Communicating Effectively & Ethically with Young People with *Learning Disabilities and their Families regarding End of Life Care Planning

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*Whilst 'intellectual disabilities' is also used in the field, 'learning disabilities was the preferred terminology of project participants

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1. EXECUTIVE SUMMARY

Introduction

End of life care services for young people with learning disabilities and their families are provided by multi-professional teams working in a wide range of health and social care settings. These settings include the young person's own home, care homes, hospitals and hospices. It is too rarely the case that practitioners providing direct care have confidence and competence in both end of life care and learning disabilities. They encounter the additional challenge of working with people in transition from childhood to adulthood with very different levels of ability which impact on their participation in decision-making. To respond to these challenges practitioners benefit from engaging with both ethical and practical components of end of life care planning. This project aimed to assist practitioners to engage with both components by providing a Values-Based Toolkit and a format for a Communication Workshop with a video resource.

Background

The evidence suggests that people with learning disabilities are 'disadvantaged in dying' and do not always receive the quality end of life care they need and deserve. To enhance care-givers' competence in end of life care planning for young people with learning disabilities and their families, Health Education England Kent Sussex and Surrey commissioned the University of Surrey to conduct a 6 month intervention project.

Methods and Project Aim

The research team developed and evaluated a Values-Based Toolkit and a Communication Workshop with a video resource. The team invited participants' perceptions of their ability to engage in end of life care planning before and after the intervention.

The overall research aim was:

- To implement and evaluate a train the trainers education programme to increase the knowledge and skills of staff in communicating effectively & ethically with young people with learning disabilities and their families regarding Advance Care Planning drawing on Appreciative Inquiry insights.

The focus of the project was amended, following feedback from the project Advisory Group, from **Advance Care Planning to End of Life Care Planning**. The latter is considered more helpful as it emphasises specific end of life choices and not general advance care needs for any eventuality.

Recruitment and Participants

With the assistance of Health Education England Kent Surrey and Sussex and through professional networks, key providers of care were invited to participate. Twenty six attended one of four workshops at the Univiersity of Surrey and University of Brighton. A fifth workshop in Kent in December 2017 attracted thirty participants.

Findings

Questionnaires were provided to participants before and after the intervention. Sixteen pre-intervention questionnaires and 10 post-evaluation questionnaires were returned. The main findings were that participants had a good understanding of end of life care planning and agreed that the goals and values introduced in the Toolkit and workshop were applicable to all areas of end of life care. Participants confirmed the challenges of keeping the young person with learning disabilities at the centre of care and reminded: 'never talk over a young person with learning disabilities'. Maintaining a balance between person-centred care and family-centred care was highlighted as crucially important. Participants identified values and values' frameworks that were in keeping with those identified in the ADVANCE framework and also with the activities in the Communication Workshop. These included listening, empathy, understanding, compassion, dignity, person-centred care and safeguarding guidelines. The importance of end of life care planning was understood, for example, one hospice team leader wrote: 'It allows people time to share ideas and wishes in advance – conflicts/disagreements can be worked out. Reduces anxiety, creates harmony.' The benefit of meeting with colleagues from other services and combining expertise and experience in learning disabilities <u>and</u> end of life care was viewed as a very positive feature of the intervention.

The **small group discussion** generated two themes and five sub-themes as follows:

(i) *Putting the person with learning disabilities at the centre of the process* – helping them to speak for themselves (highlighting the importance of creative communication skills and appropriate language); involving the family ('you've got to take the family with you' focused on challenges and opportunities with family-centred care); and end of life care beyond the end of life (this related to awareness of the need for post-bereavement family support and resources).

(ii) *Connected care, connecting values* – Bringing care-givers together; and co-ordinating care; and unifying values. The benefits of bringing together health and social care practitioners was emphasised by participants. The presence of a doctor was appreciated and commented on: 'we were blessed with a medical person which is very rare […] and that person said he'd had almost no training around end of life.' A unifying framework of values (such as the ADVANCE frameworks) was viewed positively as was good communication and team-working to prevent people falling 'through the net' between child and adult services. The framework was viewed as a means to reinforce good practice and as a reflective tool to consider 'What good looks like?' 'What's my practice like?' and 'How might I improve?'

Discussion

The project aimed to 'implement and evaluate an education programme to increase the knowledge and skills of staff in communicating effectively & ethically with young people with learning disabilities and their families regarding End of Life Care Planning'. Within the project time constraints - 6 months - we developed and implemented a

Values-Based Toolkit and a Communication skills training Workshop format. We recruited practitioners from across learning disabilities and end of life care services. Findings suggest that they benefitted from sharing experience and expertise in the workshops and from applying a unifying values framework. Regarding the more specific project research questions, we comment on each below:

- What refinements are necessary to the exisiting ACP modue - End of Life Care for All e-ELCA course – so it is fit for purpose?

The existing e-ELCA course has much of value, however, it was not developed specifically for young people with learning disabilities at the end of life. Feedback from the project Advisory Group, from parents, from practitioners and from workshop participants contributed to the development of the ADVANCE Toolkit and to the Communication Workshop resources.

- What knowledge and skills do staff have relating to End of Life Care Planning for young people with learning disabilities before the intervention?

Those who attended the Communication Workshops were generally practitioners with substantial experience and experience in one rather than both specialties (either learning disabilities or end of life care). There was generally consensus that the values and skills promoted in the project intervention were applicable across end of life care generally. A particular area of challenge and opportunity related to the negotiation of the wishes of the child (person-centred care) and the wishes of the family (family-centred care).

- What knowledge and skills do staff have relating to End of Life Care Planning for people with learning disabilities after the intervention?

Practitioners had previous knowledge and skills to respond to such situation but it seemed that there was much to be gained by rehearsing and reflecting on scenarios in a safe context. It seems likely that sharing across specialities raised awareness of opportunities for improved care for young people transitioning from child to adult services.

- What next steps are required to ensure that good practice relating to End of Life Care Planning is sustained in care services for people with learning disabilities?

The format of the intervention with pre-workshop reading (Toolkit) and attendance at the Communication Workshop seemed to work well. However, we found that not all who attended had taken the opportunity to read the material and it was of value to go through the Toolkit at the beginning of each workshop session. The input on communication generally, the video resource and sharing of anonymised scenarios with role play and reflection appeared to be a good model to replicate (see recommendations below).

Conclusions

The study identified that the values-based approach to End of Life Care Planning (EoLCP) provided a framework that practitioners felt was useful to them. The Toolkit also enabled a focus on values that were linked to the Communication Workshop such as avoiding assumptions by sensitive questioning of end of life care wishes with both the individual and the family. The important role of the learning disabilities practitioner in relation to advocacy, especially when acute health services are involved in care at the end of life, was identified in a video used during the workshop. This related to a practitioner talking about her end of life care practice. One of the key aspects confirmed by the project is the importance of enabling young people with a learning disability to take part in shared decision-making around their wishes - according to their capacity - to be involved in decision-making and to have their wishes explored sensitively by care-givers. Close family members are key to care at the end of life as they are often the people who are giving care in the home and their needs also should be explored in a family-centred approach using similar skills and avoiding assumptions by asking family members about their coping and support needs. The development of a Values-Based Toolkit and Communication Workshop format (with video resource) appeared to work well. The benefits of bringing together practitioners from learning disabilities and end of life services was a key project outcome. Limitations of the project were that it was small scale and over a short timescale. Recommendations include:

- Health Education England working across Kent, Surrey and Sussex – to make the Toolkit and Communication Workshop format with video available to all via the website. This would including offering the resources to universities and care services for use in pre-registration and continuing education provision;

- Evaluation of the project to continue by encouraging those who utilise the Toolkit and Communication Workshop format to complete the evaluation forms and return to the research team at the University of Surrey (send to nursing-ethics@surrey.ac.uk with a subject heading of 'ADVANCE Toolkit'); and

- HEE to consider commissioning research that engages directly with young people with learning disabilities and their families regarding End of Life Care Planning. This project suggests that their voices are too rarely heard in relation to this topic area.

Acknowledgements

2. INTRODUCTION

End of life care has been a neglected topic in health and social care but is now receiving more of the attention it deserves. Nevertheless, there remain marginalised groups who are 'disadvantaged' in dying (Oliviere and Monroe, 2004). People with learning disabilities – also referred to as 'people with intellectual disabilities' - are one such marginalised group. This is despite the fact that people with a learning disability are generally in poorer health and are more likely to die at a younger age (Mencap, 2007). In particular, there are concerns that staff in acute setting such as hospitals do not always recognise the palliative care needs of individuals with a learning disability' (Reed and Morris, 2008).

People with learning disabilities who are identified as needing palliative care are often treated by professionals who, although competent in end-of-life care, may have little understanding of people with learning disabilities. Consequently, they may have less confidence and lack skills in communicating with them. Caring for people with learning disabilities who are identified as at the end of life raises a number of additional issues. Challenges identified in communicating with people with learning disabilities include the time-consuming nature of effective communication and difficulties as to how best to break bad news (Tuffre-Wijne & McEnhill, 2008).These challenges are compounded by the difficulties of obtaining genuinely informed consent due to issues of capacity, knowing how to interpret unusual behaviour and how best to raise difficult issues with the family members who often share the responsibility of making end of life decisions.

Providing the opportunity to draw up an end of life care plan with people with learning disabilities presents its own unique challenges. Ultimately every person with a learning disability is unique, possessing not just unique deficits but also unique gifts, passions and beliefs. Peisah et al (2013) have demonstrated the ability of tools such as their "ASK ME" framework to help dying people with learning disabilities to express that uniqueness to the fullest possible extent, exercising maximum autonomy in making meaningful decisions about the final days of their lives. Reframing capacity as relative and inclusive rather than binary and exclusive, they show that care-givers can be educated in the knowledge and skills required to ascertain how far those in their care are capable of making and understanding end of life choices, empowering care-givers to balance their own duty of care with the person's right to have such choices respected.

The starting point for this project is the view that what is required is a model of proven efficacy for providing education for health and social care professionals to help them meet these challanges. Health Education England Kent Surrey & Sussex commissioned the University of Surrey to design and conduct a 6 month research project to develop and trial such a model. The overall research aim was:

- To implement and evaluate an education programme to increase the knowledge and skills of staff in communicating effectively & ethically with young people with learning disabilities and their families regarding Advance Care Planning

The focus of the project was amended, following feedback from the project Advisory Group, from **Advance Care Planning to End of Life Care Planning**. The latter is

considered more helpful as it emphasises specific end of life choices and not general advance care needs for any eventuality.

The education programme developed in the course of this project comprises an open learning package – a Values-Based Toolkit - and a Communication skills training Workshop with a video tailored specifically to end of life care planning. The Toolkit was developed to facilitatate participants' reflection and knowledge, builiding on existing open learning packages developed by Health Education England and other bodies. The Communication Workshop was designed to develop participants' confidence and skill in communicating clearly and appropriately with young people with learning disabilties and their familes on this challenging topic. It is based on existing techniques already used in other palliative care contexts. The project also helps to identify the next steps in improving education to ensure good practice in end of life care planning for this vulnerable group.

