

Imogen Blood & Associates

Positive risk and shared decision-making

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Executive summary

We identified and reviewed 73 documents related to "positive risk" and "shared decision-making" from the UK, including academic articles, guidance, practice tools, blogs and research reports.

We engaged a total of 39 people – mostly social care professionals – in focus group discussions about "positive risk" and "shared decision-making", exploring what these mean in practice and the enablers or barriers.

Key messages:

• "Risk" is a topic that tends to resonate most with professionals, and some family members; many individuals do not see their lives and the decisions they make in these terms.

• There is little primary research into what people who need care and support and their families think about "risk" and how they define it, and it has not been possible to gather new data on this during the timescales and resources of this commission. The evidence we have reviewed suggests individuals see quite different risks from receiving care and support services, compared to professionals. For example, this may include: the risk of losing independence; of stigma and discrimination; of not having a say; or of not being able to do the things that matter most to them.

- "Positive risk" is integral to the wider agendas of:
 - empowering and promoting the rights of disabled and / or older people
 - transforming social care from care management to a relational and strengths-based approach, with the social worker as facilitator, rather than fixer and protector.

• Positive risk taking is supported by the Social Services and Well-being (Wales) Act 2014, the Mental Capacity Act 2005, the Human Rights Act 1998 and the Equality Act 2010; however, awareness of and confidence in this is limited within social care and among health professionals. • Risk averse practice, attitudes, systems and culture do often restrict individuals' quality of life. Although we present many examples of good practice, these often involve individual professionals pushing against systems, and senior and multi-agency colleagues, or even having to do things covertly.

- The main barriers here include:
 - a "blame culture" in many social services departments, which was felt to be driven by performance management and the requirements of the regulation and inspection regime. This results in a lack of trust in professional judgement

- a lack of understanding that the law requires a positive risk-taking approach and how this differs from "negligent" practice

- a lack of time to invest in working with families to hear their worries, understand what matters to the individual, and broker alternative solutions (which can often be more sustainable and cost effective over time).

• In our report, we present a number of innovative models, which all require and / or support "positive risk-taking" approaches:

- allow greater choice and flexibility in care and support at home (including, but not limited to direct payments)
- provide methods for collective decision-making (for example, circles of support, family group conferencing, "fish bowl")
- link individuals into mainstream and sources of community support, rather than maintaining them "in services" (for example, community connectors, progression models).

• We also present a selection of tools, policies and practice examples, which have been published, mostly outside Wales, that can usefully inform the development of a positive risk-taking approach by Social Care Wales.

Recommendations

Focus group participants felt that Social Care Wales could and should embed key messages about positive risk in training, leadership development and its work to promote better understanding about the role of social work under the Social Services and Well-being (Wales) Act 2014. Specifically, there is a need to challenge the assumption that social workers' main objective is to protect individuals from harm and that they have sole responsibility for doing this.

Positive risk-taking needs to be embedded within outcomes-based and relational approaches (since it is only then that we can truly understand what matters to an individual and decide which risks are worth taking); and strengths-based approaches (since an individual's, family's and community's resources should be a key part of "risk management").

It is likely that detailed "guidance" about positive risk might get lost in the sheer volume of current publications aimed at the sector. Instead we advise that:

• A list of core principles in relation to risk be coproduced with individuals who need care and support, and with a range of professionals. These might usefully be expressed as rights and linked to the existing legislation (for example, under the Social Services and Well-being (Wales) Act 2014, the Equality Act 2010, the Mental Capacity Act 2005, the Human Rights Act 1998).

• Some of the good practice examples gathered and presented in this report should be disseminated in short (for example, one-page) flyers on Social Care Wales's website and perhaps through a series of printed posters and flyers, which highlight key principles and are accessible to social workers, other professionals, elected members and members of the public. These could be linked to and informed by the co-produced core principles (above) and should include (though not be limited to) examples of positive risk taking in direct payments.

• Social Care Wales commissions a short summary of the legal position in relation to "negligence"

and "duty of care" aimed at managers and frontline professionals. This should present short examples that distinguish negligence from defensible positive risk taking. These should ideally also resonate with health professionals and might be co-commissioned and / or branded with partners in health.

• Social Care Wales shares the findings and recommendations of this exercise with its colleagues at Care Inspectorate Wales. There is a bigger piece of work to do here to review and challenge the frameworks and methods of inspection and regulation, so they support positive risk taking, rather than act as a barrier. Again, this review should involve leaders and operational staff and should be coproduced with people who need care and support, since their experiences and outcomes should be the core measures of successful performance.

• Social Care Wales supports leaders in social care and health with learning and development, so they can model and embed positive risk taking in their organisations. This could take a number of forms, depending on budget and opportunities to link into existing or planned initiatives, such as:

- training / workshops, covering topics, such as strengths-based leadership, positive risk taking, reflective supervision
- action learning sets / communities of practice

- dissemination of what the best leaders are doing in relation to this agenda, which should include some of the commissioned initiatives featured in this report, as well as innovative approaches to performance management, staff supervision and mechanisms for gathering feedback from people who need care and support and their families.

1. Introduction

In recent years, there has been a lot of pressure on health and social care professionals to assess and manage "risks". Yet, risk assessment can sometimes prevent people who use social care services from doing the things they want to do, or living where they want to live.

Social Care Wales has produced a five-year strategy to improve <u>Care and support at home in Wales</u>. Supporting a shift in culture and practice towards an agreed approach to positive risk, and nurturing a culture of shared decision-making across social care is a priority within this. They commissioned the independent social research consultancy <u>Imogen</u> <u>Blood & Associates</u> to help them understand existing evidence and practice in this area, and work out how Social Care Wales can best support the sector to achieve this shift.

1.1. The evidence on which this report is based

The project ran from January to March 2018.

Evidence review

We carried out a rapid evidence review for published material relating to positive risk and shared decisionmaking. This involved:

• a search of the University of Manchester's ESCOhost database for academic articles relating to health or social care with the term "positive risk" in the title or abstract

• Google searches using the terms "positive risk", "positive risk-taking", "risk enablement" and "shared decision-making"

- targeted searches of the following web sites:
 - Social Care Wales
 - Social Care Institute for Excellence / Social Care Online (England)
 - IRISS (The Institute for Research and Innovation in Social Services) (Scotland)
 - Co-production Network Wales
 - Think Local Act Personal (England).

We identified 73 resources from these searches, including academic articles, books, research reports, guidance, resources and blogs. We reviewed the majority of these, prioritising those which related to "care and support" for adults at home.

Engagement

We carried out three focus groups in different parts of the country during February and March 2018: in St Asaph, Cardiff and Carmarthen. Twenty-five people took part in these discussions, which each lasted for three hours (including a break for refreshments). The majority of them worked for local authority adult social care teams, including long- and short-term teams; and specialist learning disability, transition, workforce development or direct payments / independent living teams. There was a mix of commissioners, service managers, team leaders and frontline workers. The participants also included two people in advocacy roles, two people working in provider organisations and two consultants working to support change in a number of local authorities. Two participants identified as disabled and one as a parent-carer.

We also supplemented this data with two 30-minute group interviews with a total of 14 team leaders and senior practitioners from a Welsh local authority where we were already delivering a programme of training on strengths-based leadership.

We produced a flyer providing background about the project and distributed it electronically via the networks of Social Care Wales and Imogen Blood & Associates. We recruited focus group participants through the "snowballing" of these contacts.

Through this process, and drawing on the contacts of Disability Wales and The Dementia Engagement and Empowerment Project (DEEP), we tried to identify and invite people with lived experience of disability to attend the groups. However, we had very limited success in this. We attribute this partly to the tight timescales and limited resources, but also to the nature of the topic, which perhaps did not immediately resonate with people. To engage non-professionals meaningfully in relation to "positive risk" in the future, we would advise Social Care Wales, based on this experience, to:

• meet existing groups of people who need care and support (for example, through the Dementia Engagement and Empowerment Project, direct payment-user forums already organised by People Plus, groups convened by Disability Wales or Learning Disability Wales (such as their Parents with a Learning Disability network))

• start the conversation around a wider theme of what matters most to them, and what can support or get in the way of this within services, and discuss "risk" as part of that (perhaps in a follow-up conversation, if necessary), rather than billing the discussion as one about "positive risk".

We made audio-recordings of all the discussions and conversations, and then took detailed notes from these to support our thematic analysis.

1.2. The structure of this report

We have used formatting throughout this report to highlight different types of evidence used:

• orange text boxes are used to present quotes from focus group participants

• green text boxes are used to present practice examples gathered through the focus groups

1.3. Definitions

In the literature

The most commonly used definition of "positive risktaking" in the literature examined is:

"Weighing up the potential benefits and harms of exercising one choice of action over another. Identifying the potential risks involved (i.e. good risk assessment), and developing plans and actions (i.e. good risk management) that reflect the positive potentials and stated priorities of the service user (i.e. a strengths approach). It involves using 'available' resources and support to achieve the desired outcomes, and to minimise the potential harmful outcomes." (Morgan, 2013, page 21)

In summary, in a positive risk-taking approach, decision-making should be:

• **Balanced**, recognising the potential for benefit as well as the risk of harm, and considering the possible emotional, psychological and social impact of each option, as well as the physical

• **Defensible**, that is well-founded, justifiable and recorded proportionately; not defensive, that is driven by the need to protect ourselves and our agencies

• **Collaborative** with people who use services, their families and other professionals, using all available resources to achieve the outcomes that matter most to people.

