare societies and miners' institutes. These institutes focused on self-improvement, peer support, and co-operation. Outside of their hard physical labour, they provided workers and their families with a sense of connection, community, meaning, purpose, recreation, status, creativity, and hope. The things research has shown that we all need to live well.

Although things are now better in so many ways, there seem to be important lessons from the past we have forgotten. First, the idea that the duties of care we have for ourselves and each other are paramount, and that the role of state services is to catalyse our ability to fulfil these duties. Not to do it for us. Second that health is not the opposite of illness, it is the ability to follow valued life plans, no matter what our circumstances.

Our project seeks to reinvent contemporary healthcare in the image of the old 'stutes'. It replaces the current emphasis on therapeutic interventions for sick people, with a focus on

self-management, wellbeing, and community capacity. It also softens current boundaries between service providers and recipients. In recognition of our industrial heritage, we have named our service for people living life with long term neurological conditions the Niwrostiwt.

Stori Dau (Story 2) – Ar yr dechrau / At the beginning

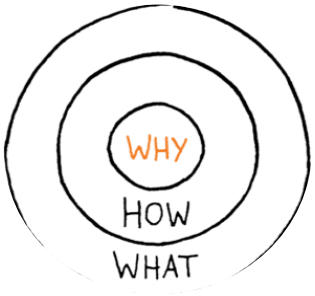
The seeds of the Neurological Conditions Recovery College go back to the days of the older of the authors undergraduate and postgraduate study. These seeds laid dormant for nearly thirty years until they were watered during a turbulent set of group sessions. The group was taking part in a randomised control trial feasibility study. The intervention was of a high quality but evidently not what the participants wanted or needed at that time. Helpfully, they were vocal about this. Due to the tight protocols that often straitjacket evidence-based research studies there was limited capacity to respond to the group's appropriate requests for what they needed at that time. The best we could do was to agree to meet with the group participants to explore, understand, and think with them about how to meet their current needs once we had completed the trial group. This turned out to be an incredibly valuable venture. It marked the birth of our collaboration with people with lived experience that is at the core of the Recovery College.

The people involved in this collaboration have given their permission for me to name them. They were Roger Roberts, Peter Kemp, Julie Davies, and Jane Watkins. Roger, Peter, Julie, and Jane became our first peer partners. They are no longer working with the Niwrostiwt but we remain hugely indebted to them. They fertilised the ground around the dormant seed that has now become the Niwrostiwt. The peer partners and health service employees that have followed them continue to tend to this ground.

Stori Tri (Story 3) – Pam yn cyntaf, ac wedyn sut a beth / Why first, and then how and what

Wilbur & Orville Wright

Samuel Pierpont Langley



Care Aims – Kate Malcomess

Start with Why – Simon Sinek

At the beginning of the 20th century the Wright Brothers and Pierpoint Langley were in a race to become the first to fly. The Wright Brothers are now famous. Pierpoint is a virtual nobody. This is despite his greater wealth, connections, and qualifications.

In his book 'Starting with the Why' Simon Sinek argues that what gave the Wrights the edge was their focus on the 'why', their appreciation of the true significance of the transformational change they aspired to. Sinek suggests that in contrast Pierpoint was driven by 'what' riches or fame he might gain from being the first to fly. Sinek argues that focussing on 'the why' became the brothers' superpower, enabling them to connect with the hopes and hearts of those around them.

Sinek's suggestions align well with the principles of the Care Aims Intended Outcomes Framework that underpins the Niwrostiwt. This framework highlights the importance of starting all strategic and clinical decisions with an exploration of the outcomes being sought. Kate Malcomess (the Care Aims author) and Simon Sinek both refer to these as the Why. These outcomes are defined by the meanings and values that are important to the people affected by the decision. This requires prefacing any decision making with a process of sense making. This essentially involves addressing questions about whose needs should be considered, what these needs are and how they relate to the wellbeing of the people involved, what these people feel is likely to help, what results or strategies need to be put in place to support the wellbeing of everyone involved, and finally what actions need to be undertaken and by who.

Put more simply this requires a decision-making process that starts with why (outcomes), then how (outputs), and then what (inputs).

The high-level outcomes for the Niwrostiwt relate to three populations – people living with long term neurological conditions, people working with long term neurological conditions, and the wider community, including communities of practice. The outcomes intended from the Niwrostiwt are summarised below. The shared commitment to achieving these outcomes provides the why at the heart of Niwrostiwt.

