

Note: Transcript is pending review and revisions by The Maintainers. Please contact us if you have any comments or questions.

Social Care August 6, 2020 Essential Worker Series

Andy: We can get started okay? So good afternoon or good evening everyone. Good morning to some of you and welcome to our discussion. My name is Andy Russell. I am one of the three co-directors of The Maintainers and I'm also the Dean of the College of Arts and Sciences at Sydney Polytechnic Institute. Our subject today is social care maintaining each other. This session will focus on social care and what maintainers can learn from more formal care relationships. We will explore various dimensions of social care such as paid and unpaid assistance for children, adults and the elderly. We'll explore how these relationships are valued and measured or if they can be measured at all and if the language and structures we use for this essential activity are useful or if they're obstructive. With so much maintenance activity falling outside market based interactions how can we classify this essential human experience of caregiving and being cared for. Our discussion today is organized by two groups. The group I'm representing is The Maintainers and we're a global research network interested in the concepts of maintenance, infrastructure, repair and the myriad forms of labor and expertise that sustain our human built world. I'm a co-director of The Maintainers along with Lee Vinsel and Jessica Meyerson. Now I'll turn it over to Naomi Turner from our friends from The Festival of Maintenance.

Naomi: Hi everyone. Thanks very much for that great intro Andy. So the Festival of Maintenance is a UK based event. We've run a couple of big festivals now over the past couple of years and our aim is really to celebrate those who maintain different parts of our world and think about how they do it so for us this really means active recognition of the often hidden work done in repair custodianship, stewardship, tending and caring for the things that matter. We're really excited to be collaborating with the maintainers in the states especially because right now the geography has no meaning and think about really what these debates mean obviously in the present moment in this pandemic and in this recovery.

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Andy: So just a few words on housekeeping before we get started. Housekeeping is a funny metaphor in its context. If you have any questions during the presentation please type them into the chat box in your zoom control panel. We'll bring them up during the presentation and we will also have time for questions at the end. Also, if you're not a guest speaker we ask that you mute yourself and turn off your webcam to preserve the quality of the recording. And now I will introduce the speakers. We have three today we're very fortunate. Our first is Stephanie Hoopes who is the National Director of United for ALICE an innovation centered around Asset Limited, Income Constrained, Employee, ALICE households working with United Ways across the country to inform policy and promote positive change. Their URL is UnitedForALICE.org. Dr. Hoopes' research has garnered both state and national media attention. She has a Ph.D. from the London school of Economics, a master's degree from the University of North Carolina, Chapel Hill and a Bachelor's Degree from Wellesley College. In her home town of Wilmington, Delaware she serves on the board of Woodlawn Trustees, the Delaware Art Museum and the Kennett Pike Association. Jamie Helm will be our second speaker. Jamie is a disabled poet, essayist and researcher and journalist in health and social care policy as well as chair of (inaudible) People's Commission carrying out research into the position of disabled people in the burrow. As someone who manages their own care package they've learned to become an expert in everything from employment law to HR and advice. They're passionate about funding social care based on self-determined outcomes rather than budgetary constraints. Our third speaker is Lydia Nichols. Lydia is an anthropologist whose research and writing centers on healthcare data, culture in the places where these issues intercept. She uses creative participatory methods to develop visions of better care futures and support policy change to bring those about. She was a senior researcher at NESTA, program manager at Doteveryone, and now consults for organizations including Health Foundation and Open Society Foundation. When not in foresight in policy she also performs standup comedy in podcasts exploring the stranger sides of science and culture. Our first speaker is Stephanie. Take it away.

Stephanie: Great, thanks Andy. I'm going to share my screen I hope and just wanted to start with as someone who's worked on both sides of the Atlantic I love the idea of this webinar and sharing perspectives from two important places and so thank you for including me today. As Andy said my work is around ALICE households. ALICE is an