The concept of "risk enablement" seems to be used interchangeably with "positive risk-taking". The Open University (2018) argues that:

"Risk enablement involves supporting people to make their own decisions about the level of risk that they are comfortable with."

"Risk management" has been defined by Gateshead Council (2009) as:

"The activity of exercising a duty of care where risks (positive and negative) are identified. It entails a broad range of responses that are often linked closely to the wider process of care planning." (Page 14)

"Shared decision-making" has been developed in relation to clinical decision-making in healthcare settings. National Voices (2014) suggests the following definition:

"Shared decision-making is a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and choosing a preferred course of care and treatment. People and professionals work together to clarify acceptable medical options and choose an appropriate treatment." (Page 2)

This process of negotiation with people who use services may still feel quite radical in some parts of the medical profession, but it is hopefully much less so in social work, where engaging people who use services in designing their own care has deep historical roots.

In the focus groups

There was a strong sense from the groups that "risk" is a topic that mostly concerns professionals, and some family members; most individuals do not tend to see their lives and the decisions they make in these terms:

"Is it 'positive risk'? Or is it more just about people making decisions about their lives?"

However, there was some criticism of the term "shared decision-making", too:

"Why should the decision-making be shared with professionals?"

Nevertheless, there was a strong sense from these groups of (self-selecting) people that this is an important topic since:

"There's a huge culture of risk aversion, which can really get in the way of people trying to live their lives well."

However, the discussions quickly broadened to cover a range of wider, underpinning topics, including:

• power, rights and the institutional discrimination of disabled and / or older people

• the transformation of social care from manageriallydriven, output-focused care management processes to a relational and holistic approach that aims to facilitate and empower people to achieve the outcomes that really matter to them.

To progress these wider agendas, it was felt that a new approach to "risk management" needs to be developed, communicated and embedded, however it is labelled. Conversely, "positive risk taking" can only be embedded in organisations if it is part of a wider shift towards rights-based and relational approaches.

1.4. Policy and legal context

There is a clear mandate from legislation and policy in Wales and across the UK to re-focus service delivery on achieving the things that matter to individuals using services. The Social Services and Well-being Act (Wales) 2014 is based on the core principles of "voice and control" and "coproduction" to help people improve their "wellbeing", as defined by them. The vision here is for services to become facilitators and brokers, supplementing rather than replacing personal and community resources.

This policy direction inevitably raises questions about risk, power and accountability: if statutory bodies are to handover control, must they also necessarily handover risk? If so, how can this be negotiated and agreed in a way that promotes autonomy for the individual and clarity for professionals in relation to the boundaries of their responsibilities? Where personal and community networks fail, when and under which circumstances is the state responsible?

The introduction of "direct payments", "selfor citizen-directed support", or (in England) "personalisation" and "individual budgets seems to have prompted much of the literature related to positive risk (for example, Carr, 2010; Hudson, 2011; Glasby, 2011). Self-directed support assumes that people are capable of making their own decisions and managing their own risks; however, the fact that they are being funded to do so by the local authority can create tensions in relation to where the authority's "duty of care" begins and ends. There is a body of legislation, which sets out the rights of disabled and / or older people and should support positive risk-taking:

The **Mental Capacity Act 2005** sets a much higher threshold for judging a person as lacking the capacity to make a decision than is commonly thought.

The Human Rights Act 1998 protects our rights to liberty (Article 5) and to private and family life (Article 8), and has been used successfully to contest risk averse practice by local authorities (for example, LB Hillingdon v Steven Neary (2011) EWHC 1377 (COP)).

The Equality Act 2010 requires public bodies to ensure their policies and practice (and those of the organisations they commission) do not have a disproportionately negative impact on disabled people or other "protected characteristic" groups. There may well be a case under the Act for arguing that, where a disabled person is facing the same risks that anyone else would face, the involvement of the council in that decision may be discriminatory. Abiding by health and safety legislation is likely to be seen by the courts as one of the few legitimate grounds for treating one protected characteristic group less favourably than another. However, where an overly cautious policy is impacting negatively, an evidence-based equality impact assessment, involving proper consultation with disabled people (or other affected groups such as older people) should be carried out to identify ways of reducing inequality.

The Equality Act 2010 also requires all services to make sure that reasonable adjustments are made to promote equality of access to services. This should, for example, include making sure that a British Sign Language/English interpreter is available to allow a deaf person's views to be heard within a decisionmaking process, and this should include the several conversations social workers should be having with individuals under the Social Services and Well-being (Wales) Act 2014.

1.5. Overview of the "evidence base"

We identified a significant number of documents – including guidance, tools, evidence reviews, briefings, think pieces and blogs – that consider the topic of "positive risk" – and "risk" more widely – in social care.

However, positive risk-taking approaches do not yet appear to have been formally evaluated in terms of outcomes for, and experiences of, those receiving services, or from a cost effectiveness or professional perspective. In the literature, as well as in the focus groups, the "evidence base" for positive risk taking is not clear cut and it broadens quickly into wider themes of:

- relationship-based care
- strengths-based approaches
- reclaiming social work
- rights- and outcomes-based approaches
- the wider transformation of health and social care.

Our evidence searches identified very few publications dedicated to the topics of "positive risk" and "risk enablement" in Wales compared to the rest of Great Britain. Writing in 2011, Wiseman suggested that these concepts may have less currency in Wales, where "personalisation" has been less market-driven and there is a stronger policy focus on solutions involving family and community than in England.

However, since he wrote this, "positive risk" has been mentioned within a range of Welsh social care documents, for example:

• The Direct Payments Guidance (Welsh Government, 2011) states that: "The benefits of increased autonomy and social inclusion may have to be weighed against the risks associated with particular choices" (paragraph 4.12, page 32)

• Transforming Learning Disability Services in Wales (SSIA, 2014) warns that risk aversion can lead to people with cognitive impairments being "over-serviced" and de-skilled by services. It positions positive risk-taking at the heart of personcentred approaches and, although it does not explore this in depth, offers a case study (page 25) demonstrating the benefits of this approach

• Social Services and Well-being Act (Wales) Act 2014 Code of Practice talks about "positive risk" being an "essential part of everyday life" (Part 3, page 27)

• Good Work: A Dementia Learning and Development Framework for Wales (Care Council for Wales, 2016) contains a short section on positive risk

• Developing a Reablement Service for people with memory problems or a dementia living at home in Wales (SSIA, 2016) contains a section on positive risk and urges its readers to: "Understand the important distinction between putting people at risk and enabling them to choose to take reasonable risks" (page 26).

There is little primary research into what people who use services and their families think about "risk" and how they define it. This gap has been highlighted by Carr (2010), Boardman and Roberts (2014) (in relation to users of mental health services), and by Mitchell and Glendinning (2007) in their review of the literature around risk in social care.

The Joseph Rowntree Foundation (JRF) later commissioned an update of this review (Mitchell et al, 2012), which identified nine publications from the intervening five years that explore the views of people who use services and their carers. Four of these study experiences of safeguarding processes; two explore people's own strategies for managing risks; and one considers risk averse strategies adopted by family carers of people with dementia.

JRF also commissioned a piece by Faulkner (2012) exploring individuals' views of risk in adult social care. This was informed by engagement with a number of disabled and / or older people, but was not intended to be systematic qualitative research. However, the report offers a number of powerful insights and themes, which are confirmed in wider research with people with lived experience. We present key messages from this body of work in the next section.

Positive risk is not without its critics. Furedi (2011), for example, argues that greater openness to risk in social care policy documents has been positioned as a response to the demands of individuals for greater freedom; when it serves as a means of cutting costs and transferring responsibility from the state to the individual. Seale (2013) argues that:

"Policy drives to increase positive risk-taking sit alongside socio-legal frameworks that place more emphasis on safeguarding and substitute-decisionmaking than they do on empowerment and advocacy" (page 239).

Finlayson (2015) argues that the language of risk assessment and risk enablement is ambiguous and ill-suited to the realm of social care work where most decisions are complex and fluid, not scientific or static. The whole concept of risk assessment "grants the authority to the professional and creates a duty to intervene". Its purpose is to evidence professional competence and protect against liability, rather than improving the lives of individuals and enabling them to manage their own lives.

While he welcomes risk enablement theory as "a very positive step forward in its highlighting of the weakness of the current model", he argues that "it still creates a confused and ambiguous concept that on the one hand thinks of risk as something to be managed and avoided and on the other encourages its promotion". He argues that we need instead to return to "ordinary language" and a focus on "human worries" rather than "risks". The time and energy of practitioners needs to be focused on articulating, hearing, responding to and supporting human worries, rather than creating a series of alternative risk assessment tools.