3. BACKGROUND

3.1 End of Life Care Planning – Definitions, History & Ethical Underpinning

End of Life Care Planning (EoLCP) is a wide-ranging process and can include Advance Care Planning, End of life Statements and End of life decisions. Broadly speaking, EoLCP involves structured conversations between care-givers and care-recipients with a view to ensuring that the latter's wishes about end of life care are invited and respected as far as possible. A useful working definition of EoLCP as it is addressed in this project, is:

> Conversations whereby people with learning disabilities - and where appropriate, families and friends - are provided with opportunities to share, have documented and respected, their wishes regarding their end of life care and treatment.

A type of EoLCP that has been receiving increasing attention since the 1990's is Advance Care Planning, now enshrined as part of the Department of Health's *End of Life Care Strategy* published in 2008. The Strategy recognises that a key part of living well is dying well. Because a 'good death' means different things to different people it is crucial to engage with each unique individual and, where appropriate, his or her family in order to explore his or her wishes and decide how best to honour them. Advance Care Planning is a process in which care professionals invite someone *with* a terminal diagnosis who is likely to face a decline in their ability to make or express decisions to record of their wishes regarding their future care. Advance Care Planning gives individuals facing a decline in their abilities a way of ensuring that their voice will still be heard and their choices honoured when they are no longer able to make such choices or have no voice left to express them. Often this means having a say in how, where and when they will die (National End of Life Care Programme 2007).

> Advance Care Planning (ACP) is a voluntary process of discussion between an individual and their care providers. It is to make clear a person's wishes in anticipation of a deterioration in the individual's

condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others

Whilst Advance Care Planning (ACP) can be treated as merely an opportunity to raise the option of an end of life directive or do-not-resuscitate order, a more positive approach is to treat ACP as an ongoing, iterative process taking into account every aspect of the individual's changing needs and preferences (Ahluwalia et al (2015). This process is, at its core, an interpersonal one and is dependent on the development of respectful relationships. It emphasises the need, for example, to find meaningful and appropriate ways to discuss ACP with individuals and families in order to accurately gauge their wishes without leading them down a particular path or causing unnecessary upset.

End of Life Care Planning can also encompass End of life Statements and End of Life Decisions. NHS Choices (A. Undated) defines an End of life Statement as:

[…] a written statement that sets down your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.

Such statements can encompass aspects of the person's life such as their religious or spiritual beliefs, their preferred place of dying, where possible, and preferences about personal care and other practical matters (for example, who would look after a pet). An End of Life Decision, on the other hand, which is also known as a 'living will' or 'end of life decision to refuse treatment' enables a person to refuse medical interventions in end of life and is distinct from other types of End of Life care planning as it has legal status.

By comparison, in other types of EoLCP health professionals may be called upon to find ways to balance the individual's wishes with the practicalities of providing the best care. Helping a young person with learning disabilities to die well and in their 'preferred place', for example, may involve careful negotiation with individuals and family members, balancing the need for a setting which provides the appropriate expertise and equipment with the need to respect the individual's wishes about their preferred place to die (Bekkema et al, 2015).

Wishes recorded in an end of life care plan are not normally legally binding, indeed sometimes the care-giver might find themselves unable to honour them, for example when someone's religious or cultural values conflict with care-givers' professional ethics. However, an end of life care plan can be valuable even in these cases because it ensures the care-giver is able to weigh the person's wishes against other important concerns when deciding how to act in their best interest.

Finding the right time to initiate a conversation about EoLCP is also crucial, especially when a decline in capacity is expected. People with dementia and other degenerative conditions may, for example, be able to decide on an end of life care plan either in the early stages of their condition or during more lucid periods in which their cognitive functioning is relatively normal, whereas those with learning disabilities may find it

difficult to understand abstract concepts such as death and dying no matter when the subject is raised (Read and Morris, 2008). The onus is therefore on working with family and other care-givers to find the optimal way to address end of life choices within the unique frame of understanding each person with a learning disability brings.

The challenges formal care-givers face in providing good end of life care to people with learning disabilities combine both ethical and pragmatic components (Tuffrey-Wijne et al, 2016). These two elements are inextricably linked as ethical and communication competence, in particular, enable care-givers to appreciate the value base and to acquire the skills required to engage in meaningful end of life care planning conversations. For example, ethical competence is likely to help formal care-givers reflect on issues such as: truth-telling regarding prognosis: issues of privacy and confidentiality regarding the location of the conversation; and consent as to who is invited to participate in the conversation.

Much can be learned from tools and interventions that already exist designed to help facilitate greater involvement of those facing a terminal diagnosis and their families in residential homes (for example, Cox et al 2017) and especially those experiencing dementia (for example, Ampe, 2017). These are areas in which it has been shown to be beneficial as a means of enabling those who might otherwise be voiceless to continue to exercise as much autonomy and self-determination as possible. Ideally it allows professional care-givers, faced with a difficult decision about the type of care someone will receive, to make the choice the young person with learning disabilities would have made for her/himself.

Introducing the idea of any kind of end of life care plan can be useful whether the person ultimately decides to make one or not. It can serve as a way of ensuring that the individual is aware of all the options available to them and creates an opportunity to discuss their needs and wishes with informal care-givers and family members. This includes options such as appointing a trusted individual to represent their wishes in the future, be it informally or by granting them lasting power of attorney. Having discussed such options can also give family members the consolation of later knowing that the difficult choices made about end of life care were in accordance with their loved one's wishes. From the person's perspective, discussing or actually making an end of life care plan also offers the consolation of relieving some of the pressure on their family to make decisions on their behalf. Having an end of life care plan on record also makes sense from the health or social care provider's perspective as it allows limited resources and personnel to be allocated more efficiently and appropriately. It could reduce, for example, the possibility that resources such as hospital beds and cardiopulmonary support equipment would be inappropriately allocated to individuals who do not want them but lack the ability to say so.

Furthermore, in an age where complex care needs are catered for by a range of professionals who may not have had prior opportunity to discuss treatment options with the person or each other, access to a record of the person's stated preferences and values allows greater continuity of care, ensuring that the care delivered is consistent and appropriate no matter who is providing it (Riley and Madill, 2013).

A Brief History of End of Life Care Planning in the United Kingdom

With more people with health conditions living longer and many of these experiencing cognitive impairments in their final years, there is renewed interest in finding ways to enable them to continue to exercise autonomy and choice as their abilities decline. What has changed in the last few decades is the emphasis on making sure such planning is widely available and delivered consistently across the UK's health and social care services and driven by a consistent set of values. This has included the introduction of more specific tools and practices under the umbrella of End of Life Care Planning (EoLCP), notably the introduction of Advance Care Planning (ACP).

In the early years of the National Health Service (NHS) such was the emphasis on coping with the widespread acute and chronic health problems of a population still recovering from war that there was little concerted attention paid to how best to deliver, let along plan in advance for, care for the dying. Indeed in its first two decades there is scant evidence of the NHS having either a coherent policy or consistent practical guidelines for helping people to die well. If the topic was raised at all it was usually by charities or other non-government organisations with an interest in specific conditions (Clark, 2014). For a long time the focus of the NHS was more on living longer than dying well.

It took years of passionate advocacy from key individuals such as Cicely Saunders, beginning in the late 1950s, to put palliative medicine and end of life care firmly on the agenda. Change came but slowly and unevenly to the various institutions that made up the welfare state, and slowly those seeking a new voice for the dying began to persuade others that concerted, sweeping changes could be made. These were changes that would allow everyone a fair chance of dying well and would need to come from above. Slowly policy makers began to talk about the needs of those who were dying and recognition grew of the need for a more strategic approach to end of life care.

End of life care really began to receive attention from the late 1970s onwards as the hospice movement grew, aided by the expansion of the specialty of oncology. Even though much end of life care was still being delivered outside the NHS by charities and voluntary organisations, these groups were now beginning to attract government funding (Dixon et al, 2015). Finally a sufficient groundswell of interest and expertise was building so that the medical, social and psychological needs of people with a terminal prognosis, whether or not they were in immediate danger of death, were catered for by specialised multi-professional teams (Clark, 2007). Finally, care of the dying was being treated as a specialty in its own right rather than simply a by-product of the failure of other branches of medicine to preserve life.

Even so, it wasn't until the 1980's that hospices became widespread enough and palliative care services sufficiently diverse and specialised that an alliance of cancer charities and end of life care providers came together with the Department of Health and NHS to advocate for a national body to represent the needs of those who provided end of life care (National Council for Palliative Care 2015). In 1991 this resulted in the

formation of the National Council for Hospice and Specialist Palliative Care Services, forerunner of the current National Council for Palliative Care.

Since the early 1990's, with the rise in popularity of Advance Care Plans in particular, EoLCP has evolved beyond being merely an opportunity to complete an advance directive or do-not-resuscitate order towards treating end of life care planning as an ongoing, iterative process (Ahluwalia et al 2015). There is research to suggest that this more inclusive model of planning delivers better measurable results in terms of efficient resource use and treatment outcomes than simply providing a one-off chance to refuse certain treatments (Singer et al 1998). This process is at its core a social one emphasising the need to, for example, find sensitive and appropriate ways to discuss end of life care plans with individuals and families in order to accurately gauge their wishes without leading them down a particular path or causing unnecessary upset.

Approaching EoLCP as a social process acknowledges, not just the need to involve family and friends in the discussion, who will play a large role in caring for the person, but crucially the person who is dying. Care-givers need to be mindful, however, that a balance is struck between realising the wishes and minimising the suffering of the person who is dying and easing the burden on their loved ones during what they know will be a very difficult time. Respecting the wishes of the dying person is the priority.

Crucially, the evolving model treats EoLCP as an ongoing process rather than a single encounter. This acknowledges the fact that someone's preferences about future treatment and care can change. Sometimes preferences are grounded in religious views or deeply held values and at other times they may be based on recent experiences, current emotional states and changing relationships. For example, someone's wishes for their own end of life care may change as a result of experiencing the death of a friend or of a family member. Professional care-givers are now therefore encouraged to re-visit a care plan at appropriate intervals to ensure the instructions that are carried out when the person does lose capacity still reflect their current wishes.

Earlier this year NHS England's Palliative Care for People with Learning Disabilities Network (2017) document "Resources and tips for commissioners, service providers and health and social care staff" sets out 6 ambitions for those delivering End of Life Care in this area:

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is Co-ordinated
- All staff are prepared to care
- Each community is prepared to help

These ambitions represent a summary of much of what has been learned about what is most important in End of Life Care for people with learning disabilities. Realising all these ambitions becomes easier when an individual's wishes and preferences for their

end of life care are understood and taken into account well in advance of the time when the resources and coordination of services will need to be operationalised.

With growing recognition of the need for a concerted approach to End of Life Care Planning (EoLCP), as evidenced by the publication of the Department of Health's *End of Life Care Strategy* (2008) and subsequent establishment of the Dying Matters Coalition, it is likely that EoLCP will become an even more powerful tool in the future. Trial programmes which are already exploring the possibility of a person's recorded wishes being made available electronically to any professional care-giver who comes into contact with them. This could be a specialist nurse who has known them for years or a paramedic who has never met them before but urgently needs to know how best to help them (Riley and Madill, 2013).