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acronym for Asset Limited Income Constrained Employee and we developed these measures after realizing the inadequacy and the outdatedness of the federal poverty level. We have been doing this for the last ten years across all three thousand counties in the U.S. and you can find out more on our website UnitedForALICE.org. I'm going to start with who is ALICE and then talk about ALICE's connection with the care industry and also The Maintainer world. So basically ALICE are households who are above the federal poverty level but below a very basic budget of housing, childcare, food, transportation and healthcare. So the bare minimum to live and work in the modern economy and they're working in low wage jobs things like cashiers, laborers, healthcare workers and then a critical component is that they have little or no savings so no cushion for when a personal emergency happens like your car transmission blows or a national disaster like the world-wide pandemic. So ALICE is clearly struggling right now and part of that is ALICE you know didn't have that money for emergencies but also didn't have that money to invest in that future; things like education and homeownership, small business, retirement. So in most states and this is just an example from our recent report, Oregon, about 10 to 15 percent of households are generally in poverty and that's most people's understanding of financial hardship in the U.S. But in every county there are also people who earn above that but below that household survival budget and it's generally another 20-25 and even 30 percent and so suddenly you're looking at a magnitude of more than double what the federal poverty level is and that has huge implications for the stability of the economy as well as the policies and support that's needed. And this is just a nice visual to make this point is if you look at the percent of households below the federal poverty level this is your view of the U.S. and you see a few dark spots but when you layer in ALICE households you see another whole layer of need and financial instability. So one of the key components of our ALICE measures is the household survival budget and here are some examples of the budget for a single adult, a senior adult and then for a family of four. So it's just the bare minimum and the reason that we present you know the full budget is because the total often seems a lot but the breakdown when you look at the actual costs for a two bedroom apartment or the thrifty food level plans that the U.S. Department of Agriculture has you know the bare minimum food budget, bare minimum transportation. You see each one of those items is far less than what most households actually are spending so you see how bare the budget

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is and then when you compare that to what folks are earning such as a retail sales person or the federal poverty level you can see the mismatch. I just layered in here to see how your stimulus check would go which most ALICE households received a month ago or so and it wouldn't even provide enough for one month of expenses for most ALICE households. So we've taken our work and the budget is an important side and then the other side are jobs and put it in a maintainer pyramid and so we looked at all the jobs reported by the Bureau of Labor Statistics and divided them up as either maintainers or innovators and then within those broad categories we have especially for the maintainers and today's discussion we have folks who work on infrastructure and then we have another category of nurturers and I think for today's conversation you know these are folks who educate and care for the workforce and they are a very important part of our economy. Fifty-two percent of those jobs in Maryland paid less than \$20 dollars an hour and that's pretty typical across our state and so these jobs are critical to keeping our economy running and our people being prosperous and have a huge impact now with Covid-19. So some of those folks are seen as essential ALICE and are getting recognition that they weren't in the past but others are not able to work and our economy is having some glitches as a result and certainly households are struggling without that income. I always think it's important to think about ALICE as a person. I love the data and the statistics but ALICE is a real person and here are some of the top jobs in Maryland is this is similar across the U.S. So the occupations are a lot around food and healthcare, personal care and you can see the number of jobs so food prep is one of the most common jobs in the U.S. and in Maryland the median hourly wage was \$10.75 an hour so not nearly enough to support even a household survival budget for a single adult. So you can see the challenge. These are jobs that we need. These are jobs that are essential to caring for our workforce, educating our future workforce and yet they don't earn enough to live in the communities where they need to be working. In terms of care one of the areas that we spend a lot of time researching and working around is childcare and you can see that the cost of certain childcare so family-based is the least expensive childcare, center-based is a little more rigorous and regulated in the U.S. and so compared to what a childcare worker earns that childcare worker couldn't afford to send their child to the place where they work but it would be 75 percent of their income for family-based and over 100 percent of their income for a center-based. So you know looking in specifically

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what's happening today around the pandemic a lot of these care providers were struggling before the pandemic and as I mentioned we look a lot at childcare providers but there's also senior care, care for folks with disabilities and then all the personal care in healthcare operations across the U.S. So many of them were having challenges before the pandemic. Certainly places that have had certain regulations and require a high number of providers to care children or seniors that makes it that expensive; quality is expensive. More people increase cost and then there have been recent increases in rent in facilities. So some childcare centers have closed before the pandemic and so vulnerable before the start then we experienced the Corona Virus and a lot of these places had to close or are now slightly reopening at a much reduced capacity so limiting their ability to provide care and also limit their ability to bring back ALICE workers that are also needed so further impacting their families. So we're seeing a number of facilities closed and one group of care providers that I really want to highlight are senior living facilities. Seniors are probably the most vulnerable group to Covid-19 and require extensive amounts of care when living in group quarters. Many of these folks are ALICE workers paid you know very minimal wages and yet really risking their lives and their families lives to be working. Many can't afford not to work and so there's a real tension in needing to provide the care and needing to work and needing to be safe. Many personal care facilities are closed, hair dressers, barbers, you know that kind of close contact is very difficult in the Covid environment. Some are trying to get reopened at reduced capacity; very hard to actually you know pay your bills by the end of the month. And then we're seeing kind of a different level around a lot of the food and healthcare where many of these workers are seen as essential and yet the way that they deliver their services have had to be shifted as well. So those are my main talking points and introduced this topic. I'll pause here and turn it back to the other presenters and hopefully we'll have some interesting discussion at the end.