In the following section, we explore the question posed in the title of several articles and reports (such as Robertson, 2011; Southern Health NHS Trust, 2012): *Whose risk is it anyway*?

2. Whose risk? Different perspectives on "risk" and "risktaking"

Different groups of stakeholders and, within these, different individuals, will have varying perceptions of risk – shaped by their roles, their circumstances and their personal values and attitudes.

2.1. The views of people who (may) need services

There is, as already highlighted, an evidence gap regarding the views of people who use services in relation to risk. However, as Furedi (2011) argues:

"People who use services don't often use words like 'risk' or 'choice'".

This point was also made by one of the focus group participants:

"The people we are talking about wouldn't identify with that [the word risk]."

Given this, perhaps we need to dig beneath what people have told researchers matters most to them to hear the "risks", even if they are not described in this way. For example, in the research we conducted for Social Care Wales (then the Social Services Improvement Agency) (Blood et al, 2016), the following risks were repeatedly identified (though not usually labelled explicitly as such) by older people who were not using services, but might be seen as being on the cusp of needing formal help:

• The risk of losing your independence: having to leave your home, move to a care home, become dependent on others, or become "a burden" to your family

• The risk of social isolation, often caused by disability, depression, poverty, fear of crime, bereavement, discrimination and difference, lack of transport and rurality (no longer being able to drive) • The risk of not being able to do the things that "make you tick" – from keeping your house and garden in order, and continuing to play a role in the community / family, to hobbies and simple pleasures

• The risk of "losing your confidence".

We also interviewed partners and family members who were in caring roles. A common theme from these conversations was that they wanted more support in making decisions – this was partly around information, rights and entitlements (particularly to support forward planning) but, for some, there was also a lack of emotional support around decisionmaking, especially where there were disagreements between family members.

Faulkner (2012) held various discussions with disabled people to inform her piece for JRF on risk. She identified the following themes:

• The risk of losing your independence was often felt to be the greatest risk – sometimes this involves taking a risk, sometimes it involves being risk averse (for example, to avoid a fall that might lead to loss of independence).

• Stigma and discrimination were highlighted as the biggest risks to disabled people's lives: contact with services itself risks abuse and loss of control (as highlighted by Speed's 2011 research to support the Equality and Human Rights Commission's inquiry into home care (EHRC, 2011), which found significant risks to people's human rights from the way in which domiciliary care is commissioned and delivered); people may fear that asserting their rights within service settings will result in victimisation.

• Risk contributes to the process of assessing eligibility for services, so there is a difficult balance to be struck between presenting enough of a risk to qualify, but not so much of a risk that you might lose your independence.

• People who use services are often excluded from decision-making about "risks".

Focus group participants, especially those with personal experience of disability, or of caring for a family member with a disability, or those working in advocacy roles, confirmed the risks that disabled people and their families are marginalised within the decision-making process.

However, there was evidence – certainly among those who attended our groups – of a determination by some to turn back the tables. The role of practitioners in building the skills and capacity of individuals to engage confidently in decision-making was emphasised by participants in all the focus groups in this study. It was viewed as especially important for some people who may find this harder, such as older people or people who have become used to being "told what to do" by services in the past.

"We're not the decision-makers anymore. It's about how we use our role to support that decision-making."

As Hamblin's (2014) research with older people and their families finds, "control" may be best understood as the ability to make decisions. She describes older people constantly adapting their behaviour to try and achieve a balance between freedom and risk – a point which Mitchell and Glendinning (2007) also identify in their evidence review:

"Preserving or re-defining choice, independence, respect and personal self-esteem are pivotal in older people's strategies for managing risk in order to maintain a normal life..." (page 27).

As a result of this, where changes are imposed by families or professionals, older people sometimes reject them and find new ways to do things on their own terms, which may involve higher levels of "covert" risk-taking.

As Clarke et al (2011) argue, when a person develops dementia, judgements and decisions about their lives move from a private, internal debate about "what is best for me" to an open public and professional debate about "what is best for him / her". Other people have an opinion, a duty and a responsibility for the "risk". This can lead to a number of "contested areas", such as going out, continuing to be involved in housework, or smoking.

This is likely to play out differently at an earlier stage in the lifecycle. Mitchell and Glendinning (2007) found that younger disabled people (as younger non-disabled people) are likely to place greater importance on fitting in, conforming to peer norms and avoiding social stigma, even if this means taking some risks in relation to their future physical health.

However, as Faulkner writes:

"In 'Careland' [that is, when a person is receiving care and / or support services], there are different rules – you are not expected or allowed to do things that might hurt you or might risk your safety even if that 'safety' means risking your own independence and wellbeing" (Faulkner, 2012, page 11).

As the following examples show, the potentially disempowering impact of being in receipt of statutory services on people's ability to make decisions about their own lives, was a significant concern among focus group participants in this study:

> "Why can't service users in the social care system make decisions just like we do?"

"They [people who enter the social care system] suddenly become 'disabled' by the system. Everything changes with that referral."

2.2. Families' views about risk

Families understandably often experience high levels of worry about their loved ones who have care and support needs. Of course, every family has different dynamics and each individual will have different attitudes, however this understandably leads to a tendency to prioritise safety. This is evidenced in the following selection of quotes from parent carers of younger adults with complex disabilities:

• Mother in Letting Go, by the BBC (2012): "It's that constant 24-hour worry that never goes away: what's happening to J?!"

• Parent supporting their disabled child to move out of the family home (Copeman & Blood, 2017): "I think a lot of people in my position (there are a lot of people who are divorced – and that is interesting in itself) – I know it's hard to let go but I think they really do also want to hang onto the benefits – if their child moves out, they will have to really re-think their lives and maybe get into full-time work – it all just feels too difficult for a lot of people; with too many unknowns. I think you have just got to emotionally disconnect to make it happen."

• Christine, Ceri's mum in Cowen & Hanson (2013): "Sometimes I come across as over protective because I can't do things as I always did but because I see her progressing I can see that I have to leave some things alone. It's hard to take a step back after all those years!"

Many focus group participants working in statutory social care roles raised the issue of families often being more risk averse, more concerned with eliminating risk and "protecting" their loved one. These attitudes were viewed by focus group participants as a significant barrier to positive risk taking in practice. It was recognised that a considerable amount of time and skill was needed to help families fully understand positive risk taking and its potential benefits before any decisions could be taken.

A social worker was asked to do a "best interests" assessment for a man who had a diagnosis of dementia and had recently been transferred from an acute hospital to a rehabilitation unit, even though she had not met him before.

Senior Health professionals had assessed him as lacking capacity and there were issues on the ward because they were trying to restrict him to his bed due to the risk of falling. He was becoming frustrated with this – he is a farmer and is used to being outside and moving around. Meanwhile, neither the hospital staff nor his family felt he could safely be discharged back to living in his farm.

The social worker refused to be rushed in her assessment and made five visits to the man and his family. She got to know them, listened to what each wanted and what anxieties they had. The man has now been supported to move back home; he is managing well and is happy, and the social worker has a good ongoing relationship with the family.

2.3. Professionals' views about risk

Morgan (2010b) reminds us that practitioners' own values and prejudices influence decision-making processes, especially around issues of "risk"; these may be built on (or in reaction to) dominant paternalistic views in services and in wider society. Ethnicity, culture, language and social class can all play a significant role in shaping how risks are perceived and responded to, as evidenced by the higher rates of sectioning of black people with mental health conditions than their white peers (Centre for Social Justice, 2011).

Based on their extensive research in the field of dementia care, Clarke et al (2011) suggest that professionals tend to take a forward view: they usually do not know the person from before their diagnosis and are typically conscious of and planning for the prognosis. This is in contrast to family members who are very conscious of what has been lost from the past.

A number of publications highlight the different types of risk issues that may arise for different client groups and the varying ways in which these tend to be perceived. For example, Robertson (2011) contrasts conversations about risk in learning disability services, where people often have their lives strongly mediated by services and the question is whether they should be given more control, and in mental health services, where the question is whether control should be removed.

As both Faulkner (2012) and Seale et al (2013) remind us, this distinction is also influenced by whether people are viewed as a "source of risk" or whether they are viewed as being "at risk", with the former group typically being denied their rights more frequently than the latter.

Perkins and Goddard (2008) point out that risks are typically inter-related, and that minimising one typically increases another. They also highlight the fact that tensions about risk are not always linked to people wanting more freedom – often they want more support, because they feel unsafe.

The weighing up and minimising of risks is integral to safeguarding practice and policy and there is a clear policy direction – parallel to and influenced by positive risk-taking – to involve adults more effectively throughout the safeguarding process. In England, the sector-led initiative Making Safeguarding Personal (MSP) has been running in an increasing number of authorities since 2012, and we found evidence of MSP in at least one Welsh authority (Conwy Social Care Annual Report 2016-17).