The options of making an end of life care plan, living will, an advance directive to refuse specific treatments or Advance Care Plan are now merely part of the broader spectrum of choices discussed (Robinson et al, 2012). The more inclusive and integrated approach emphasises making the person aware of the full range of options available to them, facilitating open discussion of these options with their families and ensuring that their subsequent wishes are taken into account in a way that honours the full spectrum of views and beliefs that reflect who they are as a person.

Ethical Aspects of End of Life Care Planning

The strongest ethical argument for End of Life Care Planning (EoLCP) relates to respecting the young person's autonomy. Autonomy is derived from two Greek words *autos* and *nomos* which mean 'self-rule' or 'self-government'. The principle of respect for autonomy involves enabling people to make decisions for themselves. In this case, it involves having information regarding options communicated in a clear and accessible way, giving people time to comprehend the information and to make decisions on the basis of it (Beauchamp & Childress 2013). End of life care planning is also supported by principles of beneficence (do good) and non-maleficence (do no harm) also support end of life care planning.

A significant ethical issue in end of life care planning is that there remain large sections of society who are still less likely to have the opportunity to plan for a "good death" (Oliviere and Monroe, 2004). One of the most disadvantaged of these groups is young people with learning disabilities. People with learning disabilities are often disadvantaged by being assumed to be a group with similar needs and preferences, lacking diversity or the ability to communicate what their needs and wishes actually are (see, for example, Blair 2016. 2017). Such assumptions can impact negatively on communication with young people and their families about end of life care. Young people with the most severe and profound problems are least likely to get the chance to make their wishes understood.

It can be argued that doing good and promoting benefit for young people with learning disabilities includes providing opportunities for them to make decisions about, and plan for, their end of life care. End of life care planning also contributes to minimising harm as the young person's involvement will help to ensure that they do not have

interventions they do not wish to have nor have needs neglected, for example, in terms of symptom control. The principles of justice also reminds care-givers that young people with learning disabilities should be treated fairly and not discriminated against in the provision of quality end of life care (Beauchamp & Childress 2013).

Other ethical lenses through which to view end of life care planning includes a human rights perspective which emphasises human dignity – the value or worth of all humans regardless of their race, class, gender, age, sexual orientation or disability (see, for example, the Human Rights Act, 1998). In terms of the ethical qualities of the care-giver a virtue ethics approach emphasises, for example, the need for respectfulness, courage, integrity and practical wisdom (Banks and Gallagher 2008) to respond to the nuances of everyday practice in relation to end of life care planning.

A range of ethical priorities can be identified in relation end of life care planning for young people with learning disabilities and these include:

- Assessing capacity and communication so the potential of the young person to contribute to conversations is known;
- Ensuring, as far as possible, that the young person understands the information that is being shared with him/her regarding diagnosis and prognosis;
- Using creative strategies – verbal and non-verbal – to put across honest information relating to end of life care options and the benefits and risks of each;
- Striving to involve the young person in care planning conversations as far as possible and drawing on a range of communication strategies to ensure he/she is able to express information relating to personal end of life choices;
- Discerning amongst the views of parents/guardians and the views of the young person regarding what is desired at the end of life – the views of the young person take priority;
- Recording the young person's wishes so that all care-givers are aware of and are in a position to respect them, as far as possible; and
- Implementing the end of life care plans made to ensure that young people live as comfortably as possible until they die and their families receive the support they need.

3.2 Learning Disabilities, End of Life Care Planning & Young People

'Learning disabilities' is a term used to describe deficits in thinking emerging early in life that impair social functioning and thus the ability of the person concerned to live a full and independent life. It co-exists with the term 'intellectual disabilities' which is more common in the United States. Learning disability is a broad term typically applied to deficits in learning or thinking skills deriving from a wide range of causes. NHS Choices (B Undated) state that:

> A learning disability affects the way a person learns new things in any area of life, not just at school […] and how they communicate. Around 1.5, people in the UK have one. This means they can have difficulty: Understanding new or complex information; learning new skills; [and] coping independently.

Learning disabilities can be mild, moderate or severe with the abilities of people ranging from those able to communicate well and look after themselves, albeit taking a little longer to learn new skills, to those who require a lot of care and support which may also include for physical disabilities. This covers a wide range of abilities and levels of dependence. It should always be assumed that young people who have a learning disability are aware of what goes on around them. However their ability to understand and communicate this will vary, as well as having difficulties in expressing themselves in relation to their hopes and wishes and symptoms.

Only about a quarter of cases can be definitively attributed to genetic disorders and in 30-50% of cases the cause of such problems, and hence their likely future prognoses, are unknown (Daily et al, 2000).

People with learning disabilities are disproportionately likely to suffer from other adverse health conditions and are at greater risk of faring poorly in the healthcare system, with correspondingly poorer health outcomes (Krahn and Fox, 2014). The average lifespan for someone with a learning disability in the UK is 16 years shorter than that of someone without one (Salt, 2017), even more so when the disability is severe and profound (Patja et al, 2001). For people with profound and multiple learning disabilities, complex and highly unpredictable life-limiting conditions are the rule and living into old age is very much the exception (Zaal-Schuller, 2016).

End of Life Care Planning with People with Learning Disabilities

End of Life Care Planning encourages people to make important decisions before they lose the mental capacity to do so. Unfortunately some people with learning disabilities may already lack the capacity to understand the relevant issues and make difficult decisions. In many cases professional care-givers may even tend to assume a lack of capacity without confirming this is the case and thus never broach the subject of an End of Life Care Plan (Van Thiel et al, 1997). Wagemans et al (2010) also notes cases in which not only were end-of-life choices made on the person's behalf but they were never even told of them on the assumption that they would not understand and even if it did it would only upset them.

For some time now the dominant narrative regarding good care is one of Person-Centred Care (Health Education England, 2014). This means more than simply focusing on people rather than problems. It means involving individuals as collaborators in guiding their own healthcare and allowing them to make decisions that meaningfully derive from their own, history, values and beliefs. As a mantra popular with healthcare organisations puts it, the emphasis is changing from "What is the matter with you?" to "What matters to you?" (Krejci et al, 2014). This is one of many aspects of health care that becomes much more challenging when applied to people with learning disabilities but also much more important.

A central pillar of Person-Centred Care is Shared Decision-making. Advance directives are often seen as an effective way of allowing shared decision-making and thereby protecting a person's autonomy when a future loss of capacity is likely (Deegan and

Drake, 2006).   However, most research into how to conduct Shared Decision-making effectively has focused on treatment decisions around management of physical conditions, whereas the scope of something like an advance or end of life care plan is rather broader, encompassing life and personal preferences as well as decisions explicitly regarding medical treatments. Moreover, research into how to make Shared Decision-making work in the context of people with learning disabilities is somewhat more limited in scope and has produced few truly compelling recommendations (Duncan et al, 2010).

Drake and Deegan (2009) see involving autonomous adults in any decision affecting their care as an ethical imperative, even when that individual suffers from cognitive impairments. When that individual is neither autonomous or an adult that imperative doesn't simply vanish in a puff of pragmatism, instead it must be honoured in different ways that take into account potential difficulties in both communication and understanding. Often the role of bridging this gap falls to the care-givers and family.

People with learning disabilities may experience difficulty communicating about day to day matters, let alone discussing complex decisions about their medical care; often they may express themselves in ways that only those who know them well are able to understand. This places ever more emphasis on the ability of professional care-givers to broach and discuss the sensitive issues around planning for end of life care with family members or other informal carers. At the same time the professional care-giver is encouraged to work with these informal carers to help the individual to participate in the decision-making process to an appropriate extent if this can be achieved without confusing or upsetting them.

This already difficult task is complicated by the fact that almost half of deaths of people with learning disabilities are sudden or unexpected, allowing little time to properly plan for care in the final days (Wagemans et al, 2010).

Young people with Learning Disabilities

Young people with learning disabilities may lack the capacity to understand the relevant issues and make difficult decisions and may also lack the legal ability to make some decisions involved End of Life Care Planning (EoLCP). For example, they must be 18 or over in order to make the decision to refuse specific treatments in the future via a living will or advance decision. Discussions about EoLCP for such individuals will again often require participation of parents or other family members, this time in the even more emotive context of planning for the death of a son or daughter. The processes of EoLCP and Advance Care Planning are ongoing and iterative. As a young person develops, their feelings, opinions and ability to deal with complex and challenging ideas change and this may include any end of life care plan they might have made. It is then very important to periodically review the young person's wishes. Every person matures at a different rate and the mental development of a young person with learning disabilities is especially unpredictable. The ability of the professional care-giver to communicate with and learn from the individual and their loved ones is once more therefore vital. The fact that young people with profound and multiple learning

disabilities account for much of paediatric care, there is again very little research that looks at planning for end of life for such individuals (Zaal-Schuller, 2016).

3.3 Project aim

The aim of the project was to implement and evaluate a train the trainers education programme to increase the knowledge and skills of staff to communicate effectively & ethically with people with learning disabilities and their families regarding End of Life Care Planning drawing on insights from Appreciative Inquiry.

The research questions which were addressed are:

- What refinements are necessary to the exisiting ACP modue - End of Life Care for All e-ELCA course – so it is fit for purpose?

- What knowledge and skills do staff have relating to End of Life Care Planning ng for people with learning disabilities before the intervention?

- What knowledge and skills do staff have relating to End of Life Care Planning for people with learning disabilities after the intervention?

- What next steps are required to ensure that good practice relating to End of Life Care Planning is sustained in care services for people with learning disabilities?

4. RESEARCH DESIGN

The project was underpinned by Appreciative Inquiry (AI), an approach that can be used within organisations to locate best practice and to bring about change. It requires a move from a problem-orientation to an appreciative stance. The project team has selected an appreciative inquiry approach because it:

- does not focus on problems and problem-solving but rather on what works well and on how things might be better;

- has excellent potential to develop trust and meaningful collaboration with staff in pre- and post-natal practice rather than identifying failings and blame; and

- contributes to the development of an appreciative learning culture where the project team works collaboratively with the staff in the healthcare settings.

4.1 Advisory Group

The Advisory Group met in months 2 and 5 of the 6 month project to share their expertise and experience and to provide input on the project methodology, ethics, findings, project report and next steps for this work. A summary of the Advisory Group meetings can be found in Appendix 5. Members of the Advisory Group were:

- Jim Blair - Consultant Nurse Learning Disabilities - Great Ormond, Street Hospital, Associate Professor Learning Disabilities, Kingston and St. George's Universities

- Phil Boulter - Consultant Nurse for Learning Disabilities - Surrey and Borders Partnership NHS Foundation Trust
- Lizzie Chambers - Development Director - Together for Short Lives
- Craig Gannon - Medical Director - Princess Alice Hospice, Esher
- Faith Gibson - Professor of Child Health and Cancer Care – School of Health Sciences, Faculty of Health and Medical Sciences, Duke of Kent Building, Stage Hill Campus, University of Surrey, Surrey, GU2 7TE
- George Matuska - Transforming Care Programme Workforce Specialist Clinical Advisor, Learning Disabilities – Health Education Kent Surrey & Sussex &
- Rhona Westrip - Programme Manager Learning Disabilities – Health Education Kent Surrey & Sussex

4.2 Recruitment and Project Participants

The workshops were advertised with the assistance of Health Education England: Kent, Surrey and Sussex (Funder and members of Advisory Group). We emailed key providers of care and invited them to take part in the education programme with a view to recruiting up to participants. The aim was to bring together and cross-pollinate the experience, skills and opinions of professional care-givers who work in closely related areas and yet might not normally have the opportunity to combine their expertise. Such roles included care assistants, consultants, specialists in conditions such as Downs Syndrome and members of multi-professional teams working in learning disabilities' and end of life care services.