Naomi: Thanks so much Stephanie and that was really interesting particularly like the segmentation of sort of innovators and maintainers. I know that it's something that first of all maintenance like we struggle a little bit to sort of articulate what like what we mean by you know maintenance versus innovations so that was really, really helpful to have that macro level analysis. So I'm going to pass over to Jamie now so and Jamie is going to speak about the personal experience of receiving care and so not kind of being a carer

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but being a receiver of care and sort of how that has been in the pandemic and before so Jamie over to you.

Jamie: Hi, thank you I'm really delighted to have been invited to speak. I always am concerned about discussions like these when they take place without disabled people and am always delighted when disabled people are kind of asked to be approached to participate in them. As someone who both manages their own care plan and has become an expert in this sector I'm in an interesting position where I'm both understanding the ways in which people look at analyzing care financially and structurally but also being the person that that analysis affects and so I'd thought I'd talk from a very personal basis about my experience and relate it more broadly to some of the pressures effecting the sector. So care as a commodity is a really complex experience to receive so as a really disabled adult I live you know I would consider independently with my wife in a flat with a dog but I also have round the clock care with a team of about six people meeting my needs. The funding structure I use is called a personal health budget and it's disseminated as direct payments. With that scheme the NHS transfers the money to a prepaid card from which I pay my employees, I pay taxes, I pay payroll etc. I have to demonstrate where the money is spent; I have to have insurer's liability insurance and I live the role of a full-time manager; by full-time I mean 24 hours a day. Direct payments of assistance offer disabled people a huge amount of independence because rather than having counsel commissioned care as coming in to as they look after us we were able to look at how we wanted our needs met and then choose the people were meeting them so we're set up more as a cash transfer system but are now far more overseeing and tightly controlled than they use to be. So when I started receiving direct payments I was 20 I was in my second year of university and I was a relatively typical wild student who would also suddenly become a manager of a team of five without ever having had a long-term job. Financial reconciliations, wages, time sheets, (inaudible) insurance, management there wasn't any support offered to me. I was entirely on my own. I made an awful lot of mistakes, employed the wrong people with lack of disciplinary issues and came to harm as a result. There was no welcome to being an employer training and there was no support in how to manage this process so nine years later I've employed a team for all of that time and my needs have become more significant over time but what stayed the same is the level of obscured labor and what I end up doing I'm never off duty. Someone could

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have approached me with a work problem when they're in my room turning me over at three in the morning. They can call in sick at five a.m. for a seven a.m. start and I need to be awake in covering their shift and setting up an on call system but there isn't a day off with a setup like this. My body doesn't take a day off. There's no space to snap, lose my temper, be grouchy or make an accidentally off-color joke because my life has become someone else's work environment and people are entitled to a positive work environment. When the organization for packages like this this is done by care agencies and it's a paid job with institutional support and training but when I do it it's something I do unpaid for about 15 hours a week. I have to ensure there's someone working at all times with someone on call to cover them. I have to navigate the needs desired and availability of the people I employ. When something goes wrong it's hard because that can be anything from fainting or into potentially life-threatening and I still have to be cool, calm, collected and professional about it. But this is a choice. My other option would be to have a commissioned care package in which an agency sent people out to me at assigned times to do the tasks they were assigned to do; if I asked them to do anything else sorry it's not on your care plan. I wouldn't have any choice on who these people were. I might be allowed to reject someone after shift but even that's kind of out of my own hands. And maintaining my body is a challenge because it does take up the full 24 hour cycle. I have support with all internet personal care so I'm regularly having to train brand new people how my body works and how I want them to approach this. When I invite people to a trialship to see how things work here I show them the most intimate parts of my personal care routine because if they can manage that they'll manage the other demands of the work but I have to also train them to understand what to do if I'm coughing and (inaudible) my chest not to panic if I aspirate, vomit and choke and that they're happy with the amateur photography of assessing my pressure sores. So I have to manage these people as people as well as the body that they're responsible for maintaining. I'm the employer responsible for maintaining them. For the good employees this is (inaudible) in pay, it's adding the time sheets up correctly, it's making sure people feel appreciated by me when I can't give them a pay raise. I can't give them any kind of structural improvement because I don't have the funding or the capacity for that. When it goes badly I'm doing disciplinary meetings, performance improvement plans, management for the same people that I'm relying on to keep my body alive. I don't have funding for sick