"MSP aims to facilitate a shift in emphasis in safeguarding from undertaking a process to a commitment to improving outcomes alongside people experiencing abuse or neglect. The key focus is on developing a real understanding of what people wish to achieve, agreeing, negotiating and recording their desired outcomes, working out with them (and their representatives or advocates if they lack capacity) how best those outcomes might be realised and then seeing, at the end, the extent to which desired outcomes have been realised." (Pike and Walsh, 2015, page 7)

The evaluation of Making Safeguarding Personal finds that an "increased emphasis on and confidence in professional judgement, especially around risk and decision-making capacity" was a key success factor (Pike and Walsh, 2015).

Yet Robertson (2011) identifies wider "organisational incoherence" in social care, in which there are conflicting messages from organisations and from national policy about how people who need support are perceived and whether the fundamental purpose of statutory agencies is to empower or control the risks.

In the next section, we present the key messages from the literature regarding this and other barriers and enablers to positive risk taking.

3. Barriers to positive risk-taking in services

A key message from the focus groups was that risk averse practice, attitudes, systems and culture often restrict individuals' quality of life. Although we heard – and will present – many examples of good practice in relation to risk and decision-making, there was still a strong sense from participants that this was usually happening only when and where practitioners had the courage, time and support to "swim against the tide". We are keen to focus on understanding and disseminating these examples, but felt it was also important to highlight the main barriers to embedding positive risk taking more widely in services.

A number of these were identified in the literature and focus groups. Where solutions and practical examples were suggested, we have included these here. We summarise the enablers in the following section.

Lack of understanding of legal responsibilities

The published literature highlighted a generalised fear of litigation, which can lead to a "just in case" or defensive approach to professional decision-making (Department of Health, 2007; Andrews et al, 2015).

More specifically, there may be a lack of understanding of the Mental Capacity Act 2005. For example, the House of Lords (2014) concluded that the Act has "suffered from a lack of awareness and a lack of understanding... The empowering ethos has not been delivered".

In the group discussions, participants highlighted the fact that much of the legal framework, including the Mental Capacity Act 2005 and the Social Services and Well-being (Wales) Act 2014, supported a positive risk-taking approach. They gave examples in which the Court of Protection had upheld positive risk-taking decisions made in a person's *best interest*, but against the family's wishes. In an example given by one focus group participant, a woman in her 90s had been assessed as lacking capacity, but nevertheless seemed keen to return to living at home. The woman's family felt very strongly that she should move into a care home due to concerns about her physical safety.

The social worker took the case to the Court of Protection, which put more weight on the woman's wishes and feelings, and ruled in favour of her returning home. She is now living very successfully at home, with a modest care package, though it has taken a lot of work to support and reassure her family.

However, there seemed to be a number of specific challenges here:

• Lack of awareness of the legislation that supports positive-risk taking, by colleagues, the general public and, in particular, health professionals.

For example, one group of frontline practitioners described how they frequently challenged unnecessarily restrictive decisions made by consultants regarding a person's *lack of capacity*, which had then been taken as given by more junior health professionals.

"I wish people would read the codes of practice [for the Social Services and Well-being (Wales) Act 2014]."

• There also seemed to be a lack of confidence amongst frontline workers regarding the wider legal framework: exactly where their "duty of care" began and ended, and what (if any) the legal consequences might be if something "went wrong" following a properly made and recorded positive risk-taking decision.

"If you do it well from the start and listen to what people want and what matters... it's less likely to go wrong or end up in court. I think that's what we've learned."

Wider dissemination of these key messages – perhaps reinforced by clear and specific feedback from a legal expert – might help allay this general sense that "legal action might follow", and reassure professionals of the distinction between negligence and positive risk-taking.

• There was a recognition that risk-averse practice can actually end up increasing the risks in some cases:

"The more we try to manage risk, the more risk there is for that person as they might just go and do it anyway without the support."

• A recurring theme related to the challenges of engaging health professionals in a positive risktaking approach. People raised the unhelpful title of the "*Social Services* and Well-being (Wales) Act 2014" as implying that this legislation only covered social services.

Perhaps the fear of being sued for medical negligence creates a much more cautious definition of the duty of care, particularly in hospitals. This contributes to "territorial" and "defensive" practice of which we heard a number of examples, in which practitioners, managers, departments and organisations protect their boundaries and seem afraid of the consequences of taking or sharing responsibility.

A young person who loves swimming also experiences regular seizures. Leisure services were initially very risk averse and terrified that he might have a seizure in the pool, and had banned him from swimming at the centre.

But with open discussion with leisure centres in the area about positive risk taking, they are now on board with idea that if an individual knows and understands the risks, and is willing to take the risk then that is okay and it's not the responsibility of the leisure service to eliminate the risk on his behalf.

In this example, we hear how an open, collaborative approach to risk helped change risk averse attitudes and reduced the fear surrounding the legal consequences of something going wrong, by effectively clarifying the limits of the leisure services duty of care.

A "blame culture"

The published literature refers to the fear that many social care professionals have of being blamed by managers, colleagues and families if things "go wrong" (Kelly and Kennedy, 2017; Mitchell and Glendinning, 2007).

The underlying worry of being blamed or not supported by managers or higher levels of hierarchy was a major concern for all participants in the focus groups:

"As professionals, can we be positive about taking risks ourselves? Is it okay for me to take a risk, if I might get into trouble for doing it next week?"

There was a significant amount of discussion in the focus groups about the crucial role of leaders in supporting positive risk taking and a strong sense that this needs to "start at the top". Leaders need to model and actively support positive risk taking and will need development if they are to truly embed this transformation (rather than simply recycling the rhetoric). We make a recommendation for Social Care Wales in relation to this.

A deficit-based view of disabled people

Risk averse practice has flourished within a professional (and wider social) culture which has a tendency to try and "fix" or protect people who are seen as "vulnerable" (Charlton, 1998) or has seen them as either "at risk" or a "source of risk" (Faulkner, 2012). This has been reinforced by the NHS and Community Care Act 1990, under which care management has focused on identifying needs, risks and deficits to demonstrate eligibility for services. Given the changes in policy and legislation identified in the introduction to this report, this can lead to conflicting messages from agencies about how people who use services are perceived and what the fundamental purpose of professionals' work with them is (Robertson, 2011).

This historical and institutional discrimination against disabled people (and perhaps especially those who are older and / or have mental health or cognitive impairments) has led to a lack of trust in individuals to cope with the decision-making process, to make the "right" decisions or to handle the consequences. Focus group participants pointed out:

"There's a perceived risk of allowing people to work it out themselves."

"Stress is part of life. As long as there is support for people to fall back on, then stress can be a learning experience... It's about supporting people to manage risk rather than doing it for them."

"People are allowed to make unwise decisions."

Recognising and tackling the institutional discrimination of disabled people was felt to be the foundation for embedding positive risk practice. The Equality Act 2010 and the human rights legislation (as introduced in Section 1.3) provide a framework and a lever for doing this. As Social Care Wales disseminates key messages in relation to positive risk taking, we suggest it links these explicitly to the rights set out by the Equality Act 2010 and the Human Rights Act 1998. This should help counter the myth that the law promotes risk aversion and emphasise the point that positive risk taking is about fundamental rights, not a "nice-to-have" or something that only applies in innovative pilots.

Against the backdrop of low expectations and aspirations for older and / or disabled people, focus group participants highlighted the false expectations (both of professionals and family members) that social workers were ultimately responsible for protecting people from harm. One participant explained concisely the change that is needed here:

"We're thinking about a culture change where people are able to take responsibility for the decisions that they make... and that we support families to really look at what matters to that person, rather than it being about blame if it all goes wrong." A woman with a long history of severe mental health issues (including self-harm and suicide attempts) had received 24-hour support for 25 years and spent five years in secure residential care. She came to a meeting at which direct payments were being introduced to people who use services and later got in touch to say that she would like to receive a direct payment.

There was a lot of professional doubt about her ability to manage her own care using direct payments. There were many concerns when she struggled to retain a PA and there have been various disruptive changes of staff.

The woman later said (practitioner's words): "I'm grateful I was given the opportunity to take those sorts of risks; for you (professionals) to have faith in me. Becoming an employer was a big deal for me, and it's been difficult and a learning curve and I've got things wrong and that's okay. By getting those things wrong I've learned that I can overcome other battles in my life."

She is now receiving 10 hours of support from a long-standing PA – this relationship has been instrumental in helping her along her journey to recovery. The woman has had no hospital admissions since taking up direct payments. She has asked to make a film about her story so that other people can understand the benefits of being in control of your own care provision.

This is an excellent example of a person overcoming the deficit-based view and deriving considerable benefits, precisely from the times when things did not go as planned.

Managerial processes and regulation

The published literature highlights the fact that current approaches to regulation and inspection across the UK tend to focus on the completion of paperwork, rather than on people's lived experience. This results in processes and bureaucracy dominating service provision, and restricting the opportunities professionals have to build relationships with people and their families and understand what matters to them (Warmington et al, 2014). Overly bureaucratic systems and procedures "strangling" creative practice and disempowering individuals were also a recurring theme in the focus groups:

"It depends what the organisation values. If it puts value on having all the forms filled in or it places value on having that conversation."

Elected members needed to understand and be prepared to defend positive risk-taking decisions, especially in cases where older people's relatives are pressuring for risk averse interventions (such as a care home placement) to be put in place.