People affected by neurological conditions will be living their best possible lives experiencing a sense of autonomy, purpose, achievement, & connection. These people include family members, friends and unpaid carers of people living with neurological conditions.	People working in services for long term neurological conditions will be experiencing a sense of achievement, satisfaction, connection, support, creativity through their work and their shared focus on what matters to them and the people they are working with.	Communities (and families and communities of practice) will be experiencing a sense of safety, knowing that they are confident and capable to support each other's wellbeing and know where to ask for help when they need it.

Rhan Dau – Underlying Principles

"There is among doctors, in acute hospitals at least, a presumption of stupidity in their patients. And no one was 'stupid', no one is stupid, except the fools who take them as stupid. Working in a chronic hospital with the same patients for years one gains a greater respect for them – for their elemental human wisdom, and the 'special wisdom of the heart'. But at the breakfast with my 'brothers' – not my colleagues in expertise, but my fellow patients, fellow creatures – and throughout my stay in the Convalescent Home, I saw that one must oneself be a patient, and a patient among patients, that one must enter both the solitude and the community of patienthood, to have any real idea of what 'being a patient' means, to understand the immense complexity and depth of feelings, the resonances of the soul in every key – anguish, rage, courage, whatever – and the thoughts evoked, even in the simplest practical minds because a patient one's experience forces one to think.

Communication in the House was instant and profound. There was a transparency, a dissolution of the usual barriers between us. We not only knew the facts about each other (Doc's leg, Mrs P's ovary etc.), we knew, we sensed, we divined each other's feelings. This sharing of normally hidden and private feelings – feelings indeed, often hidden from oneself – and the depths of concern and compassionship evoked, the giving and sharing of priceless humour and courage – this seemed to be remarkable in the extreme, unlike anything I had ever known and beyond anything I had ever imagined. We had all been through it – sickness and fear – and some of us had walked in the Valley of the Shadow of Death. We had all known the ultimate solitude of being sick and put away, that solitude 'which is not threatened in Hell itself'. We had all descended to great darkness and depths – and now we had surfaced, like pilgrims who had taken the same road, but a road, thus far, which had to be travelled alone. The way ahead promised a quite different passage, in which we could be fellow-travellers together."

The above is yet another quote from Oliver Sacks' book 'A Leg to Stand On'. It can be found on P132-133. It highlights several of the principles underlying the Niwrostiwt. The expertise born of experience, and the social nature of recovery. These and other core principles are outlined in the next three sections. Together these principles set out the broader aims of the Niwrostiwt. They speak to the Why, the reason for establishing the college at all. At its heart the Recovery College is not about increasing the provision of inputs but transforming the way we think about health and care. Our focus is on long term neurological conditions, but we see wider relevance. We see this transformation as being critical to the long-term sustainability of public health services.

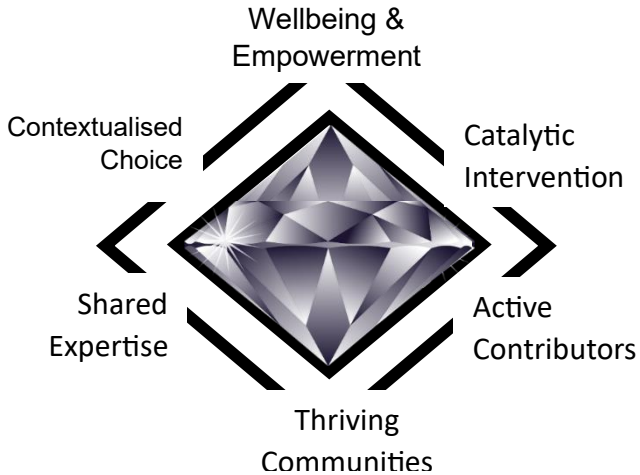
Stori Pedwar (Story 4) – Glo i mewn aur / Coal into diamonds

The links between the Niwrostiwt and the miner's institutes of the last century have already been noted. However, things have changed since then. Coal is no longer fashionable it can no longer be thought of as black gold. Carbon is a dirty word. But an interesting thing about Carbon is that the form it takes and the impact it has depends largely on the conditions with which it is treated. It is the same with people.

At the heart of our project is the ambition to transform the relationships and contract between service providers and recipients. Our strategy for doing this is through a shift in the principles underpinning our practice. A shift that is perhaps as profound as that needed to support decarbonisation or to turn coal into diamonds. For us the beliefs sustaining our old coal fired health care systems include:

- A focus on problems that are localised within individuals.
- Reliance on professionals as the main source of expertise.
- People being treated as patients who are passive recipients of healthcare.
- And a more recent focus on self-management with professionals as agents of change.