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pay. People that end up choosing whether to come in to work sick and potentially infecting me with something that could be life-threatening or whether to not come in to work and not get paid. There are a lot of downsides to this system management responsibility risk. If two people go off sick at once and no one can cover then that's on me. The stress of maintaining a staff team is on me. Recruitment assessing that the patients aren't experiencing over skill over commitment, trying to persuade people to take on shifts they don't want and hoping they'll do it with grace. Because maintaining a care package like this isn't easy. Anyone who's looked at care work knows it's not easy. Anyone who looks at the work the people I employ can see it's not easy. I explained that most of the time them and I are working as colleagues. We've got the common goal of keeping me going and that requires work and effort in both of us and the good people rise to that. We developed a sense of teamwork, comraderie, general positivity. We can go from waking me up to me being fully dressed with my physio done and having exchanged five words because we know each other and that's what I need in my life; people that enable me to live the life I'm trying to live. Because without a care package like this I wouldn't be working. I wouldn't be giving talks, doing my acting training, writing on a significant television show, sell out theater piece, arts generalism job, all of these things came out with me having enough care to meet my basic needs finally. That was what gave me the independence and support and intangibles to get on with my life. I got my first full-time job from a hospital bed because that was the first time I had the support I needed to get a job and this is never without a fight. You don't get a stable care plan and then keep it. My 24 hour care package was only approved after I was in hospital for six months. Lived an entirely avoidable pressures and serious malnutrition and then for the past five months I've been living in fear because I've been told that it would be cut by 60 percent and that cut could force me into a care home and I was told that about five days after my dream wedding. So I'm still waiting to see if that happens. I'm waiting to see whether I can fight it. I guess it's because for me having a care package is about outcomes and they're not measurables. They're work relationships, independence, happiness and then for commission it's about balancing budgets. It's about looking at me and calculating how much cheaper I'd be in a care home than in my own home or whether it would be cheaper to have me admitted to the hospital a couple of times a year for antibiotics for a pressure sore but not have someone every night to turn me when I

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need it which would work out cheaper and sadly it might be the occasional sore, the occasional admission, and it's a really dehumanizing process trying to turn yourself into a budget. At the moment I'm working on a 20,000 word document detailing my specific needs, breaking them down into the four areas you have to adjust for the personal health budget. I have the nature of my needs, how intense they are, how complex they are, how unpredictable they are. I have to tell people about the intimate personal functions of my body people who are there to try and see if they can make those intimate personal functions quicker. I start the document with a paragraph about how great my life is and how that's because of the 24 hour care package. I put a photo of myself on stage at the (inaudible) on the sellout of opening night of the solo show and showcase I've put on but there isn't a box in the care package from for that. There isn't a box on the continuing healthcare application form for are you happy; yes. There isn't a way of quantifying the fact that it's given me a quality of life and it's impossible to quantify independence because if you look at me and say well you don't live independently people do everything for you then no I'm not independent but for me independence it's about knowing that you're making your own decisions and telling employees that their job is to work with my arms and legs and do the things my arms and legs can't do. They might be supporting me in everything I do but they're supporting me in ways that I need and that I make the choices about. I'm filled for them with gratitude for their dedication of many of the people I employ now or have been employed over the years and I resent needing to be grateful for this but I'm glad to choose to be grateful. I've made the decision that despite the quantification, the workload, the effort, the three a.m. management discussions when I was fast asleep all of this it's worth it to be living my independent work in life. That's the way I want it. That's how I want to live and if I need (inaudible) space in the system to look at things this way thank you.

Naomi: Thanks so much Jamie and we've spoken before and it's just as shocking the second time around and to hear you describe all of the things that you do and then don't think about you know that a care home is you know a very real option for your future. It is just as shocking and thank you yeah thank you so much for sharing and I'm sure we can unpack some of your points around kind of measurement and what can and can't be measured in the discussion afterwards so thank you.