Networks and direct invitations were sent to relevant organisations including:

- Local NHS Trusts offering care for young people with learning disabilities
- Local Council Learning Disability Support organisations
- Academic centres for learning disabilities and end of life care
- Hospices offering care for young people with learning disabilities
- Domiciliary Care Organisations
- Charities and NGO's caring for those with learning disabilities

Sixty one practitioners and managers, working in learning disabilities and/or end of life care, were recruited via professional networks and organisations serving a variety of types of professional care-givers who cater for young people with learning disabilities. The 56 practitioners who attended have represented a broad spectrum of organisations providing care for young people with learning disabilities, both health and social care and public and privately funded care-providers. Participants were split fairly evenly between those focused on providing end of life care and those specialising in caring for young people with learning disabilities. Venues were booked at the University of Surrey, The University of Kent and Brighton University. Not enough people signed up for the Kent workshop to make it viable but in the event 2 of the 3 who did sign up were able to make it to one of the other workshops. Subsequently, the South Kent Coast & Thanet Community Learning Disability Team Kent Community Health NHS Foundation

expressed an interest in hosting an ADVANCE workshop and this as arranged for 6th December 2017 with 30 participants.

Details of the workshops completed or scheduled are as follows:

Monday 4th September 9.30 to 12md	*University of Brighton* 5 attendees (2 cancellations)
Tuesday 5th September 9.30 to 12md	*University of Brighton* 6 attendees
Wednesday 6th September 9.30 to 12md	*University of Surrey* 6 attendees (1 cancellation)
Monday 18th September 9.30 to 12md	*University of Surrey* 9 attendees (2 cancellations)
Wednesday 6th December 1.30 to 3.30	*Hall Place Canterbury CT2 9AG* 30 attendees

4.3 Procedure & Development of ADVANCE Values-based Toolkit

Prior to taking part in the education programme, participants were sent copies of the Participant Information Sheet and Consent Form, allowing them time to raise any queries as they considered participation. Signed consent forms were obtained from all participants who volunteered either electronically, via post or at the start of the workshop as the participant preferred.

Before beginning the education programme, each participant was asked to complete a questionnaire to gauge their existing views and knowledge about advance end of life care planning for young people with learning disabilities. The participants had a choice of receiving the questionnaire on paper via the postal service or electronically as an email attachment. They were asked to repeat this questionnaire after the education programme was completed to gauge how useful they thought it was and how much effect it had on their confidence and skills. Both questionnaires could be completed at a location of the participant's choosing and then returned either electronically as an email attachment or physically by post.

The education programme itself comprised two parts. First participants completed a specially designed Toolkit which had been emailed to them at a time and place of their convenience, taking no more than approximately two hours.

Participants then attended a two hour communication based on a tried and tested model and focusing on how to discuss advance care planning for people with learning disabilities and their families. The workshop content and format were developed by Dr Anne Arber, an expert in advanced communication skills with many years of experience

of workshop design and facilitation. Workshops allowed for a maximum of 10 participants and were run in meeting or conference rooms in locations convenient to the participants. A video resource formed part of the workshop.

Following one workshop a sample of participants, who had taken part in the education programme attended a discussion of how the programme has affected their practice, examining which aspects were most useful and discussing whether such education should be made more widely available.

The small group discussion was designed to explore the impact of the education intervention they had participated in and to gather ideas about how and where it might be improved and utilised in the future. Discussion in a small group was desired as this typically generates different interactions to those found in the workshops and allows individuals to reflect more deeply on their impressions of their education experiences and needs. A small group approach allowed the discussion to unfold more naturally amongst group members with the facilitator only intervening when necessary to keep the things on course (Morgan, 1997).

The small group discussion was audio recorded and fully transcribed for future analysis. Lasting almost an hour, it was facilitated by a project researcher from the University of Surrey. Only two workshop attendees felt able to stay for the group discussion as the others were unable to take more time out of their busy schedules or felt they had already fully expressed their views in the evaluation forms or during the workshop.

An alternative approach might be to invite workshop participants to attend a focus group on a separate date when they are not already tired from just having taken part in a two and a half hour workshop in end of life care. This also presents additional challenges of getting participants to give up another section of their working day and travelling to the location a second time without offering the compensation of taking part in a workshop that offers them work-relevant education. Nonetheless, the accounts of the two workshop members who took part in the small group interview produced a very rich and insightful conversation.

Development of the ADVANCE Values-Based Toolkit

The Toolkit underwent an extensive development process following consultation with experts working in the areas of learning disabilities and end of life care. Initially it was focused on Advance Care Planning specifically but eventually the decision was made to focus more broadly on the full spectrum End of Life care planning.

The acronym ADVANCE captured the values-based approach favoured by the research team and Advisory Group. The acronym was designed to provide an easy to remember yet comprehensive summary of the values and issues central to delivering ethical and effective end of life care planning (see next page). We have incorporated insights from the Health Education England eLearning materials 'End of Life Care for All' (see https://www.e-lfh.org.uk/programmes/end-of-life-care/).

The ADVANCE Framework

A Values-Based Approach to End of life Care Planning (EoLCP) for Young People with Learning Disabilities

- **A**ssumptions – Avoid making assumptions regarding the abilities and wishes of care-recipients and families. Care-givers need to be well informed about the person's health status, capacity and family and support network. What this means in practice is that care-givers need to check out the young person's understanding of their health status and of the most appropriate means to communicate with him/her.

- **D**ignity – Respect the worth of each individual in the care context. There needs to be open-mindedness to, and respect for, diversity. This is not only in terms of disability but also related to race, class, gender and sexual orientation**.** In practice, this involves engaging with the young person first and taking time to get to know him/her before moving to finding out EoL preferences.

- **V**ulnerability – Be sensitive to people's vulnerability towards the end of life. This includes young people, families, friends and professional care-givers. Less experienced care-givers will also need support to enable End of Life Care Planning**.** This also involves advocacy and awareness of safeguarding responsibilities.

- **A**utonomy – Strive to maximise information-giving and understanding of all regarding end of life care options. A HEE e-learning resource states that EoL care planning 'is a [person] centred dialogue carried out and reviewed over a period of time. The content of any discussion shoulearning disabilites be determined by the [person] in question, they may be encouraged to include an informal carer, relative or significant other in the discussion if this is their wish.' Advocacy is also an important aspect of supporting autonomy.

- **N**on-Discriminatory practice – Respect the rights to care of a person with learning disabilities. As the HEE e-learning resource states: 'Professional care-givers should be open to any discussion which may be instigated by the [person], even if it goes against their own initial opinions'.

- **C**ommitment – Care-givers require ethical qualities such as kindness, patience, justice, honesty and integrity. As the HEE resource reminds us: 'They need to be able to fully provide the [person] with relevant information about the range of options that are likely to be available to them in the future should their condition worsen.'

- **En**vironment of care – Ensure this is safe, peaceful, private and as life-affirming as possible. The HEE resource highlights the importance of 'time and setting'. The conversation 'should take place in private, be allowed adequate time, with the decision of who else to have present' left to the individual.

4.4 Data Analysis

The anonymised results of the before and after questionnaires were used to suggest the effectiveness of the programme.

The small group interview transcript was subjected to a qualitative thematic analysis (Braun and Clarke, 2006). This inductive approach uses the data as the basis for the systematic generation and ongoing refinement of categories at different levels of abstraction. The process of thematic analysis allows for both methodological rigor and the flexibility to sensitively capture the patterns found in participants' accounts whilst maintaining a reflexive awareness of the researchers' own biases and preconceptions. Close reading of the data resulted in the generation of initial themes which were then refined, pruned and amalgamated to produce overarching themes at higher levels of abstraction. The analysis was validated by another member of the research team, resulting in the thematic structure presented below.

4.5 Ethical Considerations

Ethical review was sought from the University of Surrey's Research Integrity and Governance Office and university Ethics Committee for the recruitment, training, data collection, analysis and reporting activities.

Informed consent was obtained from all participants via the Participant Information Sheet (Version 2, 16/05/17) and the Consent Form (Version 3, 30/05/17) prepared for this study, which are included in this submission.

Participants' details were anonymised and any personal data relating to them specifically is stored separately from their anonymised data. Data was processed in the strictest confidence and no individual named or identified in any report or publication arising from the study. Personal data was handled in accordance with the UK Data Protection Act (1998).

Research data will be stored securely on the university server for at least 10 years following their last access and project data (related to the administration of the project, e.g. consent forms) for at least 6 years in line with the University of Surrey policies.

5. FINDINGS

5.1 Analysis of Pre- and Post-intervention Evaluation Forms

Participants were asked to complete evaluation forms before and after taking part in the education programme. The following section is a summary of the 16 pre-workshop and 10 post-workshop evaluation forms that were returned.

The vast majority of participants already evidenced a good understanding of what end of life care planning was involved and why it was important.

> *It is a plan that you make which includes your wishes on how you would like to be cared for, on how your needs will be met in the final stages of your life when you may not be able to tell others how you feel or what you may want* (Learning Disabilities Nurse)

> *A way to ensure that anyone coming to the end of their life has the right information and support to enable them to have control over the end of their life to die with dignity in the way they choose. End of life planning needs to also ensure that people are enabled to live their lives now whilst they can* (Transition Programme Lead)

A key feature of the descriptions offered was that the goals and values cited were applicable to any and all groups facing the end of life, not just young people and not just those with learning disabilities. That said, participants were very aware that applying end of life planning to these groups often involved special challenges, in particular ensuring that those values are applied to an individual who may have trouble communicating and risk being ignored while carers spoke instead to family members.

> *While person centred they are a centre of a key environment and family must be afforded the same respect and dignity with no difference – fears need to be address. Never talk over a young person with learning disabilities however disabled* (Transition Coordinator)

> *Putting the person at the centre of the plan and involving carers and those that know them best. End of life care planning should include a holistic overview of their needs including emotional, sexual and social needs* (Senior Social Worker)

The paradigm of person-centred care is here seen to be applied to the whole family. Those around the young person may require almost as much consideration as the individual themselves, nonetheless there can be no doubt that that it is the young person and their needs and wishes that are paramount. This can be a difficult balancing act. Indeed, one objective of end of life care planning was seen as clearly establishing the young person's wishes to reduce the pressure on those around them:

> *It puts a big responsibility onto loved ones to make decisions about your life and they may wonder if they are doing the right thing for you. By having a plan you are taking away this burden for them as you would*

already have a list of your wishes, beliefs and what you value (Learning
Disabilities Nurse)

Using End of Life Care Planning (EoLCP) to make a difficult time a little easier for the person's family was seen as having knock-on benefits to the social ecosystem that surrounds them. That is, the family worry less and the young person worries less about them rather than picking up on their guilt and distress when it is too late to do anything to mitigate it. Indeed, while most participant's descriptions of EoLCP centred around the time before death a few took pains to acknowledge that another key aspect is ensuring that things go as smoothly as possible after death, everything from funeral arrangements to helping those left behind feel they have done their best for the young person by fulfilling their wishes.