It can be argued that health care improvement initiatives too often focus on trying to do these things better. Services getting better at finding problems, developing staff expertise, and creating hi-tech treatments. It can also be argued that these efforts need to be matched or superseded by efforts to do better things. Things that are underpinned by new ways of



thinking about our work. Ways of thinking that enable the production of diamonds and move

past the delivery of coal. Some of the changes embraced by the recovery college are outlined in the Figure 1. This figure illustrates the value placed in the Niwrostiwt on focussing on:

- Wellbeing, hope, and control – rather than problems and deficits.
- The contextualisation of life challenges within people's history, family, values, choices, culture, and community.
- Creating capable communities with professionals as the catalysts and not the agents of change.
- Shared expertise and the need for the prudent use of all skills, assets & resources, to achieve the greatest good, and
- Working in the citizen space[1] with everyone as active participants and equal partners in co-creating thriving communities.

These principles not only speak to the relationships between practitioners and people living with neurological conditions, but they also speak to the links between individual and community. This is another area of discrepancy between the way practitioners and the people talk about health. In an anthropological study of healthcare, a group of researchers at the Mayo Clinic in Boston, an internationally renowned centre of healthcare excellence in the United States, observed that "*Health for members of the community is not defined as the medical community defines it, that is, as the absence or presence of disease, a risk score, or a score of comorbidity. Instead, community members defined "health" as the ability to meet the needs of the people who depend on them.*"

The above invites a re-conceptualising of health at a community level. Shifting focus from individual symptoms and symptom management to community capability - the ability of a community or community of practice to support collective wellbeing - with a greater focus on services acting as catalysts for the hidden capabilities of community, reserving more direct interventions for times where even the most organised community is unable to support the wellbeing of its members.

[1] Cormac Russell, (2020). Rekindling Democracy: A professional's guide to working in citizen space. Cascade Books.

Stori Pump (Story 5) – Gweitho yn yr gofod cymuned / Working in the Community Space


William Frost

There is a subplot to the story outlined earlier about the formative years of aviation. Seven years before the Wrights, Bob Foster an impoverished carpenter from Pembrokeshire, reportedly flew 500ft, 350ft further than the Wrights. Foster is a classic example of the unsung heroes and hidden treasures of Welsh communities. This is the other superpower that the recovery college aims to tap into.

In their book 'The Connected Community: Discovering the Health Wealth, and Power of Neighbourhoods, Cormac Russell and John McKnight suggest six building blocks that can be used to identify these hidden capabilities. These are:

(1) Contributions of Residents – These include the gifts, skills, passion, experience, and knowledge that residents contribute to the collective wellbeing of the neighbourhood. *Gifts* are innate talents that people are born with and happy to share. *Skills* are what people have learned to do and know well enough that they could teach a neighbour for free. *Passions* are what people care enough about to act on even tough they may not have a particular talent to bring to the issue. *Experience* is what people have lived through and come out the other side of. *Knowledge* is what people know well enough that they can share with their neighbours.

(2) Associations – these are clubs, groups, or small local organisations run by their members and networks of unpaid citizens.

(3) Local institutions – these are groups of people who work together for pay. They include not for profit organisations, non-governmental organisations, and public services.

(4) Local places – these are the built and natural environments that form the stage on which the first three building blocks become visible.

(5) Exchange – Russell and McKnight note three non-monetary forms of exchange - the exchange of intangibles; the exchange of tangibles (bartering/swapping); and the exchange of alternative currencies (e.g. time banking).

(6) Local Stories – the power of stories has already been noted. The power of local stories includes fostering community connectedness, refocussing attention from what is wrong to what is strong, reinforcing and shaping local culture, building a sense of pride and hope.

The importance of focussing on community capability is central to the discipline of Community Psychology. In their book titled 'Critical Community Psychology', Kegan and co-authors describe a set of core values for Community Psychology. These are very closely aligned with those of the Niwrostiwt. They are:

(1) Social Justice as a value articulated as the right to: equitable distribution of resources; peace and freedom from constraints; fairness; and self-determination.

(2) Community as a value articulated in the hope and desire: for companionship, love, tolerance, inclusion, celebration of diversity; that our individual and collective flaws will not hide our potential; and acceptance for who we are.

(3) Stewardship as a value leading to a duty and responsibility; to look after our world and the people in it; to enable people to contribute and gain a sense of belonging; not wasting things, people's lives, time; and thinking long-term to make things last longer than us.

The approach of Keegan and colleagues is unashamedly rooted in their local community in Manchester. To illustrate the rationale for their local emphasis, they cite Bauman (2007) who draws attention to the importance of place in constructing wellbeing:

"It is around places that human experience tends to be formed and gleaned, that life sharing is attempted and managed, that life meanings are conceived, absorbed and negotiated. And it is in places that human urges and desires are gestated and incubated, that they live in the hope of fulfilment, run the risk of frustration."