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Jamie: Thank you very much.

Naomi: So let's pass over to Lydia who's our final speaker and so Lydia's going to talk a little bit about measurement I think but also probably lead us in some provocations for really kind of what care is now and what care could be in the future because it's clear they need to change and so Lydia please take it away.

Lydia: Hi, so I'm going to try to stay on the time just because this was such an enormous topic that the last time that I spoke on related issues I went over by a large amount so this will probably be quite bare bones but I'd love to get into things in the discussion. So yeah I have been working for the last three and a bit years on issues around data and analytics for social care. The images in this will come from the work I did with doteveryone mostly because a lot of photos that I've taken for the projects cannot be shared because there's so much fear in the sector in the UK for reasons that I will get into later. A lot of people just didn't want any photos taken of them because those could be used against them and because quite a lot of my recent work has been online and so I haven't taken that many pictures on zoom calls. But yeah I want to talk about what we measure and how that has become what we measure and what that causes in how we develop social care in the UK. So it's useful to remember that long before Covid social care within the UK was part of what was called the grave and systemic human right's violations by UN special (inaudible). In so far as how disabled people are treated in the UK their particular findings were not just but disabled peoples means for living especially through budgets have been cut, but also that they faced a continuing struggle to access the things that needed in order to live and that "nothing was made easy" is a quote. So how do we actually understand social care at the moment? The answer is essentially not that this is the conclusion of the Office for Statistics Regulations series of reports on social care in England, Scotland and Wales. Social care is not just poorly measured it has been systemically stripped of what measurement capacity it did have over the last ten years. I commissioned a report called Better Data for Better Care about 18 well it was finished about 18 months ago with Giselle Cory who is now CEO of DataKind. It is extraordinarily creative in skilled data analyst. We worked from the principle of trying to work out what question we wanted to ask in social care and to work out whether that could be asked and if it couldn't what resources would be needed in order to get them. So

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the specific question was what is good social care and then also what kind of interventions impact whether social care is good. Now what we've found is that there wasn't just one or two missing data sets in fact it's more that it is easier to list what we don't know. This is a list of combined things that we absolutely do not know about social care that is combined from both that report that I commissioned and the Office for Statistics Regulations report. In the UK pretty much all of our data is beginning to change as Scotland takes a bit more control of its social care but a lot of that effort was frozen due to Covid so exactly what point we were at is complicated. I did a six months project with the government up there and even with that contact I can tell you that it's complicated so apologies to any Scots in the audience for continuing to use UK when the policy decisions are actually different up there. Essentially we get our data from local authorities which is what statutory controlled care is like is listed here so we don't know very much about any social care that is outside of what is funded by local authorities; i.e. if you're paying for your own care that often isn't captured. We don't know anything about the access and the barriers to statutory controlled care which is important because the eligibility criteria are changed continually so someone may be eligible one year change their life to fit around that and then begin to gain something like independence, happiness and acceptance and then the eligibility threshold will change and while nothing else in life has changed they're totally taken away. Individual experiences and quality of care exactly are you happy is not generally asked and if it is it is asked what's the word inconsistently at different kinds of points in the care system. I have interviewed a lot of care home managers and managers of domiciliary care and some of the ones who are doing a fantastic job will tell you that they absolutely do ask whether the people that they're working with and for are happy but that they don't necessarily always that is something that is happening within the organization and so isn't something that is asked in a way that can be compared between two or more homes say. Oh what's that? We don't know much about long-term outcomes. Do you die sooner if you get local authority care or not? You know does it actually do harm because of process of access in care is so stressful we absolutely don't know and also we cannot even compare how much money is spent due to the fact that all of the different systems that we use to provide care don't match up so hospital catchment areas, CCG's which (inaudible) organized healthcare in these clinical commission groups that doesn't match up with local authorities so we