Regulation, audit and inspection were felt to place too much emphasis on throughput, and participants identified the importance of inspectors really understanding positive risk taking, and finding more flexible ways to define and measure "success", including hearing the voices of people using services.

"Asking providers to do innovative things but then that gets shut down by the inspectorate tomorrow because they don't understand."

"Regulation frameworks and audit... puts massive pressure on everyone to do the right thing; and we all get very process-crazy. It would be great if those institutions understood positive risk-taking... Let's have an audit of that!"

Participants called for bold and creative thinking in co-producing a regulatory system, which better supports positive risk-taking and the wider transformation of social care. We make recommendations for Social Care Wales in relation to this.

Lack of trust of professional judgement

The literature highlights the existence of a topdown approach to organisational performance management in social care that does not allow for contextual decision-making at the front line (Patterson et al, 2011). Practice is often geared towards protecting organisations from potential financial and reputational risks (Carr, 2011). This has led to a loss of confidence in professional judgement (Furedi, 2011). In the focus groups, several managers described the dilemmas they faced in relation to balancing trust in frontline staff with a need to use traditional performance management processes.

One described the "huge backlog" of reviews to be done in their service and suggested that, rather than "mechanically" reviewing all aspects of the care a person receives as the processes require, it would be better to focus on the outcomes that really matter to the person receiving the care. This seemed sensible, yet still felt like "a bit of a gamble".

Another manager described having to place more trust in the professional judgement of the team of community connectors she manages, due to the more flexible and proactive nature of their roles. She explained how a key part of this had been to take more time to understand individual staff members – their personalities and how they work, and to invest more time in reflective supervision. This feels like a very practical example of strengthsbased leadership: helping managers reflect on the learning from such practice examples could form a part of the leadership development programme we recommend Social Care Wales runs in relation to positive risk.

Safeguarding concerns

Morgan and Andrews (2016) highlight the way in which approaches to safeguarding that discourage emotional connections between people using services and staff, as they could be interpreted as grooming for abuse, can get in the way of a more flexible, relationship-based model of social care.

The tensions between "empowerment" and "safeguarding" were evident in many of the focus group discussions. Safeguarding concerns were raised as a particular barrier to the more widespread use and promotion of direct payments. Statutory workers were especially concerned about the safeguarding risks where family members are acting as PAs and / or have applied for a direct payment on behalf of a family member who frequently lacks capacity. Although these fears may of course be well-founded in some cases, there is a risk that they can lead to a reluctance to promote direct payments more widely within an authority, despite the potential benefits outlined in the good practice case above. More publicly available examples of the ways in which direct payments have been successfully used by people who might be seen as "vulnerable" or "high risk" and an honest conversation about the learning from where things have not gone as planned could help this.

A task-focused approach to delivering care

The literature identifies a poorly-defined model of care, particularly for older people, which tends to be task-focused and inflexible (Nolan et al, 2006; Blood, 2013). This can act as a barrier to positive risktaking, since it reduces the opportunity for genuine relationship-building (Morgan and Andrews, 2016) and sees meaningful activity, leisure, learning and social connection as luxury extras rather than fundamental human rights. As one focus group participant explained:

"The whole point about the independence agenda is to have a good life. We are imprisoning people in their own homes... For me, positive risk taking is doing all those things that actually enhance the ability for that person to have control, have a meaningful life, be valued."

In section 4, we present a number of initiatives across Wales in which this task-focused model has been shaken up to create more opportunities for people to do the things that matter most to them. We recommend that Social Care Wales disseminates these across the sector, with a particular focus on how these projects have managed risk and what the learning and benefits of this have been.

4. Enablers to positive risk-taking in services

We have begun to highlight possible levers for change in the previous section. Here, we present a number of themes emerging from the literature regarding the enablers to positive risk-taking in organisations and illustrate these with examples and quotes from the group discussions.

Developing a learning culture

Pattoni (2014) argues that experimentation, followed by an honest review of why approaches did or did not work is essential to improvement in services. Nesta (2013) found that people are more able to deal effectively with challenges when they are "given permission" to fail, and where failure is viewed by their organisation as an opportunity for learning and not blame:

"While failure is never a desired outcome, fostering a culture of regularly taking small, smart risks and learning from failures is advantageous" (Nesta, 2013, page 18).

Participants in the focus groups felt very strongly that a move away from risk averse practices and systems could only be achieved by a systemic willingness across all agencies, partners, and levels of the workforce, to embrace and support positive risktaking in practice.

Many suggested that a new attitude to experimenting, innovating, and taking risks was required and that people should be allowed to learn from their mistakes rather than fear a punitive response. They also emphasised the importance of nurturing a culture that celebrates successes, looks for people's strengths, and is flexible. Leaders can be instrumental in helping create an asset-based approach, which demonstrates flexibility, and most importantly, trust and in practitioners' professional judgement.

Social Care Wales – as we argue in the final section of this report – can play a key role in supporting and developing leaders. A key part of this should involve the development of supervisory skills, so that performance is managed and confidence in relation to risk built more effectively through reflective supervision (one-to-one and in groups, using techniques such as "fishbowl" as discussed in section 5.3), rather than paper-based outputs.

Promoting a rights-based approach

Morgan and Andrews (2016) argue that the rights and citizenship of people who may need care and support should be placed at the heart of a framework for positive risk-taking. At present: "Practitioners do not often think in terms of rights, so they become more easily violated" (Morgan and Andrews, 2016, page 126).

As we have seen in the previous section, the need to frame positive risk-taking in terms of the rights and responsibilities of disabled people, and those that support them, also emerged from the focus group data. As one participant explained very clearly:

"The 'positiveness' [in 'positive risk'] is about promoting personal autonomy... rather than eliminating all the risks."

Participants felt it was vital (and required by the Social Services and Well-being (Wales) Act 2014) to have strengths-based conversations with individuals and their families from the outset, and to set discussions about "risk" within this context. These should include what matters most to individuals and how their personal histories might influence decision-making.

"It's wonderful when you start from a different assumption – what matters to the individual – then for the organisation, behaviours change."

There was concern among a number of focus group participants about a lack of skills, time and permission to support the effective use of values-led, rights-based and truly person-centred social work practice:

"I don't think we've moved into an era in social work where we have skilled practitioners who can have that [positive risk-taking] conversation... that work takes time. You can't resolve that problem in one session."

Shared decision-making around risk

Morgan and Williamson (2014) argue that we are more likely to be risk averse in our practice where we are making decisions on our own. In contrast, shared decision-making, which involves the person, their family, community supporters and a multi-agency group of professionals, may be more supportive of positive risk-taking (Clarke et al, 2011; Manthorpe and Moriarty, 2010; Andrews et al, 2015).

Promoting decision-making about risk that is collaborative, multi-agency and co-produced with the individual and their family was high on the agenda of participants. Ideally all parties should be able to express their hopes and fears in a safe environment where people can challenge each other's assumptions and share possible solutions.

The manager of a residential care home for older people described a deliberate approach they have taken to engaging family members more. Staff had always tried to be welcoming, but this rarely got beyond basic pleasantries unless there were complaints or concerns. Instead, they initiated a more structured "circles of support" approach (outlined in more detail in section 4). This involved spending more time building relationships with families when they came to visit and inviting family members to meetings. This open and inclusive approach has resulted in families feeling more empowered and valued, and has led to more constructive and collaborative conversations about "risk". The manager felt this has brought huge benefits in terms of attitudes and approaches to risk within the home.

Building trusting relationships

As the above example illustrates, shared decisionmaking can only happen where meaningful and trusting relationships have been built (Andrew et al, 2015). As a result, Mitchell and Glendinning point out: "...supported personal risk-taking takes time, effort and resources" (page 23). Robertson (2011) also highlights a potential vicious circle here, since risk averse practice can push people away and lead to disengagement, which may increase risk in the longer term. Valuing and promoting "human conversations", being able to work at the individual's pace – making effective and preventative use of advocates, and regularly revisiting care plans, capacity and best interest assumptions were felt by focus group participants to be crucial both to building trust and supporting positive risk once trusting relationships are in place.

A manager of one service explained how support planners now work with individuals who have cognitive impairments in their area as part of a community brokerage project. Instead of automatically referring people to day centres, the support planners invest more time working with individuals to identify their aspirations and priorities and plan a positive risk-taking approach to achieving these, using all available resources.

As a result, lots of individuals have been supported to access a wide range of voluntary opportunities that fit with their interests. One young woman wanted to work as a volunteer with children and was interested in the criminal justice system as her mother is a police officer. She now works in prison nursery. The service has provided travel and independence training and tailor-made support to enable this to happen.

Supporting resilience and creativity

Seale et al (2013) argue that positive risk-taking needs to be built on a framework of strong principles, co-produced by professionals and people who use services. The last thing we need, they argue, is more guidelines for "best practice" - these can simply reinforce a culture where the focus is on reducing the risk of getting it wrong and can bog workers down in additional layers of bureaucracy. In supporting individuals to make decisions, we need instead to build the capacity for creativity - to vision what if something goes right, and find possible solutions. Workers, people who use services and their families need to be supported to build resilience in the face of uncertainty and stress, and to develop "a political response to disabling and disempowering circumstances".