For the same reasons the Niwrostiwt is similarly rooted in place. The perspective is unapologetically local. This does not represent a narrow 'not from around here' perspective. Instead, it recognises that residents, local associations, local institutions, and places across Wales have much to offer. These are the people who are best placed to understand what is valued locally, what is strong, what is at risk or already impacted, and what might help to address any risks and impacts. The stories of local innovators and heroes in this report are offered as illustrations of this potential.

Stori Chwech (Story 6) – Adferiad Personol / Personal Recovery

Perkins and Repper 1996 highlight the need for a model to guide health care. They argue that "*The models we use determine our understanding of the person's problems and leads us to different priorities and interventions. For example, if we adopt a wholly medical model then we will only assess symptoms: if we adopt a skills-based model we will assess a person's competencies and train them. The model we use also determines the type of intervention we adopt, the ways in which we judge success and ultimately the morale of both staff and clients*." (P18).

Following Perkins and Repper, the model adopted by the Niwrostiwt leans heavily into the literature on personal recovery. In 1993 William Anthony described this as a "*deeply personal unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and contributing life, even within limitations caused by illness*".

Personal recovery is as it says on the tin, personal. It relies on making sense of, decisions about, and setting goals for the outcomes that matter to that person's wellbeing. This in turn is linked to their unique pattern of beliefs, relationships, and values. This is opposed to clinical recovery which focuses on the restoration of more general physical functions. The significance of individual meaning in personal recovery is illustrated in the following stories.

One of the authors has a brother who had a spinal cord injury at the age of 19. With extended, intensive, and specialised rehabilitation he recovered some function in his left leg, arm, and hand, with more compromised functioning on his right side. Fortunately, he was left-handed. His physical recovery could be described as patchy. This has not stopped him from living a full and fulfilling life. This has included many overseas trips, with trips to Rugby World Cups, Lion's Tours, and a solo drive from the Cape of South Africa to Egypt.

Our team have recently worked with two gentlemen who both had strokes profoundly affecting their communication. Both were understandably devastated by this. However, one appeared to fare better in terms of retaining some sense of wellbeing. This gentleman was a farmer who was happiest in his field with his herd of cows where no words were required. The other gentleman was a linguist who spoke and taught many languages. These brief clinical stories highlight the importance not only of physical symptoms but the way these are linked with the things that are most significant to a person's wellbeing.

Over many years and across many countries there has been volumes of research exploring the factors contributing to human wellbeing. This research has identified a range of frameworks with different but overlapping sets of wellbeing factors. One of the most well researched frameworks is the Human Givens. This set of 10 wellbeing factors was first outlined by Joe Griffin and Ivan Tyrrell in the late 1990s. Research into the Human Givens reveals a high level of consistency across geography, culture, and time. The Human Givens are summarised in the graphic below.

It is becoming increasingly clear that it is not only the wellbeing of the people accessing services that is important. There is overwhelming evidence that the wellbeing of those people who care for them either as family and friends or paid employees is also increasingly at risk or currently adversely impacted. For instance, a 2024 BBC Wales article reported that a freedom of information request to the main health boards in Wales and the ambulance service revealed that 33% of all staff sickness was due to stress, anxiety, depression, or other mental health conditions.

The Niwrostiwt recognises the need to support the wellbeing of all those affected by and working with long-term health condition by extending the concept of recovery to one of 'recovery & discovery'. Borrowing from the definition of recovery, provided by William Anthony (please see above) the latter is defined as a "*deeply personal unique process of changing one's attitudes, values, feelings, goals, skills, and roles to create a satisfying, hopeful, and contributing work life, even within resource limitations*". The interrelatedness of wellbeing in caring relationships is illustrated well in Mike Nolan and colleagues (2006) Senses Framework for Relationship Centred Care. This wellbeing factors outlined in this framework overlap considerably with the Human Givens. They are summarised below and can also be found via the following link [The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2. - Sheffield Hallam University Research Archive (shu.ac.uk)](#).

A sense of safety

For service recipients : Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain and discomfort.

For staff: To feel free from physical threat, rebuke or censure; secure conditions of employment;. emotional demand of work recognised; supportive culture.

A Sense of Continuity

For service recipients: Recognition and value of personal biography. Skilful use of knowledge of that to help contextualise present and future.

For staff: Positive experience of work with older people from an early stage of career, exposure to positive role models and good environments of care.

A Sense of Belonging

For service recipients : Opportunities to form meaningful relationships, to feel part of a community or group as desired.

For staff: To feel part of a team with a recognised contribution, to belong to a peer group, a community of gerontological pr actitioners.