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absolutely don't know what services someone is capable of getting. We don't know how much care is given by families. We don't know how much care is given by people who are doing this work based on an advert that might not have been in English that is put up in a corner shop and answered by someone who has no formal qualifications in the sector and we absolutely don't know how much unmet needs is out there. So if we don't know that what can we know how to build. If we don't know what is working right now what can we do? So I've done an enormous amount of interviews and workshops with people up and down the country. When I say the country around England and Scotland and Wales. I have not been to Northern Ireland to work out what it is that people want and rather tragically I would say that this is probably a lot sums up the kind of feeling that I have encountered amongst people that essentially that work of there is a desperate hunger to be able to translate the qualitative experience of care into something that a capitalist system will render as real or tangible or valuable and I have read many excellent and very angry articles about how undervalued people feel. I have done interviews with people who talk of centers of betrayal of mental breakdowns and self-harm rising from the stress of continually having to prove what you need in order to survive trying to take up space in a world that is trying to prove you at every point that it seems to not want or need you and so this kind of quote has very much stuck with me of trying to prove that you're cheaper if you're happier because that's the only time that the system will care. Interviewing people who provide care has not really proven that much more positive. This is from a series of interviews I've done over the last couple of months with registered care managers which in the UK means that you are the main person in charge of a particular chunk of care provision services. We've created a system which is so focused on process over people that at almost every level individuals are given tasks that are quite literally impossible given the budgets that they have access to which pressures just about every actor within that network to either to lie or to misrepresent or essentially to be exploited because if you're going to provide the level of care that is of the quality you are willing to live up. I've spoken to quite a lot of care workers and specialists, nurses who have quit the profession because they with the resources available they couldn't provide a level of care that they felt was ethical or in line with their morality. You either work harder than you're being paid for generally or you find a loophole or you switch to solely working with the private sector and charge people more than local

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authorities would pay because we are not willing to pay you what care costs. As a means of making clear exactly how bad that is in the UK we spend between 22 and 28 billion a year on the social care that is provided through local authorities. There is other spent on social care but that's it. As many of you who are on Twitter will be aware Jeff Bezos is currently making about ten billion pounds a day so that's what wealth hoarding looks like. I have a series of slides that kind of go onto what we want beyond Covid but I feel like that's been my ten minutes and it's probably best to kind of open up to questions from that. Cool.

Naomi: Awesome, thanks Lydia. Yeah it was quite a shocking set of slides there. Thank you. So clearly in terms of like the questions that we have lined up I know we have questions from the audience as well and there's clearly like there's tension between sort of you know we must understand care more in order to be able to fund it better but obviously by understanding it then it means then we can kind of (inaudible) it and you know make this sort of un-measurable measurable and therefore cut it and cut it and cut it which is then the dominant ideology in the UK and I imagine so with the U.S. as well and perhaps someone can correct me. In terms of I suppose I want to get on with a UK based question and it's a question for Lydia and Jamie and I'd be interested to hear Stephanie's point of view as well but the plan is to combine social care sort of within the NHS's remit and has attracted a lot of questions then because there is the danger of pathologizing care you know and making you know sort of day to day living like you know an illness and but I mean is there any sort of sense that might help us kind of understand social care a little bit better or I mean it's a huge question.

Lydia: Jamie do you want to start?

Jamie: I'm trying to think where to begin with this. I think whatever we do the minute we make un-measurable measurable we lose something about it. The minute we try and quantify something into any structure of commission and funding if I'm sort of understanding directly but I think we lose the ability to define outside the specific box that it is that we're building to collect data and this is why I don't think any of the existing data driven approach is going to necessarily be improved and better targeted to suddenly give us what we are looking for from the perspective of disabled people in independent living which is the entire services broken at the core and an independent

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living service needs to begin with people's views about their life and then go on from that to define the support they need in terms of the outcomes they want and to give people the same possibilities anyone else could have access to. But I was lucky enough to abroad for a period of time and for some of that time to receive care funding because I was considered an (inaudible) resident in the UK and it was part of my degree and that just wouldn't be funded nowadays. There would be no chance of it. That allowed me to become fluent in Spanish and to get a first class honest degree which I would not have gotten had I missed out on living in Spain and studying at university there for nine months but how do you justify that when the rules are so tight around care package funding because the rules are broken. You need to start from what people want and what they need to achieve and believe in people when they tell you that they know what they need.