Participants also often saw end of life care planning as having other, more pragmatic benefits. For example, it gives them time to assess if the young person's wishes were realistically achievable. If so, to put in place plans to ensure they are followed and if not to negotiate acceptable alternatives with them. This was especially important given the time and bureaucracy involved in getting appropriate measures in place, for example, special adaptations to the home to allow the young person to die in their own bed. It was also crucial given the necessity for multiple care-givers and specialists to coordinate their efforts if the best possible end of life care is to be achieved.

> *To consider parallel planning, to make sure wishes, beliefs etc, and taken into consideration and contingency plans are in place. To consider mental capacity* (Hospice at Home Nurse)

> *We can evaluate whether end of life care wishes are feasible, how we can prepare and implement them, the individual will have some autonomy and feel a degree of control over what is a frightening process* (Paediatric Consultant)

This issue of autonomy and control is a focus of the ADVANCE toolkit, encouragingly, raised here before the participant took part in the programme. Clearly an awareness of the overarching issues, both ethical and pragmatic, already exists to be built upon.

When explicitly asked about the values underlying end of life care planning for young people with learning disabilities there was already an encouraging degree of consistency is the values participants raised. These frequently included:

- Listening
- Empathy
- Understanding
- Compassion
- Choice
- Comfort
- dignity
- Positivity
- Communication

Though a few participants when asked this question tended to refer instead to health and social care service principles and guidelines which codify these values rather than the values themselves, including:

- Person centred planning,
- Care Act,
- Mental Capacity Act
- Safeguarding
- Best interests

Furthermore, participants were keenly aware that the wishes of the young person, even if they are realistic and achievable, may not be shared by the parents. This can place health care providers at the centre of an emotive and highly delicate series of negotiations in which honesty and clarity are paramount.

> *Open and honest communication in a timely manner. To establish what they understand and try to be guided by them as well. Get the balance right between respecting parent's wishes but also act in the young person's best interest* (Hospice at Home Nurse)

> *Acknowledge not everyone will agree, recognise different opinions and support to reach a positive outcome* (Learning Disabilities Nurse)

Whilst end of life care planning can bring such conflicts to the surface it can also provide sufficient time and a safe forum to resolve them before it is too late.

> *It allows people time to share ideas and wishes in advance – conflict/disagreements can be worked out. Reduces anxiety, creates harmony* (Team Leader, Children's Hospice)

Another balancing act participants felt they had to achieve was between honest and positivity in a situation that is anything but positive.

> *Making it as positive as possible, not focusing on the negative but making it as peaceful as possible* (Community Learning Disability Nurse)

Given that most participants already had quite a thorough understanding of all these issues, the purpose of end of life care planning and the complexities of applying it to such a vulnerable group, the task of the ADVANCE programme, and other future training interventions in this area, was therefore framed more as finding ways to do end of life care planning well. After all, the series of balancing acts described above can be complex enough to manage when a person is an adult with full capacity. However, when that person is a young person with a learning disability who has never had capacity and may never develop it, the challenge is all the more daunting.

Participants seemed to get the most out of the workshops when they were able to interact and share ideas with health and social care workers they would normally not have the opportunity to meet due to the highly specialised and hierarchical organisation of care services and often poor communication between these "silos".

I found that multi professional workshops like this work really well. I learnt a lot from other people's perspectives and experiences. Thank you very much (Hospice at Home nurse)

What struck me was the need to have further conversations with experts by experience and think about the language we use and how that can be alienating sometimes. Influencing the medical world is still important as sometimes practitioners can lack empathy and not want to be honest (that is true across the disciplines) (Transition Programme Lead)

By the same token, participants got the least out of the sessions when groups were more homogenous in terms of specialisation or even consisted largely of their own colleagues:

The group I was with were all from the hospice world except one. We all work in this field daily so some of this was not relevant to our group. (Director of Children's Services at Hospice)

[…] lack of diversity in the group were unavoidable but the opposites would have contributed to a better learning experience. (Social Worker)

Dealing with issues of death and dying, be it directly or indirectly, is something that unites almost all who work in health and social care services. The workshops, like the toolkit, therefore have the potential to be a medium for bridging these gaps and bringing together health carers, managers, consultants, nurses and hospice workers at all levels, all focusing on an issue that concerns them all, bringing much needed consistency and connectivity to a potentially fragments and confusing service.

Indeed, finding ways to build more connectivity and stronger communication into the various aspects of care needed to see an end of life care plan followed consistently was a major theme when participants were asked what would help them deliver good end of life care in the future

To continue to link in with local hospice. Set up a pathway for referrals and formulise individual end of life care plans with clients and family carers (Community Learning Disabilities Nurse)

Participants seemed to appreciate that the format of the workshop was interactive and flexible enough to allow them to address and discuss the end of life issues that were important to them. This is helpful to keep in mind going forward as it will allow future workshops to adapt to the needs and interests of different types of groups, some of whom already knew about end of life care planning and some who had a lot of experience in working with young people with learning disabilities, but all of whom have to deal with the same frustrations when seeing someone they have provided care for dying and believing they could do nothing about it. Although participants often said they discussed how to deliver end of life care with their immediate team members, having the opportunity to talk about the broader issues of how to deal with young people dying with colleagues they might not normally have informal contact with seemed to be a cathartic experience for them:

One thing I did take on board is as a nurse we can't fix everything, and accepting that. (Community Learning Disabilities Nurse)

5.2 Analysis of Small Group Discussion

The small group interview provided a forum for discussing both what worked and what didn't work about the learning programme. It also provided data regarding the future training needs of those working in the fields of learning disabilities and end of life care more broadly. Furthermore it allowed the themes and ideas raised, as important during the workshop and on the programme evaluation forms, to be explored in more depth. It also afforded a useful opportunity for those who had participated in the workshops to sum up what they had taken away from the experience having had a chance to reflect. Several themes and sub-themes emerged from the discussion which will be outlined in table x below.

Themes	Sub-themes
Putting the person with learning disabilities at the centre of the process	• Helping them speak for themselves • "You've got to take the family with you" • End of life care beyond the end of life
Connecting care, connecting values	• Bringing care-givers together and coordinating care • Unifying values

Table 2: Themes and sub-themes from small group interview

The first key theme was that in any job involving the care of young people with learning disabilities a key concern must be finding ways to give the person a voice. This was felt to be even more so when planning how they will spend the final days of their lives.

Theme 1 - Putting the person with learning disabilities at the Centre of the Process

Helping them speak for themselves

Participants were already keenly aware that the young person with learning disabilities needed to be at the centre of the process of planning their end of life care.

However, given how difficult it can be to communicate with individuals with more severe learning disabilities, and the need to constantly be looking of ways to better understand them and interpret the often highly individualised ways they express themselves, this was also an imperative that could not be restated too often. The values framework of the ADVANCE framework was seen as a useful reminder of this:

Often [people with] learning disability are a forgotten group, others speak on their behalf, others make decisions on their behalf, and it puts the

young person here with the learning disability in the centre. So that's the starting point, which this document looks like maybe what is good practice.

Participants often spoke of person-centred care but also felt that it was entirely possible for the person to be at the centre of the process and yet still not be listened to. If they are unable to express themselves there is still the risk that they will be ignored, the silent centre of the maelstrom of care-givers, family members, equipment and medical staff surrounding them, attending to their care and yet forgetting about their needs as a person.

A key tool in finding ways to put the young person at the centre of the process was finding the communication tools and techniques that might suit them. This was a topic participants felt both the workshop and the toolkit would do well to cover in more depth.

Moving forward, if you develop it, it's about what communication aids people might use with learning disability. Because actually whilst it was mentioned here that people may be very proficient in Makaton and then working with some support worker that knows only one or two signs, but actually also doing the homework with the young person, knowing what's available … eye gaze is becoming a particularly useful communication tool with quite a lot of our young hospice people. So it is what mechanisms of communication are out there.

Given that the short film shown during the workshop was well received, participants also suggested that a further film might be useful demonstrating the specific and subtle ways different people with learning disabilities might find to communicate:

[….] showing different ways people communicate, cos my experience with medical people sometimes is that they don't all … have not come across a lot of learning disability issues, might not recognise or understand some of the ways people communicate, the small nuances and things. So I think to see it about 'Did you see that eye gaze meant this?' or 'This means that they're in pain'. And so some of the examples about what (inaudible) … and again it's person-centred, so everyone's different how they communicate, but I think once you get beyond Makaton or using the talker, people struggle who are not doing it all the time.

Similarly, the topic of how to use verbal language appropriately was seen as something that might be incorporated into future workshops. This was something that featured strongly in workplace training delivered by one participant as part of her job, particularly when it came to talking about death itself and the language people use when they have no choice confront their mortality or that of a loved one:

On the training that I deliver on end of life in my service, it's one of the activities around the different words, things we associate with death, and it always comes up … some people say something we've never heard

before and it means something to them culturally or in their family, and how it doesn't make sense to everybody.

[…] sometimes people try and soften it by using different language. That's misunderstood by the person and causes more upset (inaudible) confusion. Yeah 'gone to sleep' that's the one that … 'gone to sleep' … I spoke to someone who was terrified to go to sleep because their mum had gone to sleep, so they thought when they go to sleep they would die.

The tendency to use comfortable euphemisms when talking about death was also a key example of one of the main difficulties participants found in conversations about planning for end of life care, namely the need to clarify what the young person and their family understand by different terms. Participants, who generally preferred amongst themselves to speak plainly of dying rather than talk about "passing away", "passing over" or "passing on", felt it was part of their role to be sensitive to the language the individual and their family preferred, use it where appropriate but also be careful to check they weren't creating more confusion by doing so.

This created difficulty both in establishing the extent to which they understand, and indeed are capable of understanding, their prognosis and in clearly ascertaining their end of life care wishes and needs:

That's one of the real challenges to get the training going forward right from this document that you do have clarity of what you're talking about, because you're dealing with young people and young people who have got a learning disability, you've got to find out what their level is.

Often a key factor both in ascertaining the degree to which a person is capable of understanding their prognosis and making informed decisions about their future care, as well as being able to communicate such decisions, was finding sensitive and appropriate ways to involved their family members in the process. The next section will look at the roles family members can play both in helping to communicate with the young person and taking part in decisions about their End of Life care.