A Sense of Purpose

For service recipients : Opportunities to engage in purposeful activity, the constructive passage of time, to be able to pursue goals and challenging pursuits.

For staff: To have a sense of therapeutic direction, a clear set of goals to aspire to.

A Sense of Fulfilment

For service recipients : Opportunities to meet meaningful and valued goals, to feel satisfied with one's efforts.

For staff: To be able to provide good care, to feel satisfied with one's efforts.

A Sense of Significance

For service recipients : To feel recognised and valued as a person of worth, that one's actions and existence is of importance, that you 'matter'.

For staff: To feel that gerontological practice is valued and important, that your work and efforts 'matter'. (Based on Nolan 1997)

Stori Saith (Story 7) - Places and Spaces for Recovery and Discovery

Griffith Jones was born in Penboyr, Camarthenshire in 1684. In 1731, he started what became known as 'circulating schools'. These schools were held in one location for about three months before moving ("circulating") to another place. The idea was met with enthusiasm, and by his death in 1761, it is estimated that 3,325 schools were held and as many as 200,000 scholars - something like half the population of children and adults across Wales were taught to read. Given the scale of the venture, Jones needed to build a community of capable practitioners who in turn contributed to the unlocking of the capabilities held by the wider communities of Wales. The circulating schools are seen as one of the most significant educational experiments in Europe from that era.

Like Griffith Jones' circulating schools, the Niwrostiwt aims to build places and spaces for learning. Although on the surface the goal of the circulating schools was to provide literacy lessons to enable people to read Welsh, according to Jones the deeper intended outcome was that people would have access to and "know those things necessary for their salvation". The latter being 'the why' for the existence of the schools. Like the circulating schools, the intention of the Niwrostiwt is not simply the provision of (psycho)education but instead to unlock and enhance the capability of citizens, health and care workers, and communities to live well and to reach their full potential.

The tables below outline the characteristics of the places and spaces for recovery and discovery that the Niwrostiwt aims to facilitate. The top portion of the table contrasts the features of more traditional ways of working on the left, with the features of collaborative working promoted by the Co-production Network for Wales on the right. The middle section outlines the Conditions for Success taken from the work of Bush, Harris & Parker. The bottom right section summarises the intended aims of recovery. The bottom left sketches key features of the mindset that we see as supporting co-production, recovery, and discovery. This section attempts to describe the spirit of the Niwrostiwt approach. It uses quotes from different people with the hope that these help to illustrate the emotional and relational qualities of this mindset, as well as the more conceptual elements. The second of the tables below uses images to represent the same themes as the first table, again the hope is that these tap into different cognitive channels and help to contribute to a deeper appreciation of the mindset.

Traditional Ways of Working – Problem Focussed Model

- Valuing professional expertise with a focus on diagnosing and fixing problems.
- Building relationships of trust, with the balance of power and influence held by professionals.
- Focussing on clinical needs of the identified patient.
- Professionals as agents of change and 'patients' as recipients of care.

SURFACE CHANGE

New Ways of Working – Places and Spaces for Recovery and Discovery

- Valuing all participants with a focus on building their strengths and resources.
- Building relationships of trust, reciprocity, and equality by sharing power and responsibility.
- Doing what matters to the wellbeing of all the people involved, rather than just focussing on the problems of the identified patient.
- Recognising people as change makers and adopting the role of an enabler, rather than assuming the role of active agent of change.
- Developing networks of mutual support.

DEEP CHANGE

Conditions for Success

Openness to self-change; respect for other people's autonomy and freedom of thought/choice; willingness to make best efforts + Time + Space.

DEEP CHANGE

Intentions

People will be experiencing a sense of recovery and discovery through a deeply personal process of changes to attitudes, values, feelings, goals, skills and/or roles with the aim of creating a way of living a satisfying, hopeful, and contributing life, even within limitations caused by illness or resources.

Mindset of Recovery & Discovery

- "*Taking off the NHS spectacles*" (Nigel Crisp): Health is not the same thing as healthcare.
- "*Musicians must make music, artists must paint and poets must write if they are to be ultimately at peace with themselves*." (Maslow): Health is the ability to follow personally valued life plans.
- "*People are as wonderful as sunsets*" (Carl Rogers): Belief in people's ability to identify and solve challenges to their health and wellbeing. (This is not the same as saying they can provide all aspects of healthcare.)
- "*Seeing the whole kitchen, not just knifeiness*" (Michael Sheen): People seen as part of biological, social, and environmental eco-systems rather than individual entities.
- "*Health is made at home, hospitals are made for repairs*" (Nigel Crisp): People's capability to live healthily is moderated by their personal resilience and ecosystems with a crucial role for mutually supportive, empathic, and enabling relationships, and enriching environments.
- "*Professionals as guests in other people's life, rather than hosts in their clinics*" (Don Berwick).
- "*Professionals as catalyst of change, rather than active agents*" (Kate Malcolmess).
- "*First do no harm*" (Hippocrates): Healthcare can support people's health but also impair it.
- "*People as authors of their own story*" (Atul Gwande): Any unnecessary involvement of health care in people's life damages individuals and population health.
- *"Knowledge democracy"* – a more democratic way of creating, managing, and applying knowledge.