A recurring theme from the group discussions focused on the importance of building and

nurturing people's natural networks of support, bringing families and the wider community (outside "services") in as part of the solution.

We heard how a "progression model" is being used for young adults in transition. This involves supporting individuals to be as independent as possible, and to have the confidence to do the things they want to. They work at the individual's pace, gradually aiming to reduce statutory involvement where possible and draw more on community-based support. This is based on the principles of building capacity; taking a longerterm, forward-looking view; and promoting positive risk-taking.

We also heard how "community connectors", who interestingly have no formal social work training (and are therefore felt to be less constrained in their thinking), spend time having a "what matters" conversation with individuals. There have been many examples of risk enablement from this model, including a man with a cognitive impairment who had previously attended a day centre, five days a week.

The community connector identified that he was keen to volunteer and was interested in the building trade. They got in touch with a local builders' merchant; talked through the worries all parties had at first; and helped the builders' merchant create a volunteer policy. The man now has a fulfilling voluntary role there, feels part of the team, and is really enjoying the experience and sense of belonging and companionship.

The service manager explained that, at the outset, she found herself questioning everything and being quite risk averse in her thinking – identifying lots of "what if" negative scenarios. However, she felt her own perspective on risk had been effectively challenged by open discussions with the community connectors.

This example highlights the value of introducing different, "real-world" or non-professional perspectives into discussions about "risk", and of starting from a "can-do" position. There are "risks" involved in community-based support and these need to be identified and planned for; but there are also huge potential benefits in relation to social integration and sense of identity.

The risks of putting in a formal service are often overlooked, compared to the risks of not, or of doing something different. In this example, day centres are not "risk-free" – for example, they tend to segregate disabled people within service settings, which reinforce their identities as "service users", and there will be risks of accident or abuse within the day centre, as well as the builders' merchant.

5. Examples of good practice

5.1. Policy

Gateshead Council (2009) was supported by Steve Morgan to produce a <u>Positive Risk-taking Policy</u> for its community-based services for disabled adults and older people. This is published on the Think Local, Act Personal website (and was mentioned in one of the focus groups carried out for Social Care Wales as having been influential in the development of Flintshire's positive risk policy).

The policy is very comprehensive, providing a clear introduction to risk and why decisions about day-today risk-taking are different for older and disabled people to whom the local authority may have a legal duty of care. It sits within the context of the council's corporate risk policy and sets out the underlying principles of a positive risk-taking approach within a social care context. It argues that:

"A structured approach to the identification, assessment and management of risk and the review of incidents is essential" (page 11).

Defensible decision-making in relation to risk needs to include the following steps (page 12):

• Formulation of a logical, informed opinion as to the severity of risk

• Organisation of discussions with the adult, their family and any health, social care, advocacy or independent sector professional involved

• Inclusion of the adult and their family in decisionmaking

- Identification of conflicting opinions and interests
- Clarification of lines of accountability
- Justification of actions.

The policy makes some key points:

• That where a disabled person is facing the same

risks that anyone else would face, the involvement of the council in that decision may be discriminatory (page 12) (as we highlighted in section 1.3)

• That positive risk taking (and this is key in the legal context) is very different from "negligent ignorance of the potential risks" (page 13)

• Disabled / older people and their families are not just the source or potential victims of risk; they are key partners in the identification, assessment and management of risk (page 13)

• Working to short timescales with small goals can support risk management (page 15)

• Where people decide to behave recklessly outside of agreed or advised boundaries, this decision should be recorded (page 16)

• Positive risk-taking needs to be embedded in the organisational culture and backed-up by staff training

• "It is not a one-off experiment, but the natural first line of thinking" (page 16)

• Where incidents of concern occur, the policy sets out the process for, and principles underlying, the subsequent review, including starting from a position of "no blame", offering support and supervision to staff and families and keeping them informed, performance managing any identified negligence or bad practice, and disseminating findings for wider learning (page 16).

Cumbria Learning Disability Services – Positive Risk-Taking Policy: Easy Read Version

Although dated 2006, this easy-read policy was based on the views of people who use services and still appears on the *In Control* website as an example of good practice. It sets out some key rights and concepts in relation to positive risk clearly, for example:

• "It is the job of people who support you to help you think through and take risks so that you can get on with living your life!" (page 2)

• "Sometimes you can make decisions, which other

people think are wrong. This is ok because everyone makes decisions that don't work out sometimes. Everyone makes mistakes sometimes. This does not mean that you can't make decisions" (page 5)

• "Sometimes people will tell you that you can't do things because of health and safety or because of risk assessments. Health and safety policies should not be used to stop you thinking through the risks you want to take and having support to do so" (page 5).

5.2. Practice examples

Seale et at (2013) identify a lack of practice examples illustrating creative and positive risk-taking practice. Our review confirmed that publicly available practice examples are hard to find around this topic.

5.2.1 Practice examples identified in the literature:

Supporting a person to achieve something new / independently

In her article for *Progress* (transition guide for 12- to 25-year-olds with additional needs), Dela Begum, the learning disabilities service manager at SweetTree Home Care services, provides examples of young adults living with "full assistance" who have achieved personal goals (in the face of concerns by their families) to get a voluntary job, or go unaccompanied to the gym (Begum 2015). She argues that the key features of this positive risk-taking work have been:

- Focusing on strengths and goals
- Building a step-by-step plan, working up to the goal gradually, testing and reviewing
- Thinking about the "what ifs" and planning what to do if they happen.

Supporting a person to reconnect with something that matters to them

In Blood (2016), we present a positive risk-taking example in which Fred, who is living in a care home with advanced dementia, and his wife Mary, in the early stages of dementia, are supported to go out to the pub together for a weekly drink.

Relationship-based care and professional boundaries

The DEEP website contains <u>a couple of case studies</u> on this theme:

• Car boot sale: in which a woman who is receiving care and support at home is invited by one of her home care assistants to come along with her to a car boot stall

• The train to Cardiff: in which a man living in a care home who had become depressed following the death of his wife is supported by carers to fulfil a last wish to take the train to Cardiff.

Hospital discharge

The Department of Health (2007) guidance contains a number of case studies, including one relating to the hospital discharge of a man following a stroke to return to be supported at home by his two teenage daughters (pages 16-17).

5.3. Tools to support positive risk taking

The Department of Health (2007) guidance contains a Supported Decision Tool (pages 49-51).

This has been designed to guide and record conversations between the person, their family, practitioners and managers regarding choice and risk, and in conjunction with existing needs assessment and care planning processes. The tool contains 21 questions – all are clear and simple, and record a broad picture of the person, their aspirations, their circumstances, and their and others' perceptions of any risks.

In its entirety, the tool is very comprehensive: it effectively starts from scratch, which will be useful in some contexts but may duplicate in others. However, the questions could usefully inform wider care planning processes, and questions about specific risks could then be drawn out from the menu. The overall message is an important one, though, that positive risk-taking conversations need to grow out of and build on a strong foundation of strengths-based and person-centred assessment.

Clarke's four stage process

Clarke et al (2011) suggest a four stage process for discussions about risk involving people with dementia and their families (though the stages seem to be adaptable for other groups of people coming into contact with social care):

1. Identify risks in the life-context of personal biography and everyday life (and therefore impact on quality of life)

2. Identify risk perspectives (of all the people involved)

3. Weighting of risks (to establish high and low risk concerns – and including "silent harms" – impact on emotional, social and psychological well-being)

4. Identify current and past strategies for managing risks (to allow identification of protective and substitute activities).

Risk enablement "heat map"

In their guidance for the Department of Health on risk enablement and dementia, Manthorpe and Moriarty (2010, page 52) have developed what they describe as a "heat map" (shown below). This allows us to consider the level of risk of an activity against its potential benefits for a person's quality of life. For example, where risks are high, we should not go ahead if the impact on quality of life is low; we might substitute for an alternative activity if the likely impact on quality of life is medium; but go ahead, managing risks as much as possible, where there are likely to be significant gains for quality of life.

Contribution to quality of life Carefully balance safety enhancement and activity management to protect the person Minimal safety enhancement enhancement and risk management necessarv- carrv protect the ndividual and manage out with normal High levels of safety enhancement Substitute- can Minimal safety enhancement the same personal safety enhancement and activity necessary- carry benefit be delivered in a different way out with normal levels of safety seek different activities? enhancement Allow the activity of the activity to the individual- seek Low of risk is not related to or seek alternatives that will provide a alternatives that are more attractive and lower risk to the person- find alternatives better relationship with their needs High Medium Low 'Risk of harm or quality of life to the individual

Personal Risk Portfolio ('heat map')

(Manthorpe and Moriarty, 2010, page 52)

Ten questions to guide shared decision making about risk

In Blood (2016), the author developed the following list of questions to inform positive risk-taking and shared decision-making. Again, the audience for this tool was professionals seeking to enable people living with dementia, though the steps are more widely applicable and seem to resonate with those working across adult services.