"You've got to take the family with you"

In this area and others participants were eager to emphasise that a key part of being able to communicate with young people with learning disabilities about end of life care planning is communicating with their families. This adds an extra layer of complexity and sensitivity in an already highly difficult and emotive process. After all, it is not simply a matter of communicating clearly with the family whilst keeping the young person at the centre of the process, working with families also requires a great deal of relationship building, winning their trust and being mindful of both their own emotional and practical needs and how these needs impact on the young person they are caring for.

Working with parents, that's a big piece of work, not ignoring them. Yes we obviously are centred on the young person, same as we are with any dying person, but you've got to take the family with you.

The phrase "take the family with you" is telling. Elsewhere the participants describe the end of life care process as a journey, here they extend this analogy to suggest that it is a journey taken together with not just the care-giving team and the person, but all the people who are important in their lives as well.

This appears to be a complex and problematic process, something one learns to navigate by experience and intuition but can nonetheless be prepared for by training. An easy pitfall to be aware of, for example, is to pay too much attention to the family because it is easier to communicate with them, and risk giving them the impression that you're ignoring the young person with learning disabilities. Conversely, if the young person doesn't like or trust the professional care-giver the family are likely to pick up on this even if the care-giver doesn't, which can create problems for their relationship going forward.

Talking to parents and other family members about the death of the young person presents a whole new array of challenges, indeed participants suggested that in some cases it was more difficult than raising the subject with the young person themselves. Moreover, there was never any way to predict how a parent would respond when the subject was broached.

> *They've been protecting them for the last 18 years and their role is as a protective parent … therefore they're reluctant and don't know how to have some of these conversations.*

> *It sometimes blows parents' minds when they say 'Do you know what Jimmy said to me yesterday?' Because that's not a conversation they would ever have had, but they're relieved that someone else has … you will always get the angry parent 'What are you doing talking to my child about sex and about death?' But by and large if it's not threatening most are very pleased, and their realisation that actually their son or daughter is also an adult and has their own thinking and their own processes. And watching the relationship between the parent and the young person is fascinating, and that's probably some of the most rewarding work, and actually the parents normally are always very thankful.*

The only consistency in these conversations appears to be that a parent is likely to have to live with the memory of the moment care-giver told them they needed to plan for their son or daughter's death. No wonder then that participants put just as much stock in needing training and practice to prepare them for this conversations and they did for talking to the young person themselves.

End of life care beyond the end of life

Just as respecting the wishes laid out in an end of life care plan doesn't necessarily end when the person dies, looking after their family can likewise be a continuing concern as they go through their own process of grieving. Helping the dying person to

find ways to help their loved ones after their death was another key aspect of care planning participants felt should be included in the workshop or toolkit.

> *If you ask most people what's their main concern around their own death, it's how my family will cope, and that's the key bit.*

> *It's not just about around death and dying but if you're talking about funerals, oh what do you want to do? What do you want to happen after you die? People have got to understand the language about cremation or … if you don't understand what burial is … so I think there's something around the language around … the whole thing around death.*

> *For us as professionals we …although it's really sad and it's awful when this happens – it doesn't usually stay with us forever, but the family members, if it's not done correctly, it does.*

The final extract is a poignant reminder that whilst the person dies and the care-givers must move on to other cases and other sick young people who need their help, the family are the ones who have to live with the loss.

This was another topic participants felt warranted inclusion in the ADVANCE toolkit and potentially also discussion in the workshop.

> *I think there's something about the support after the person … not passed, but if a person's died. So you know whether it be family or it's the staff, that kind of … not necessarily loads of stuff, but just some of the resources to point on that kind of bereavement stuff.*

So important was the role of families for participants that one suggested end of life Communication Workshops might include family members who could give health practitioners guidance on how best to conduct such conversations based on their own experience. For workshops that do not involve other family members, they suggested an additional film clip in which a parent of a young person with a learning disability spoke directly to the camera to raise points for discussion. Again, the emphasis was on the power of grounding the idea being discussed in real-life cases.

> *And doing a video of a parent talking to you. I mean we … obviously in the hospice we have a number of parents who have agreed to be videoed who talk about their experience of end of life care for their son or daughter. And I think whilst everyone's experience will be different, you know one or two of those examples could be quite stark where those parents are eloquent and able to tell you both the good and the bad.*

> *have workshops with family members because we could think this is everything that a family want, but their take on things or their experiences … so as professionals we all say 'Oh this is happening, it's wonderful, but we've looked at the video and we think yeah that was a good example'. But the family might have said something different about what had happened or have different things that are important that we forget….*

having feedback from family members, people with learning disabilities. I like it when I read stuff like this when it's got some quotes from those groups as well, makes it real.

The need to find such ways to engage and bring together health and social care practitioners and the benefits of doing under the umbrella of an overarching framework of values was the topic of the second overarching theme to be discussed in the next section.

Connecting Care, connecting values

Bringing care-givers together and coordinating care

Participants appreciated that the workshops provided a forum for bringing together health and social care professionals whose fields overlap but who rarely get a chance to speak. One described how useful it was that their workshop included a paediatric consultant who provided a new, and yet reassuringly resonant, perspective on familiar problems.

It's quite a good example today – we were blessed with a medical person, which is very rare, and at consultant level, and that person said he'd had almost no training around end of life care…. So actually this hierarchy of people thinking the doctors know everything, actually they need support. You know he came because he wanted to have the information, and as he honestly said 'I've had no training on this'.

Really the thing for me was hearing the medical view of it. And it was reassuring some of those concerns that they had … cos sometimes we work in isolation. …. I think one of the things I wrote down to take away, and from the training that we deliver, is to kind of ask whether managers and senior support staff could be speaking to the doctors and doing those conversations together. Whereas often they might happen without them being present, or they might be passive in their … and it just strengthens to me the importance of collaboration and the benefits of why that's so important.

This sort of collaboration was felt to be even more important when delivering end of life care for people with multiple complex health needs, which typically requires the seamless coordination of several different health organisations to be done well. To this end one participant argued that the workshops might be improved by involving an even wider range of practitioners.

In terms of the spread of the people here, generally everyone was more medical or service led rather than hands-on people. And so I think there's something about support workers learning about the issues that medical people have, and the hands tying like we talked about, but also medical people hearing from support staff and the day to day people who know the people they're supporting very well, and learning about the

challenges they have and the perceived barriers that the support worker feels when they're going to meet a health practitioner, because often it's very scary and they feel that they can't challenge [them]…. so I think it would be useful to have a bit of a broader range of people.

The opportunity the workshop provided, then, was seen to be a boon, both from the perspective of facilitating a conversation and helping people make connections more broadly that could ultimately benefit the care they can provide.

At the same time the eclectic mix of health and social care providers also created a challenge in finding ways to make the workshop content relevant and useful to all groups:

I can see it being useful for people in an environment where they're not coming across learning disabilities all the time. But also … like we talked about in the session, people who support people with learning disabilities, but end of life isn't their usual arena as well, so I can see there might be both those needs, I thought it was good.

Simply getting as many of the different types of practitioners required to deliver good End of Life care together in a coordinated way, then, was seen as highly beneficial. What was seen as an even greater benefit was giving those practitioners an overarching framework of values which they could all relate to, felt was relevant t their work and could help them deliver such care consistently. This will be the subject of the next section.

Unifying Values

At the same time participants felt that having an overarching framework of values to draw on helped make the toolkit and workshop relevant and accessible to everyone attending, no matter what their background or level of seniority. Discussing this led them to suggest that the same principle made the Advance approach relevant to anyone planning for end of life care. Be they young people or adults with learning disabilities or without, everyone was due the same standards of care and the same ethical values.

I wouldn't separate young people and adults in this. I think the young people is a subsection of adults with learning disabilities and I don't think there's anything in it that wouldn't meet the general adult population as well. And so sometimes we make different pigeonholes when actually one thing … and because it's so individual centred I think it could be used in all those.

I think that's important because you get more silo working. And having crossed the arena of young people and adults, we know as more financial pressure comes on services people are put into boxes and silo worked, whereas if you have a universal document for a universal population you are going to have more successes.

The first of these extracts suggests that just as the ADVANCE framework suggests that avoiding making assumptions about people with learning disabilities is vital to understanding their abilities, the same can be true of other members of the health care profession you may not have had the opportunity to communicate with.

This again also brushes up against the recurring motif of the tendency of health and social care services to be compartmentalised, where a need for specialisation creates a danger of working in silos that do not communicate with each other, cannot coordinate care delivery and risk delivering inconsistent care based on inconsistent values.

> *Why don't you just all just work together, stop duplication, you know there's a lot of investment in people's jobs having the silos, but universally it's a bit like the end of life care plans, they're all very different, so if you did one in Leeds the way it looks, the way feels, the questions, are all very different. And when I asked Professor [name], who is the guru on end of life care why isn't there one document, because that's what there should be, and she says the Care Act or the Children's Act mean that people can interpret it as they want locally….And that to me is a bi-product of bad practice.*

The impact of a fragmented service provision was felt to be especially problematic when it came to young people with learning disabilities making the transition to adulthood, and the inconsistency in carers, resources and infrastructures that often results:

> *Transition is the key. My concern would be that an adult might think this didn't apply and not use … you know look at this and actually as you say in that transition period it's often the most dangerous position for a young person about which services they're actually getting, and that consistency.*

> *A real issue in transition that people fall through the net and people aren't accountable because it was someone else's job, it was someone else's paperwork. If this is to be a success going across children's … well going across all people with learning disability. It's not age focussed – that will make it a success.*

The key to this success was seen to lie in good communication, team-working and consistency of values, as well as the ability to coordinate a provision of care so that the person in question saw the same familiar, trusted faces and didn't lose touch with carers who had come to know them and know best how to communicate with them. This was another respect in which the tendency towards compartmentalising care was seen to create problems, setting up an artificial dichotomy between the needs of a young person with learning disabilities and the needs of the same person as an adult, a distinction that is even more difficult to apply to someone with learning disabilities who may mature at a different rate to other individuals.

And they cross over anyway though because the Mental Capacity Act applies from 16. So there is that crossover anyway in law, and so realistically there's not really a point where someone's no longer an adult … they're a child and they're an adult, it's a kind of a journey.

While the values were seen to be universal, just as crucial was how these principles could be applied in different contexts. In particular, it often required specific types of skill, experience and ethical sensitivity to deliver them to children and those with learning disabilities who could not necessarily speak for themselves. These challenges were felt to be common to both children and adults with learning disabilities and included both practical the difficulties and the danger of undignified infantalisation.

I think the issues are similar aren't they, because children are often assumed to not be able to have the choice and have capacity, and (inaudible 7:48) clear that we want family involvement but the chid has a say, which is the same as for an adult with learning disabilities are often perceived to be like a child when they're an adult. And so I think the same issues apply to both groups.

The strength of the 2-stage ADVANCE programme in this respect was that the Toolkit provides a framework of values, setting the ethical agenda whilst also providing tangible, real-world examples of how these principles might be applied. Whereas the workshop that followed is then flexible and interactive enough to focus on the specific skills of communicating with different young people with learning disabilities and their families.

Participants felt the toolkit could be improved further by incorporating real life examples and quotes from people with learning disabilities and their families to illustrate each of the values underlying the advance framework.