Lydia: That seems like a really good point for me maybe jump off on. So I was part way through a PhD working in data in hospitals when I quit to take a job looking at data in social care because it became so clear to me and it has been for a long time through various personal research reasons what the differences are in...like medicine has a status has a hierarchy right so I for instance have two long-term conditions one has a biomarker and a genetic test that can easily be pointed at and the other one is just migraines right that's like that is wrapped up in self-reported pain it's something seen as a woman's issue most likely but that affects me a lot more than the genetic issue does. When I walked into a doctor's office it is so obvious what the doctor cares about you know the thing that's rare and has a really interesting kind of chemical signature let's look at that let's talk about that we know about that we know exactly what the biomarkers are and what we can do to fix that. The other thing is related to my self-reporting. When we begin as Jamie said to apply that kind of model to care you usually encounter profound problems. Healthcare is generally built on a model of fixing things or keeping them fixed and then kind of returning into your life whereas social care is about living well with the body that you have and the mind that you have and sometimes and that involves profoundly different methods. Although of course I need to sort of shout out to the fact that the healthcare model kind of isn't really working for healthcare either. We know that asking people what matters in a long appointment with the doctor has enormous impact on their you know the biomarkers of the various specific health conditions not just the general

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well-being. But there is definitely a case and I've seen it made well. It was raised by I can't remember his name, but the chair of the Disabled Members Committee of unite about nationalizing social care in such a way as to remove the postcode lottery while allowing services to be linked to local issues and local needs and there are quite developed worked out plans that have been led by disabled people on that issue. I can absolutely see the value of that but tying it to the NHS means tying the two together it means entrenching cultural problems that are already beginning to damage healthcare's ability to deal with the health problems of today let alone the social problems of today if that makes sense.

Naomi: Yeah absolutely. I've got maybe one more question before we hand it over to the audience. So kind of zooming out to sort of the macro level and probably relevant to Stephanie as well so in the U.S. we have this problem where you know the people who are kept (inaudible) you know we're not maybe recognizing their condition their working conditions and then that means they're kind of like their conditions are deteriorating as a result and I wondered Stephanie and Jamie and Lydia I mean are there any examples of kind of where measurement or kind of where sort of measuring kind of what's going on has like the better outcomes. For example, you know at least publicizing working conditions of care workers. Maybe Stephanie.

Stephanie: That's a great question. We are a bit frustrated in the U.S. right now. A lot of these care providers are in what we call the gig economy and have variable hours, there's variable schedules and actually variable tenures at their jobs that they work in these positions for three, six, nine months and then switch. So we have terrible data on this. The Bureau of Labor Statistics is not good at collecting it. They're collecting data from an economy that was functioning three decades ago and all this variation is hard to capture and so just picking up a little bit on the previous question to is I think it's so important to ask about is the patient happy, but I think that the care is also hugely related to is the provider happy and a lot of social care providers are low paid with tough working conditions and are you know as you can see from the other side of the ALICE presentation are struggling with things at home and probably have you know family members with healthcare issues or other challenges and so you know you can't just look at a person as an employee they come from a family a household and have their own

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constraints and if they are low paid they have even more stress and challenges to stay healthy, meet their bills, and other family responsibilities.

Naomi: Lydia or Jamie are there any...?

Lydia: I would absolutely say that statistics can help. We know that I'm very grateful for the continual work of several charities that the only reason that we have any stats on say the amount of unmet needs that there is in the UK and the work of say for instance the care worker's charity that has done work on looking at well-being amongst care workers or that might have been (inaudible) sorry...and that helps us get an idea of what is happening in these economies yeah I mean similarly in the UK an enormous proportion maybe I cannot remember the figure but it's one of the ones that's shocking but if you get it wrong I'd probably say it lower than it would be but an enormous proportion of people working in home care environments on zero hours contracts and a large proportion of those working in care homes are on zero hour contracts. There is enormous turnover and there are tens of thousands of vacancies in the sectors so it is difficult to capture the experience of care workers and yeah having more visibility that would allow us to make more concerted cases about what's needed. Yeah I mean I've quoted that LSR report. Ed Humpherson who's the Director General of Statistics Regulation although he kind of said we cannot have parity of policy in the sector until we have parity of measurement. There is so much that we don't know so we can't fix and while it was absolutely true that there are things that we cannot quantify within care there is a lot that could be fixed without needing to quantify that. Like if you can make sure everyone is getting a decent standard of care not just a basic standard of care but something decent. If you knew that people had sick pay so that they were able to go home when they weren't well that would improve the kind of ineffable and unquantifiable area like feeling of trust and safety right. So there are practical things that you can take off that sort of include that qualitative and psychological experience that is hard to put in numbers.

Naomi: It isn't like a utopian policy right it's quite basic kind of (inaudible) relations.