1. What exactly is being proposed here? What are the options we are considering?

2. Does the person have capacity to make this decision? Are we making a best interest decision here or are we simply coming together to advise, support and problem solve?

3. Why does / might this matter to the person and their family? How much is doing it / not doing it likely to impact on their quality of life?

4. What are the specific risks? How likely are they to happen? What level of harm is likely / possible if they do?

5. What are the potential risks and benefits to family members, carers and the wider community here?

6. What are our own fears and the fears of others here? These might be specific fears about harms or they might be general fears, for example, about being blamed if things go wrong.

7. What ideas do we have for doing what (we think) the person wants AND reducing the risks?

8. What's the bottom line here?

a. What are the rules or conditions which we all agree to follow?

b. What is the contingency plan (if things go wrong)?

9. Which roles and responsibilities do each of us have here? Is there anyone else we need to involve?

10. Which changes should trigger a review of this decision?

Pilotlight

Pilotlight was a five-year programme funded by the Scottish Government and hosted by IRISS (The Institute for Research and Innovation in Social Services in Scotland) to support the implementation of self-directed support.

The programme co-produced a number of tools and resources relating to positive risk taking – some of these are now quite old, but still have value. For example, Scottish Borders (undated) developed a *Choice and Control Support Plan,* which acts as a template for a discussion and agreement between a person taking a direct payment and social services. This includes a section (question 6), which asks:

"Is there anything that could stop this plan working or lead to risks? For example, in the way you have chosen to manage your support; because you are doing things for the first time."

The form then identifies "possible problems" and their likely impact on the person and encourages them to consider how they will deal with these and what forward planning they can do for such eventualities. There is space to indicate "if the person wants to accept a degree of risk and any advice that was given by the care manager / support planner". It suggests that a separate risk assessment might be needed if the risks are "complex".

Making it Real

Think Local Act Personal (TLAP) is the sector-wide commitment to transform adult social care in England through personalisation and communitybased support. *Making it Real* (TLAP 2012) is a framework against which success can be judged; its development has been led by the National Coproduction Advisory Group.

Risk enablement is one of the six criteria against which the scheme marks progress and a series of "I statements" from people who use services are presented to illustrate why this theme matters to people:

Risk enablement: feeling in control and safe

"I can plan ahead and keep control in a crisis."

"I feel safe, I can live the life I want and I am supported to manage any risks."

"I feel that my community is a safe place to live and local people look out for me and each other."

"I have systems in place so that I can get help at an early stage to avoid a crisis."

• People who use services and carers are supported to weigh up risks and benefits, including planning for problems that may arise

• Management of risk is proportionate to individual circumstances. Safeguarding approaches are also proportionate and they are co-ordinated so that everyone understands their role

• Where they want and need it, people are supported to manage their personal budget (or as appropriate their own money for purchasing care and support), and to maximise their opportunities and manage risk in a positive way • Good information and advice, including easy ways of reporting concerns, are widely available, supported by public awareness-raising and accessible literature

• People who use services and carers are informed at the outset about what they should expect from services and how to raise any concerns if necessary. From page 7, Think Local Act Personal (2012)

Scottish Recovery Network

Perkins and Goddard (2008) have developed a training module for the Scottish Recovery Network about *Sharing responsibility for risk and risk-taking in mental health services*. Although a detailed focus on the work of community mental health teams is beyond our focus, there is transferable learning here. They argue that hope, control and opportunity are essential to promoting recovery, and we would argue that they are essential to the mental wellbeing of anyone receiving services. They argue that risk averse practice gets in the way of these three aspects, and therefore impedes recovery and wellbeing.

In one particularly useful tool, they ask professionals to consider the likely impact of their organisational procedures and policies on the sense of hope, control and opportunity of people using their services.

How might you be able to implement this policy, in a way that 	fosters hope?	
	helps people to take back control over their life and problems?	
	enables people to do some of the things that are important to them?	
How would you recommend that this policy be changed to address the concerns of the organisation and better	fosters hope?	
	help people to take back control of their life and problems?	
	enable people to do some of the things that are important to them?	

Taken from page 135, Perkins and Goddard 2008

Magic moments

Magic Moments in Care Homes (Andrews et al, undated) brings together fifty examples in which care home staff in Wales have enabled individuals living in care homes to have an experience that connected them to their pasts or to other people. These range from bringing a lamb and a donkey into the care home, taking someone to a football match, re-enacting the wedding of one of the staff, and re-creating a beach in the care home garden; to simpler acts of kindness, such as bringing someone a nectarine, or taking the time to read the newspaper to them.

Steve Morgan reflects on the role of "positive risktaking" in this collection:

In all these examples a consistent message is that someone took a risk in order for the "magic moments" to emerge. Positive risk-taking, in this context, is all about creating the experiences that produce that tear of joy, the passing smile, the kind word, a tiny act, a bold action, a big achievement, or a rekindled wish (page 24).

In the reflective exercises that follow the examples, there are several questions for reflection related to risk:

• What does risk and taking a risk mean for the person / people we are working with?

• What risks were associated with your own "magic moments" and were they worth taking?

In planning a more involved "magic moment":

• When will we know it is too risky?

• What will we do to stop this activity if and when it is becoming too risky?

"Fish bowl"

"Fish bowl" is a simple process to support group discussion and shared decision-making, and we heard in the focus groups how some authorities are using it as a form of group supervision to support positive risk taking. The person bringing a case dilemma explains it to the rest of the team, who have an opportunity to clarify what they have heard. The team then – in a structured and carefully facilitated way – bring possible solutions, and challenge each other's thinking.

We heard examples in which "fish bowl" had been used in team and multi-disciplinary settings (for example, to consider risks related to a person's drinking), and to discuss risks related to direct payments in a group consisting of both the direct payment recipient and a number of professionals.

5.4. Positive risk-taking and alternative models of care and support

There are a number of initiatives across Wales, which aim to provide care and support "differently" – in a more relational, choice-based, person-centred way. In this section, we highlight some of the examples, both from the published literature and the focus groups, and explain how these relate to positive risk.

DEEP (Developing Evidence-Enriched Practice)

This collaborative action-research project involving older people, carers, researchers and staff from social care and health organisations aimed to use research and relevant evidence from *A Better Life* (Blood, 2013) to improve services in Wales.

In the Carmarthenshire pilot, those participating in the initial focus group identified relational risk averse practices (for example, professional conduct policies) and the avoidance of physical risks as getting in the way of relationship-based practice to empower older people. A range of professionals, including service managers, an occupational therapist, a social worker, a nurse, a psychologist, a training officer and an experienced carer worked together to develop a rights-based approach to risk management with older people. They developed "Thinking Together" sessions and a series of events, bringing together older people, social care, health and third sector professionals to embed the approach (see Andrews et al, 2015, page 14-15).

The Raglan Project

The Raglan Project in Monmouthshire aims to provide care and support to people living with dementia in their own homes in a different way to traditional domiciliary care. It aims to move away from task-based care provided at specific times (usually by a number of different people) to a more flexible and relationship-based approach involving a couple of permanent staff. A key part of this model involves employing care workers on decent terms and conditions, and giving them more autonomy over how their time should be spent each day. A key principle within the model is that the social and emotional needs of people with dementia are as important as their physical needs.

This relationship-based and flexible approach has resulted in people who were previously at risk of selfneglect or admission to care homes being gradually supported to "get their lives back" and take a number of "positive risks":

"My husband is now able to enjoy the vegetable garden with the help of Roma. Every day he waters and tends his garden... We're now starting to go out on the bus together. I tell them (the team) that if we're not back, don't worry and don't ring the police – we're just trying to get our lives back." (Wife and carer, page 3)

All Care

All Care has been working in partnership with the Vale of Glamorgan since October 2016 to pilot an outcomes-based approach to domiciliary care called Your Choice. The overview report (All Care/ Vale of Glamorgan, 2017) states that, from the outset, both partners were clear that positive risk taking needed to be embraced and this was part of the training.

The pilot offers flexibility in relation to "banking" care hours (for example, when a family member is able to provide personal care) or by switching how care slots are used to support the person's priorities. This has led to people receiving care being supported to: attend a regular meeting of veterans in the pub; have a debate about current affairs with a support worker; go for a little walk to the park / local shops; and attend council meetings.

Co-production Network for Wales

A number of the examples included in the network's collection of co-production case studies (Public Health Wales / Co-production Wales, undated) deal explicitly and implicitly with questions of risk and how groups have worked together to co-produce new policies or initiatives to promote positive risk taking. For example:

• Grŵp Gwalia's co-produced Sharing Lives and Professional Boundaries Policy.

• Fford Gwynedd Health and Care Team – an integrated older people's team, which aims to help people live their lives as they want to. This has involved stripping out some of the layers of assessment and bureaucracy that were getting in the way and re-developing a four-step process of "value steps":

- find out what matters to the citizen
- help them find solutions and discuss choices
- help them implement the choices against what matters
- review effectiveness of outcomes against what matters.

• Time to Meet – a social network organised by people with cognitive impairments, their families, friends and support staff in Swansea Neath Port Talbot.