But I still think this is a really good toolkit, however if it's going to make a difference and do what it says it's got to have the information and the voice of the people it relates to … then that gives it its credibility I think.

The potential to present broad ethical principles and then ground them in a concrete reality practitioners can instantly relate to their own working experience was something participants thought could be highly valuable if made available on a wider basis.

The benefits of a values-based approach in making an End of Life care plan that could be applied consistency in any end of life care context were also seen in helping to provide continuity and consistency wherever the individual went:

Which is why I think this is good, the values-based approach, because I imagine it's not, when it's finished completely, won't have specific paperwork because you can go … someone could be at school in Leeds and then go and live in York with their parents and go somewhere else, so that paperwork might not look the same, but the values and the underpinning approaches shouldn't make any difference to what the

paperwork looks like, but the process should be done the same way in terms of person centred.

When it's launched as a national document the people that you should be dealing with should be GPs, community workers, support workers, supported people in homes - all of those sort of people … cos that's where you'll get the change.

Although most participants seemed already versed in the values surrounding health care, they also found it useful to have the framework as a reminder of those values, putting their application into context and reminding them what was important. Equally it was useful to be made aware of and reflective about one's own values and assumptions to see if there are ways you could be delivering better care you are simply not aware of due to being focused on other aspects of the problem at hand.

[,,,] nothing stark and really new, but a reinforcement of what good practice should be, a reinforcement of the time it takes with people with learning disability, the awareness of your language, self-awareness of your own assumptions that you bring about your own attitudes around end of life are very useful always. You don't always have to learn something new, though you tend to always get something. But it's more about you know just touching base, what "good" looks like – am I still doing it well, that reflection of what's my practice like, could I improve, am I doing it right?

On the whole, participants seemed to feel that it was useful if such training workshops could teach them something they didn't know and how to use a new communication tool for example. Sometimes it was just as important to provide an opportunity for them to discuss and reflect on the care they deliver with other practitioners they might not normally get to speak to in relation to a framework of values they could all relate too.

Simply allowing these disparate practitioners to realise they shared the same beliefs, priorities and frustrations about End of Life care was a worthwhile goal. What was even more useful was the opportunity to formalise those beliefs as a framework of values they could take away and apply consistently whenever they are called upon to discuss End of Life care planning with young people and their families.

6. DISCUSSION

The project aimed to 'implement and evaluate a train the trainers' education programme to increase the knowledge and skills of staff in communicating effectively & ethically with young people with learning disabilities and their families regarding End of Life Care Planning'. Within the project time constraints (6 months), we developed and implemented a Values-Based Toolkit and a communication skills training workshop format. We recruited practitioners from across learning disabilities and end of life care services. Findings suggest that they benefitted from sharing experience and expertise in the workshops and from applying a unifying values framework. Regarding the more specific research questions we addressed, we comment on each below:

- What refinements are necessary to the exisiting ACP modue - End of Life Care for All e-ELCA course – so it is fit for purpose?

The existing e-ELCA course has much of value, however, it was not developed specifically for young people with learning disabilities at the end of life. Feedback from the project Advisory Group, from parents, from practitioners and from workshop participants contributed to the development of the ADVANCE Toolkit and to the workshop resources.

- What knowledge and skills do staff have relating to End of Life Care Planning for young people with learning disabilities before the intervention?

Those who attended the workshops were generally practitioners with substantial experience and experience in one rather than both specialties (either learning disabilities or end of life care). There was generally consensus that the values and skills promoted in the project intervention were applicable across end of life care generally. A particular area of challenge and opportunity related to the negotiation of the wishes of the child (person-centred care) and the wishes of the family (family-centred care).

- What knowledge and skills do staff have relating to End of Life Care Planning for people with learning disabilities after the intervention?

Practitioners has previous knowledge and skills to respond to such situations but it seemed that there was much to be gained by rehearsing and reflecting on scenarios in a safe context. It seems likely that sharing across specialities raised awareness of opportunities for improved care for young people transitioning from child to adult services.

- What next steps are required to ensure that good practice relating to End of Life Care Planning is sustained in care services for people with learning disabilities?

The format of the intervention with pre-workshop reading (Toolkit) and attendance at the Communication Workshop seemed to work well. However, we found that not all who attended had taken the opportunity to read the material and it was of value to go

through the Toolkit at the beginning of each workshop session. The input on communication generally, the video resource and sharing of anonymised scenarios with role play and reflection appeared to be a good model to replicate (see recommendations below).

The study identified that the values-based approach to End of Life Care Planning (EoLCP) provided a framework that practitioners felt was useful to them.   The Toolkit also enabled a focus on values that were linked to the Communication Workshop such as avoiding assumptions by sensitive questioning of end of life care wishes with both the individual and the family. The Appreciative Inquiry underpinning of the project proved to be in keeping with the ethos of the Toolkit and Communication Workshops. Participants were comfortable discussing 'what worked?' and committed to learning from the intervention and each other.

The Toolkit and the Communication Workshops enabled people from different health and social care professions to explore from their perspective the different issues they face in having conversations about end of life care. It was acknowledged that many of the values in end of life care planning are shared across all individuals and caregivers at the end of life whether someone has a learning disability or not. However, it was recognised that making reasonable adjustments for those with learning disabilities is a legal duty under the Equality Act 2010. Therefore, helping those to understand what is happening to them and managing issues of consent were identified as critical to quality of care at the end of life but also a legal duty.

Another issue that was raised was the importance of a written care plan that is shared across services. This was identified as extremely important when a young person was transitioning from child to adult services. Documentation already exists such as the hospital passport and 'my information plan' this would include personalised information about feelings, beliefs, support etc. to improving their practice.

The role of the learning disabilities nurse in relation to advocacy especially when acute health services are involved in care at the end of life was identified in a video clip which was used during the workshop of a practitioner in learning disabilities talking about her end of life care practice. One of the key aspects confirmed by the project is the importance of enabling young people with a learning disability to take part in shared decision-making around their wishes - according to their capacity -to be involved in decision-making and to have their wishes explored sensitively by care-givers. Close family members are key to care at the end of life as they are often the people who are giving care in the home and their needs also should be explored in a family-centred approach using similar skills and avoiding assumptions by asking family members about their coping and support needs.

7. CONCLUSIONS & RECOMMENDATIONS

Overall, the development of a Values-Based Toolkit and Communication Workshop format (with video resource) appeared to work well. The benefits of bringing together practitioners from learning disabilities <u>and</u> end of life services was a key project finding.

However, the project was small scale and over a short timescale. To evaluate the intervention as a 'train the trainers' model would require more time and follow-up of those who participated in the initial workshops.

We have three areas of **Recommendation:**

- Health Education England working across Kent, Surrey and Sussex (Intellectual Disabilities Programme) – to make the Toolkit and Communication Workshop format with video available to all via the website. This would including offering the resources to universities and care services in Kent, Surrey and Sussex for use in pre-registration and continuing education provision;

- HEKSS to encourage ongoing evaluation of the project to continue by inviting those who utilise the Toolkit and Communication Workshop format with their teams to complete the evaluation forms and return to the research team at the University of Surrey (send to nursing-ethics@surrey.ac.uk with a subject heading of 'ADVANCE Toolkit'; and

- HEE to consider commissioning research that engages directly with young people with learning disabilities and their families regarding end of life care planning. This project suggests that their voices are too rarely heard in relation to this topic area.

8. ACKNOWLEDGEMENTS

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10. APPENDICES

Appendix 1: Participant Information Sheet

UNIVERSITY OF SURREY

End of Life Care Planning for Professional Care-givers of Young People with Learning Disabilities
Information Sheet for Participants (v2, 16/05/17)

Introduction

You are being invited to take part in a research study evaluating an open learning package and Communication Workshop for professional care-givers about advance end of life care planning for children and young people with intellectual disabilities. Before you decide whether to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything that is not clear, or if you would like more information please get in touch with the research team (contact details at the end of this information sheet).

What is the purpose of the study?

The purpose is to implement and evaluate an education programme designed to help professional care-givers to develop their skills and confidence in communicating effectively and ethically with children and young people with intellectual disabilities and their families regarding end of life advance care planning.

Why have I been invited to take part in the study?

You have been invited to participate in this study because you are a professional care-giver involved in providing care for children or young people with intellectual disabilities. Providing you with the opportunity to take part in this education programmes and then assessing its effectiveness will be extremely helpful in assessing how useful such education programmes may be to others in the future.

Do I have to take part?

No, you do not have to participate. It is completely up to you whether you do so or not. There will be no adverse consequences in terms of your employment if you decide not to participate. If you do decide to participate and then later change your mind, you are free to do so. You can withdraw at any time without giving a reason.

After the data collection is complete you can request your data be withdrawn at any time before the publication of the study report (15th September 2017), in which case all data associated with you would be removed from all reports and analysis. Similarly any researcher's notes relating to you would be withdrawn and all transcriptions and recordings locked away, unaccessed, for the required period before being destroyed. In the case of focus groups, it may not be possible to recognise and delete your contribution. However, be assured that other data will be deleted and all contributions anonymised.

What will my involvement require?

You will be asked to first complete an open learning package about advance care planning for children and young people with intellectual disabilities lasting approximately 2 hours and then participate in a communications training workshop lasting approximately two hours.

The training will take place at sites in four geographical areas (London, Kent, Surrey and Sussex). You will be invited to the venue most convenient for you so you will not have to travel far or incur any significant travel costs.

You will be asked to complete a questionnaire concerning your knowledge and opinions before and after the education programme to gauge how effective it was. Several weeks later you may be invited to a facilitated focus group discussion with other health and professional care-givers who have also taken part in the education programme, exploring how the experience has informed your practice. Attendance at the focus group will be entirely voluntary and not a condition of receiving the education programme. These discussions will be audio recorded and all data collected will be anonymised; no-one will be able to recognise you when the findings are analysed and reported.

What will I have to do?

If you would like to take part please sign the attached consent form and return it via email or post to the researchers.

What are the possible disadvantages or risks of taking part?

We foresee no disadvantages or risks to taking part. However, if as a result of the education programme, issues are raised which you wish to discuss further, the researchers would offer immediate support by suggesting additional resources that may be helpful, for example, counselling support.

What are the possible benefits of taking part?

It is hoped that taking part in the learning programme will help to enhance your skills, knowledge and confidence in communicating with children and young people who have intellectual disabilities and their families about advance care planning. It is also hoped that the study will lead to the development of better education programmes to ensure that good practice is sustained in care services for children and young people with intellectual disabilities.

What happens when the research study stops?

It is hoped that not only will the education programme be useful to you whenever you deal with advance care planning in the future, but that you will be able to share something of what you have learned with colleagues who may face similar challenges.

What if there is a problem?

If you wish to make a complaint or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact Professor Melanie Coward, Head of School, Faculty of Health & Medical Sciences, University of Surrey, Duke of Kent Building, Stag Hill Campus, Guildford, Surrey, GU2 7TE. Telephone: 01483 682507. Email: m.coward@surrey.ac.uk.

Will my taking part in the study be kept confidential?