Lydia: Yeah. So yeah there is something special about care but I think as a society we often say that it is special and therefore it can't be measured therefore it can't be improved without deep philosophizing and that is absolutely, absolutely true that we have

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a broken narrative we have a broken system and some of that has been deliberately done through media portrayals of disabled people and carers but it's not necessarily a magic ineffable thing but people need to be paid better they need to have a career structure; they need to have sick pay; they need to be paid at least minimum hopefully living and probably more in terms of wage and that that would improve how much energy and joy people can bring to their work environment right like if you don't know whether you can feed your kids that's going to impact how you treat the people you work with day to day. It's not too complex.

Naomi: Of course. I'm aware that Jamie hadn't answered this question but there are some questions from the audience and that I have not got to yet and we only have a couple of minutes and so Lauren (inaudible) said thanks for sharing Jamie, I'd love to hear more about how you approach your work as an advocate relating to your creative and artistic projects. Alright Jamie.

Jamie: I suppose all of my projects kind of come down to a concept of independence that I have defined for myself as the right to make bad decision and the right to make one's own decisions. So my photo show was called Not Dying and it took a kind of tragedy narrative for the first third and then took it on its head into a kind of confrontational you know you enjoyed lapping up the tragedy but what about your complicity in the way that disabled people are oppressed. My work as an advocate is very much about looking at why disabled people are being underserved by a system and with that focus on people having access to what they need to live the life that they want to live whether that's ways in which licensing can enforce access to (inaudible) or whether it's looking at (inaudible) for social care and how that's done. So I guess that's how everything relates and then I'm also just one of those people with a dreadful (inaudible) career (inaudible) because I love it.

Naomi: Thanks Jamie. And then final question from Ben before we wrap up. So it's a question for Lydia about really if there's anything that gives hope on the measurement questions and so I mean are there ways to improve the data and feedback the qualitative experience and design of systems that exist but just aren't being used?

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Lydia: Kind of. So I've been working with The Health Foundation over the last few months and Jamie was at some of the workshops exploring ways that the data analytics capacity at the social care sector could be improved and how to build that into ongoing funding calls from them and from others and I absolutely see the impetus to fix this well this challenge that perhaps comes out of the horrors that the carnage in the social care sector due to Covid but I'm a little less likely than some maybe to take hope in the whole like now it's a crisis so now it's opportunity to change because I just know how exhausted so many people are and so it's also a time of vulnerability. I don't know about hope but I just see such interesting and brilliant discussions and battles happening within the system. I have to assume that something will change. I also see a growing awareness of now tied well-being is to success on more kind of capitalist legible outcomes right like when people feel good and when they feel understood just about everything in their mental and physical health tends to improve and those interlinked right it's not just one causes the other but people are beginning to kind of...I'm seeing awareness of that at every level including within like even kind of tertiary care within specialist hospitals but how long that will take and how hard people are going to have to continue fighting I don't know and I just I hope that more and more people see this as a step to whether it is a source of extraordinary creativity and skill and resilience among sort of people that work in and give and receive and exchange care. Like I work with a coop a care coop that does great things there. You know they measure with consent from workers and from the people who are receiving care services and people who exchange care so they're are completely other models of doing it and I've seen that workers (inaudible) patient organizations so yeah I see that cooperative and power sharing version of measurement. There's a lot of different answers out there.

Naomi: Yeah, no absolutely. Alright thank you so much and to all our speakers so to Jamie, to Lydia and Stephanie who I think has had to shoo off already but before we go yeah just to wrap us. So I think first there are like real clear sort of parallels but like this idea of maintenance and the things that we're learning in maintenance and about how important it is to (inaudible) and sort of how that is being enacted in social care on all sorts of levels but it's clear you know there's just so much more to cover so perhaps we

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can revisit this in the future. The recording for this roundtable will be posted ASAP and we'll be following up with a Google doc and the questions that we didn't get to today.

Lydia: I know that we discussed earlier I really hope that we can continue these discussions in a way that can be more representative along a lot of other lines.

Naomi: Absolutely.

Lydia: Thank you, yeah.

Naomi: Yeah, one that's yeah it's representative in lots of other ways including race particularly in the UK obviously you know we have disproportionate disadvantage in varying communities and we haven't been able to represent our state so I do hope we can continue that and do this better. So we're at themaintainers.org, the Festival of Maintenance in the UK and you can join our mailing list and connect with us on Twitter. We'd really, really like to hear from you about things that you like to see round table in the future and you know we're kind of looking for ideas all the time so please get in touch. Thanks everyone.

Thank you.

End of audio.