Circles of support

A "circle of support" can offer a simple, tested model of shared decision-making:

• A circle of support is a group of people that the person chooses to meet together as friends – it could include friends, family, paid workers, neighbours, and so on.

• The group help to support the person to make their own decisions about their life.

• The most important thing is that the disabled

person is in charge, or is supported to be in charge, of the circle.

• The circle should be about finding out what the person wants and how they can get it.

• Meetings are held where the person feels comfortable – their home, someone else's home or in a pub or café.

• Some circles meet every few weeks, some meet every few months. From Foundation for People with Learning Disabilities (2015)

The approach has also been used to empower people living with dementia (Macadam and Savitch, 2015) and has been implemented in Wales by Circles Network, Co-production Network for Wales, and some care and support providers, such as Mirus.

Family Group Conferencing

A Family Group Conference (FGC) is a formal meeting where the individual concerned, family, extended family members or relevant others, and professional practitioners, work closely together to make decisions that best meet the needs of the individual.

The participation of the individual is fundamental: he / she chooses who else to involve and can be represented by a person of their choice if they cannot / do not want to attend. The whole process is facilitated by an independent co-ordinator, who is not part of the professional network. Meetings are led by the family, with the aim of facilitating families / networks to work together to design solutions, and make decisions which best meet the needs of the individual. This approach has been used in adult safeguarding and in care planning for adults with complex needs and / or where capacity may be an issue (for example, SCIE, 2018).

The key principles of this approach include:

• Families / social networks are the experts in their own situation; professionals only ever see a limited picture

• FGCs mobilise the natural resources of the adult's family, friends and social networks, reducing reliance on services, if it is safe to do so

• People are more likely to stick to plans they have helped develop

• FGCs enable families to cope with problems in a manner that is consistent with their own culture, lifestyle, history and resources.

Fulfilling Lives, Carmarthenshire

Fulfilling Lives is a new way of providing care and support at home in Carmarthenshire. It enables individuals and their key workers to decide how best to use their funded hours. This required a "leap of faith" but has already seen dramatic outcomes in relation to staff retention, outcomes for individuals and a reduction in hospital admissions.

A crucial foundation for the model has been a positive risk-taking training course, commissioned as part of the initiative, funded by GPs, and engaging a wide range of participants from across many agencies and at different levels of seniority).

There were overwhelmingly positive reviews by participants of this training; it was widely felt to have been the most valuable and transformative training they had received. Many felt they now understood their roles much better. The fact that their organisations had already signed up to the new approach increased the effectiveness of the training because participants knew that they had the support to put the approach into practice.

Direct payments

Focus group participants shared many examples of how direct payments are working well to support individuals to take control of their own care and support, and lead the lifestyles they want to. However, there was also a lot of discussion about the risks associated with direct payments, both for the recipient (for example, of abuse from personal assistants), and the personal assistant (for example, a lack of formal training or supervision). We heard how forums of direct payment employers and employees organised by People Plus can help counter some of the risks by bringing people together.

6. Recommendations for Social Care Wales

We asked focus group participants how they felt Social Care Wales could best support positive risk-taking approaches. We present these themes here, before drawing out some specific recommendations.

1. Broad engagement and communication

Participants at the focus groups saw a role for Social Care Wales in influencing public and professional perceptions of social care and its purpose. Positive risk was felt to be inextricably linked to the wider transformation of social care and the "reclaiming of social work" under the Social Services and Wellbeing (Wales) Act 2014.

Social Care Wales could and should therefore send out clear messages about how social workers are and should be facilitating people to make their own decisions regarding risk, rather than being expected to remove all the risks.

• Visible leadership and communication of the positive risk-taking agenda by Social Care Wales:

"They need to embed [positive risk-taking and the wider transformation agenda] in everything they do."

• Participants understood Social Care Wales's primary role as being in relation to the social care profession. However, they felt it was important for Social Care Wales to communicate consistent and positive messages to the wider health, housing and voluntary sectors about the purpose of social care and the role that other agencies should play in delivering the Social Services and Well-being (Wales) Act 2014.

Specifically, there is a need to challenge the assumption that social workers' main objective is to protect individuals from harm, and that they have sole responsibility for doing this, and instead promote social workers as facilitators, mediators and brokers of the outcomes that matter most to individuals.

"We are not going to make these changes if those people [all social care partners including third sector, housing, advocacy service, health] aren't involved."

• Embed a values-based approach and specific examples of how to apply this in practice within mainstream guidance and training. Opportunities include:

- Code of Professional Practice for Social Care

- Regulation and Inspection of Social Care (Wales) Act 2016

- Social work training programmes
- Continuing professional development
- Registration of the domiciliary care workforce.

• We were conscious that our engagement had not succeeded in reaching people who receive care and support and their family carers. Participants felt that Social Care Wales had an ongoing role to engage those who use and provide services, to ensure they stay close to their views and experiences. It was suggested that regional forums might be a mechanism for this.

2. Performance measurement, regulation and audit

There was consensus within the focus groups that the current national performance management framework can act as a barrier to creative, positive risk-taking practice. Participants felt that, with its new role in relation to regulation, Social Care Wales had an opportunity to influence change in the way in which services are regulated:

"Social Care Wales and the Welsh Government should say: the purpose of this work is to enable people to achieve what matters to them, that's what we need to worry about. As organisations, you have the responsibility of measuring how well you are doing this. Then you have to think rather than just do what you're told. There's lots of different ways to do that and we'll learn what works ... people will come up with different solutions." Participants suggested that these frameworks should place more weight on outcomes, including the views and experiences of people using services and the impact that services have had on their quality of life. They should also allow more scope for services to co-produce and generate their own ways to measure progress.

3. Developing leadership

Participants were clear that sustained changes in practice and organisational culture are only possible if leaders (operational and senior managers, but also senior practitioners and elected members) are confident about positive risk-taking and have developed strengths-based leadership skills. They suggested:

• Longer term leadership development programmes / action learning sets that build the confidence of leaders to promote positive risk taking in their organisations

• Leaders, inspectors, and Social Care Wales should go and see the work that is happening "on the ground", and listen to the views and experiences of people who use services and frontline staff

• Promotion of champions and role models in the sector: what are the best leaders doing and learning? Which research is informing their practice and thinking?

"If we are going to work in a new way... we need to start building new approaches to leadership training in which positive risk taking is valued into all training programmes across the social care workforce."

4 .Supporting best practice

Participants felt that Social Care Wales is well-placed to act as a "conduit" for good practice relating to positive risk across the sector. Its website can act as "an important hub" for providers, as well as those working in statutory social work roles.

However, practice examples and tools need to be easy to find and digest if they are to be used by workers who are busy, including those with lower levels of literacy:

• Develop a collection of easily accessible materials relating to positive risk targeting frontline professionals

• Genuine co-production of any tools and guidance with disabled and / or older people, their family carers, and a range of frontline workers

• Promote opportunities to share and reflect on practice.

Based on these broad themes, we have developed a number of specific and concrete recommendations for Social Care Wales as to how it might take forward the positive risk-taking agenda.

It is likely that detailed "guidance" on positive risk might get lost in the sheer volume of current publications aimed at the sector. Instead we advise that:

• A list of core principles in relation to risk be coproduced with individuals who need care and support, and with a range of professionals. These might usefully be expressed as rights and linked to the existing legislation (for example, under the Social Services and Well-being (Wales) Act 2014, Equality Act 2010, Mental Capacity Act 2005, Human Rights Act 1998).

• Some of the good practice examples gathered and presented in this report should be disseminated in short (for example, one-page) flyers on Social Care Wales's website and perhaps through a series of posters and flyers, which highlight key principles and are accessible to social workers, other professionals, elected members and members of the public. These could be linked to and informed by the co-produced core principles (above) and should include (though not be limited to) examples of positive risk-taking in direct payments.

• Social Care Wales commissions a short summary of the legal position in relation to "negligence" and "duty of care" aimed at managers and frontline professionals. This should present short examples which distinguish negligence from defensible positive risk-taking. These should ideally also resonate with health professionals and might be co-commissioned and / or branded with partners in health.

• Social Care Wales shares the findings and recommendations of this exercise with its colleagues at Care Inspectorate Wales. There is a bigger piece of work to do here to review and challenge the frameworks and methods of inspection and regulation, so they support positive risk-taking, rather than act as a barrier. Again, this review should involve leaders and operational staff and should be co-produced with people who need care and support, since their experiences and outcomes should be the core measures of successful performance.

• Social Care Wales supports leaders in social care and health with learning and development, so they can model and embed positive risk-taking in their organisations. This could take a number of forms, depending on budget and opportunities to link into existing or planned initiatives, for example:

- Training / workshops, covering topics such as strengths-based leadership, positive risk-taking, reflective supervision

- Action learning sets / communities of practice

- Dissemination of what the best leaders are doing in relation to this agenda. This should include some of the commissioned initiatives featured in this report, as well as innovative approaches to performance management, staff supervision and mechanisms for gathering feedback from people who need care and support, and their families.

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