Traditional Ways of Working – Problem Focused Model

- Valuing professional expertise with a focus on diagnosing and fixing problems.
- Building relationships of trust, with the balance of power and influence held by professionals.
- Focussing on clinical needs of the identified patient.
- Professionals as agents of change and 'patients' as recipients of care.

SURFACE CHANGE

New Ways of Working – Places and Spaces for Recovery and Discovery

- Valuing all participants with a focus on building their strengths and resources.
- Building relationships of trust, reciprocity, and equality by sharing power and responsibility.
- Doing what matters to the wellbeing of all the people involved, rather than just focussing on the problems of the identified patient.
- Recognising people as change makers and adopting the role of an enabler, rather than assuming the role of active agent of change.
- Developing networks of mutual support.

DEEP CHANGE

Conditions for Success

Openness to self-change; respect for other people's autonomy and freedom of thought/choice; willingness to make best efforts + Time + Space.

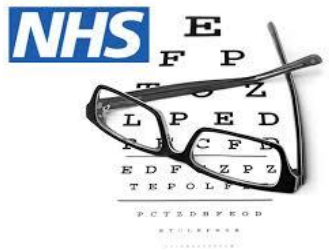
DEEP CHANGE

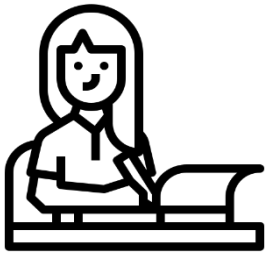
Intentions

People will be experiencing a sense of recovery and discovery through a deeply personal process of changes to attitudes, values, feelings, goals, skills and/or roles with the aim of creating a way of living a satisfying, hopeful, and contributing life, even within limitations caused by illness or resources.

DEEP CHANGE

Mindset of Recovery & Discovery



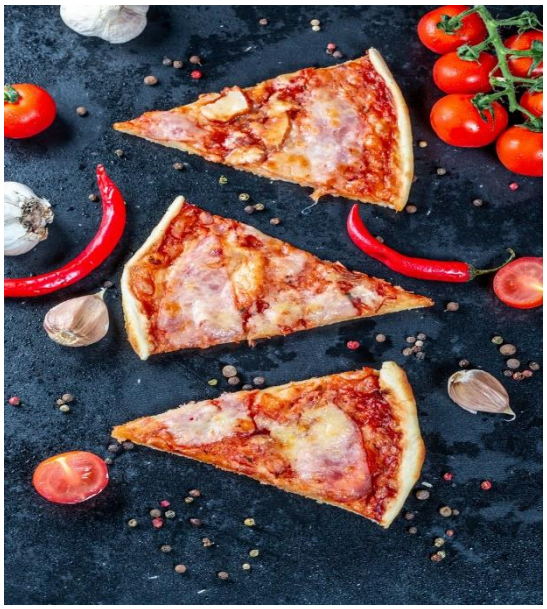


Stori Wyth (Story 8) Y Pryd Eidaladd Perffaith/The Perfect Italian Meal

This section provides an outline of the Niwrostiwt through the story of Italian Welsh cafés. There was a time every small town and community in Wales had an Italian cafe and ice cream parlour. Before the second world war there were over 300 Italian Café's across the country. Although many of them have now disappeared, dispossessed, and superseded by giant multi-national chains, this section pays tribute to these cafes and the people who ran them.

One of the key requirements of a good pizza is a good base. It's the same with the recovery college. The base for every aspect of the college is the values and beliefs outlined in previous sections.

Like a pizza the Niwrostiwt can also be divided into different slices, each being a different faculty. The three slices, or faculties, of the Niwrostiwt are illustrated below.



Living Well Faculty

Community & Communication Faculty

Physical Faculty

Continuing with the pizza metaphor, each faculty (slice) of the recovery college can be seen as having several toppings, with each topping taking the form of a group module or workshop. Core modules are listed below, with more detailed descriptions being provide in the appendix.