Yes. Although of necessity your employer will need to know that you are taking part in the study because they will need to have released you from your regular duties to take part in the education programme as part of your continuing professional development, they will not have access to any of the raw recorded data. Managers will have the opportunity to receive a copy of the report in which participants and organisations are fully anonymised if they would like one.

All the information which you give as part of this study will be kept strictly confidential in accordance with the Data Protection Act 1998 and in line with the University of Surrey's regulations on data management. All data will be stored securely within the Faculty of Health and Medical Sciences at the University of Surrey; access to data will be restricted to members of the project team at the University of Surrey. Nobody external to the university will have access to the recordings or transcripts of your data even if they are involved in the project in another capacity. Any information recorded about you will have your name removed and you will be allocated a 'participant number'. Data collected for this project will not be used in any other project. You will not be identified in any report or publication that arises from this study. Should it be disclosed however that you or someone else is at risk of harm this may have to be reported to an appropriate authority.

Contact details

For further information, please contact: Prof Ann Gallagher, Professor of Ethics and Care, University of Surrey, Faculty of Health & Medical Sciences, Duke of Kent Building, Stag Hill Campus, Guildford, Surrey, GU2 7TE. Telephone: 01483 689462. Email: a.gallagher@surrey.ac.uk.

Who is funding the research?

This study is funded by Health Education England.

Who has reviewed the project?

The study has been reviewed and received a Favourable Ethical Opinion from the University of Surrey Ethics Committee.

Thank you for taking the time to read this Information Sheet

End of Life Care Planning for Professional Care-givers of Young People with Learning Disabilities
Consent Form for Participants (v3, 30/05/17)

Principal Investigator: Prof Ann Gallagher, Professor of Ethics and Care, University of Surrey, Faculty of Health & Medical Sciences, Duke of Kent Building, Stag Hill Campus, Guildford, Surrey, GU2 7TE   Tel: 01483 689462   Email: a.gallagher@surrey.ac.uk

- I the undersigned voluntarily agree to take part in the evaluation of an open learning package and communication training workshop for care professionals about advance end of life care planning for children and young people with intellectual disabilities.

  ☐

- I have read and understood the Information Sheet [V2 16th May 2017]. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

  ☐

  ☐

- I agree to complete questionnaires before and after the education programme.

- I understand that I may be invited to take part in a group discussion by a researcher on the project; I understand that that my participation in this discussion is voluntary and not a condition of receiving the education programme. However, if do take part in the discussion, I agree to being digitally audio recorded.

  ☐

- I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators.   I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being.

  ☐

- I consent to my personal data, as outlined in the accompanying information sheet, being used for this study. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

  ☐

  ☐

- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. I understand that if I request my data be withdrawn before 15th September 2017 all data associated with me will be removed from all reports and analysis. Similarly any researcher's notes relating to me will be withdrawn and all transcriptions and recordings locked away, unaccessed, for the required period before being destroyed.

- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS) ....

Signed   ....

Date   ....

If you would like to be kept appraised of the results of the study please tick here (optional)

Appendix 3: Education Programme Evaluation Form

End of Life Care Planning for Professional Care-givers of Young People with Learning Disabilities

EDUCATION PROGRAMME EVALUATION FORM

Please answer the following questions to tell us how useful and effective the education programme was for you.   All responses are fully confidential.

Name:

Practice Role:

1.   What do you understand by "end of life care planning"?

2.   Do you think end of life care planning is important? If so, why?

3.   What key ethical issues might arise in end of life care planning in end of life care for children and young people with intellectual disabilities?

4.   What are the key principles underpinning end of life care planning for end of life care for children and young people with intellectual disabilities?

5.   What experience have you had of taking part in end of life care planning?

6.   How confident do you feel about discussing end of life care planning with patients and families generally?

Not at all confident		Somewhat confident		Very confident
1	2	3	4	5
☐	☐	☐	☐	☐

7.   How confident do you feel about discussing advance care planning with parents and families of children and young people with Intellectual Disabilities specifically?

Not at all confident		Somewhat confident		Very confident
1	2	3	4	5
☐	☐	☐	☐	☐

8.   How do you rate your communication skills in relation to advance care planning?

Very good		Adequate		Very poor
1	2	3	4	5
☐	☐	☐	☐	☐

9.   What would help you continue to deliver good practice in end of life care planning in your area of practice?

10.   Would you like to make any additional comments?

Principal Investigator: Professor Ann Gallagher, email: a.gallagher@surrey.ac.uk
Research Fellow: Dr Matthew Peacock, email: m.peacock@surrey.ac.uk

Thank you for completing this evaluation form!

End of Life Care Planning for Professional Care-givers of Young People with Learning Disabilities

Focus/small Group Topic Guide

Check understanding of project (has participant read PIS – any questions?) and consent process (understood what is required and signed consent form?):

- Welcome and introductions – Who are you? Where do you work and what is your role?

- Group views of open learning module – What was good about it? What was not so good? How might it have been improved?

- Group views of the Communication Workshops – What was good about it? What was not so good? How might it have been improved?

- Understanding of end of life care planning - What did you learn, if anything, about end of life care planning?

- How has taking part in the education programme affected your confidence in holding conversations about end of life care planning with young people and their families.

- How, if at all, has your understanding of the ethical aspects of communicating with young people with learning disabilities and their families changed during the project?

- Has your ability to recognise ethical issues when dealing with young people with learning disabilities changed?

- Changes in your practice – what changes, if any, have you introduced in your work as a result of taking part in the project? Have you shared any of your learnings with other colleagues?

- Future support - What would help you in the future to promote ethical care in your work?

- Any other thoughts about the project?

Appendix 5: Summary of Advisory Group meeting

Developing Knowledge and Skills to Communicate Effectively & Ethically with People with Learning Disabilities and their Families regarding EoL Advance Care Planning

Advisory Group meeting 1 – 5/5/17

Attendees

Research team – Ann Gallagher (PI); Anne Arber & Matthew Peacock,

Advisory Group Members - Jim Blair (by phone); Phil Boulter (in person); Lizzie Chambers (by Skype); Craig Gannon (in person); George Matuska & Rhona Westrip (via Skype).

Summary of meeting discussion

Project summary

GM and RW provided background to the commissioning of this project. The work builds on previous Health Education England (Kent, Surrey & Sussex) scoping work relating to intellectual disabilities and end of life care. End of life care during a time of transition – aged 14 to 18 – for people with intellectual disabilities is of particular interest as it has received little previous attention. The focus of the project is on developing the knowledge and skills of the workforce in relation to advance care planning for people with intellectual disabilities and their families

AG provided an **overview of the project** from the initial proposal as follows:

The *research aim* is to implement and evaluate a 'train the trainers' programme to increase the knowledge and skills of staff to communicate effectively & ethically with people with intellectual disabilities and their families regarding (EoL) Advance Care Planning.

The **research questions** which will be addressed include:

- What learning resource will promote knowledge relating to Advance Care Planning for young people with intellectual disabilities and life-limiting illness?
- What knowledge and skills do staff have relating to Advance Care Planning for people with intellectual disabilities before the intervention?
- What knowledge and skills do staff have relating to Advance Care Planning for people with intellectual disabilities after the intervention?
- What next steps are required to ensure that good practice relating to Advance Care Planning is sustained in care services for people with intellectual disabilities?

The project design is underpinned by Appreciative Inquiry (AI), an approach that can be used within organisations to identify best practice and to bring about change. It

requires a move from a problem-orientation to an appreciative stance. The project team has selected an appreciative inquiry approach because it:

- • does not focus on problems and problem-solving but rather on what works well and on how things could be even better;
- • has excellent potential to develop trust and meaningful collaboration with staff in pre- and post-natal practice rather than identifying failings and blame; and
- • contributes to the development of an appreciative learning culture where the project team works collaboratively with the staff in the healthcare settings.

Project Design: A 6-month (1st April to 30th September 2017), 2 stage train the trainers project with evaluation before and after the educational intervention.

Stage 1 – Development of knowledge re 'advance care planning' – participants to complete **an open learning resource/toolkit** relating to Advance Care Planning for people with intellectual disabilities and their families.

Stage 2 – Development of a face to face communication skills workshop format – we propose approximately 10 two hour sessions with an expert Communication Workshop facilitator adapting a tried and tested model (for MacMillan) which will focus on communication relating to advance care planning for people with intellectual disabilities and their families. We aim to train up to 100 care-givers.

Regarding evaluation of the interventions – this would be twofold: an evaluation format before and after the knowledge intervention (attached) and qualitative focus groups to follow the workshops with a questionnaire developed for trainers to capture the knowledge of their team.

Research sites and recruitment of participants

We agreed that the training workshops would take places in Kent (to be agreed), Surrey (University of Surrey) and Sussex (to be agreed) with one workshop in London (Great Ormond Street Hospital). We would invite workshop participants via Advisory Group members' practice colleagues and connections.

Contents of the Open Learning Resource

- • There was much constructive discussion relating to the draft open learning resource including:

- • We need more clarity about **the scope of the project** - (i) **Who does it relate to?** E.g. people with capacity? People who lack capacity? – In the first instance, we will be developing a resource for formal care-givers of young with life-limiting conditions who have intellectual disabilities with <u>some</u> capacity (ii)

Who are we planning to train? E.g. family members? Formal care-givers? – In the first instance, we will focus on formal care-givers in a range of settings.

- **Definition of Advance Care Planning** - we need to have a clearer definition /explanation as to what this involves – is it planning relating to what interventions are declined? Or what contributions to a good death – We agreed we would see the views of families on this.

- **Principles underpinning Advance Care Planning** - it was agreed that this would be the focus of the open learning resource/toolkit – again this would be developed following a meeting with families who have experience of end of life care.

- We need to revisit the activities in the light of the responses to the issues above and drawing on the resources suggested by the Advisory Group on how to work with the health/social care 'system' i.e. where to go for help on specific matters? and what resources are available?

- We also to focus on how to make the ongoing process of advance care planning accessible and inituitive for families.

Content of Communications Workshop

This will be developed following completion of the open learning resource/toolkit.

Next Steps/Action Points

1. **Advisory Group members –** Please send relevant resources/links relating to Advance Care Planning and young people with intellectual/learning disabilities to Matthew (m.peacock@surrey.ac.uk). Thank you.

2. **AG & MP –** To develop pre- and post-questionnaire to send to the University Ethics Committee with the project proposal (see attached).

3. **AG –** To arrange suitable time and date to come to Great Ormond Street Hospital to meet with families/parents – in consultation with JB and Yvonne Newbold.

4. **AG & MP –** To develop the Open Learning Resource/Toolkit and circulate to the Advisory Group and Parents'/Family Group for comment. This includes identifying key underpinning principles for Advance Care Planning.

5. **MP –** To engage with Advisory Group to recruit participants and arrange training sites. We aim to run workshops in Kent, Surrey, Sussex and London. Community nurses. Participants to include: Liason Nurses; Special Schools staff; Volunteers; and Hospice staff.

6. **AA –** To develop the communication skills training workshop format in collaboration with AG & MP.

Next Advisory Group meeting to be scheduled for late August