- Making sense of my stroke or brain injury
- Making sense of functional seizures
- Fatigue Management
- Rebuilding Your Life
- Living well

Living Well Faculty

- Communication café
- Creative opportunities
- Family & Friends Support Group
- Peer to volunteer
- Vocational Network

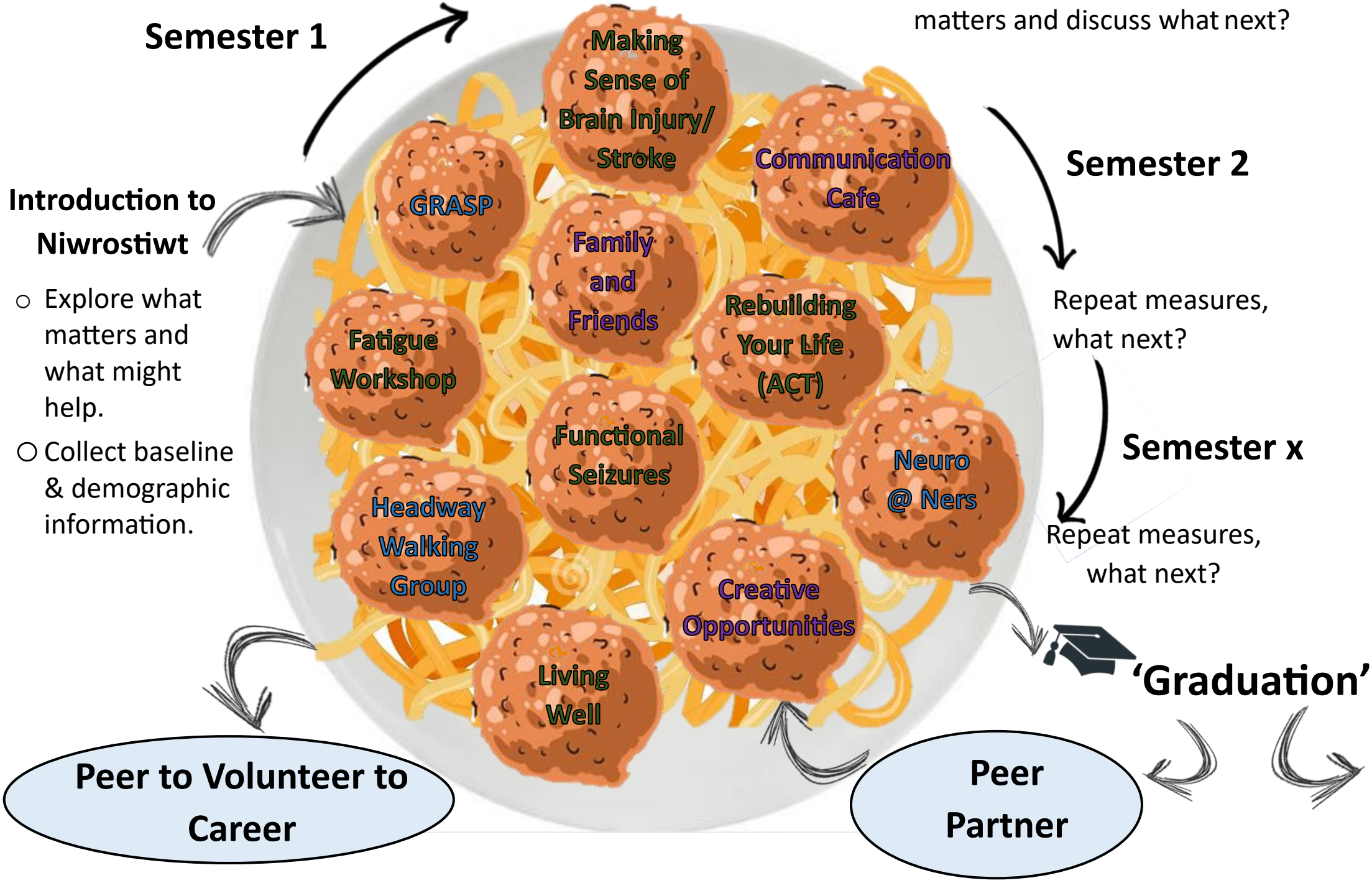
Community & Communication Faculty

- Neuro@NERS
- Grasp Group
- Community Activity Groups

Physical Faculty

If the pizza course describes the structure of the Niwrostiwt, the pasta course provides an overview of the process. On the menu are meatballs and spaghetti. If you like playing with your food, the great thing with this dish is that the spaghetti can be used to connect each meatball in any number of ways. The Niwrostiwt incorporates the same flexibility. Participants can start by joining any one of the modules. They can then choose to follow this up with pretty much any of the other modules. There are a couple of exceptions with the Making Sense of Functional Seizures and Communication Café being focussed on people with relevant presenting problems.

Participants generally complete one module at a time, and one per semester. They are free to take as many modules as they want and can repeat modules if they think that this will be helpful. Prior to entering the Niwrostiwt and between each module they complete core assessments and are supported to consider what is important to them at that point and what is likely to help.


Repeat measures, explore impact on what matters and discuss what next?
Semester 1
Introduction to Niwrostiwt
Explore what matters and what might help.
Collect baseline & demographic information.
Making Sense of Brain Injury/ Stroke
GRASP
Communication Cafe
Family and Friends
Fatigue Workshop
Rebuilding Your Life (ACT)
Functional Seizures
Neuro @ Ners
Headway Walking Group
Creative Opportunities
Living Well
Semester 2
Repeat measures, what next?
Semester x
Repeat measures, what next?
'Graduation'
Peer to Volunteer to Career
Peer Partner

When participants and facilitators feel that they have got as much as they can from the Niwrostiwt modules to support their wellbeing they still have options. They can choose between 'graduating' and leaving the Stiwt or taking a voluntary role as a peer partner. These roles offer a variety of opportunities ranging from co-facilitating group modules to participating in Stiwt co-production meetings, to project work, to undertaking formal training with the health board enabling them to join the growing team of Stiwt graduates who are supporting FFrind-i-mi the Health Board's befriending scheme. The aim is to make these opportunities as widely accessible as possible, offering various levels of commitment from being involved in quarterly meetings, to supporting weekly group sessions. Support, supervision, and training are also offered to help people thrive in peer roles and to support the integrity of the Stiwt model.

Graduates are also encouraged to think about whether their involvement in the Stiwt has created opportunities for informal ongoing support. Whilst autonomy and free choice over these opportunities is paramount, a key message from Niwrostiwt modules is that connection and community are important both for human wellbeing and health.

Rhan Tri – Yr Dysg / The Learning

In Welsh the word 'dysgu' is the verb 'to learn' but it can also be used casually to mean provide tuition. This double meaning is well suited to the ideal of the Niwrostiwt where the aim is for all participants to learn as well as offer opportunities for other people to learn. This bi-directional learning includes using feedback from everyone participating in the Niwrostiwt to further improve impact, capacity, access, and efficient use of limited resources.

Continuous improvement is also supported by an ongoing cycle of action research. Stiwt collaborators plan, they do, they analyse, they learn, and then they plan for any changes. Crucially this process of learning extends beyond learning to do things better, to a deeper exploration of the attitudes, values, feelings, goals, skills and/or roles guiding our actions. The aim being that we are always exploring ways that we and the communities and communities of practice that we are part of to live and work with greater wellbeing. This is essentially the process of recovery and discovery that was described earlier.

In planning and carrying out this evaluation we have received invaluable support from the Bevan Commission Exemplar Programme. This support has impressed on us the importance of providing a balance of evidence to meet the different needs of various stakeholders.

Another important contribution from the Bevan Commission has been support to use the Most Significant Change Method (MSC) to inform improvement through evaluation. MSC is an approach to evaluation that was developed in the context of complex and messy public health initiatives, where control is limited and outcomes uncertain. It starts by gathering stories from the frontline which are focused on capturing *change outcomes* that have resulted from an intervention or programme. Unlike case studies, MSC stories are *by* people, not *about* them. They are first person stories that are led by the people being interviewed rather than tick box performance measures.

The MSC process has 3 stages: (1) Gather stories of change (good or bad) from the frontline; (2) Explore and learn from the stories in story selection panels attended by managers and people who can influence policy and practice development; (3) Provide feedback on what has been learnt and the implications for policy and practice development. The report on the Most Significant Change study is available separately. Key findings from this study are included as evidence in the relevant sections of the summary of the Niwrostiwt 2023-24 evaluation below.

Stori Naw (Story 9) – $E = MC^2$

This is clearly one of the most famous mathematical equations ever. Most of us have no idea what it means, other than it was penned by Albert Einstein and to do with relativity. I think this much is common knowledge. What is less well-known is that an essential part of the equation, the equals sign (=), was invented by Robert Recorde a Welsh physician and mathematician. Recorde was born in 1510 and one year before his death in 1558 he also introduced the pre-existing plus (+) and minus (-) signs to English speakers.

In many ways the above is the perfect way of introducing the Niwrostiwt evaluation. This is because it is a story about numbers, well at least about mathematical notations. This parallels the use of stories and numbers in the Niwrostiwt evaluation to illustrate the social return on investment.

The figure below summarises the key domains targeted in the Niwrostwit evaluation. Each of these domains are explained below alongside the data we have captured to illustrate the impact of the Recovery College.