- **Question 1:** What changes do you see as important to ensure that disabled people in Ireland are fully included in society in line with the vision of the UNCRPD? (Maximum 500 words)

This response has been informed by consultation with the service users we work with. The issues they raised included:

The individualising of services. At present there is a sense that service users have to fit into a model of care offered by services, rather than services providing individualised care to service users. Such services should also consider factors such as age/type of disability/access to transport etc when designing their model of care.

Acknowledging that as one gets old, ones needs change should also be part of the decision making when it comes to service delivery. As one service user mentioned "*Integrating these people in line with the UNCRPD is going to take more than just implementing the recommendations of those policies.*

Our service users noted that people with disabilities tend to be marginalised. This can be evident in issues such as employment, education provision and involvement in local communities. Whilst there has been legislative input to change these factors there needs to be additional measures. One of our service users mentioned ensuring that children are educated in issues around people with disabilities. This should be continued an expanded on as children get older, in addition adults should be targeted with positive messages about people with disabilities.

Structural factors such as rural transport, or lack thereof can impact disproportionately on people with disabilities. Ensuring its availability and that it is accessible would improve the ability of all to attend employment/education/day service etc. Services should be pressured into ensuring that they do all they can to provide transport options. Its important that employers/education services educate themselves around any issues that may arise and develop individualised plans with service users to ensure the efficacy of any services.

Ensuring the agency of people with disabilities was also important when we consulted our working group. Whether the issue was relationships/identity/access to disability allowances/accessing services there was a sense that this group did not have sufficient agency over decisions impacting on their own life.

Service should be centrally involved in all aspects of decision making, this should be evidenced and accessible to all service users. This should apply to all services (financial services/education/health etc). Whilst this is legislated for there is a lack of enforcement and could be part of an ombudsman type service should there be one.

In addition to the above issues such as accessibility to health care, including mental health care, primary care (GP) , etc was an issue for our working group. In addition access to advocacy services, and ancillary services (such as ISL approved sign language experts) that would improve service engagement were mentioned as key components to improving service delivery and outcomes. All of the above should impact on funding

decisions, services that are not open to change/flexibility/learning should be impacted when it comes to funding decisions.

- Question 2: What needs to happen for these changes to be achieved? (Maximum 500 words)

There are many areas that need to change. They range from legislative to attitudinal to measuring delivery outcomes and ensuring that funding is impacted by these factors. From a legislative perspective, the United Nations Convention on the rights of persons with Disabilities should be implemented without delay.

On top of that attitudinal changes are needed to ensure the above fully impacts on the lives of all those who are intended to be the recipients of these services. This needs to begin at an early stage to ensure the efficacy of the message. Services should be sufficiently robust to manage the challenges brought by people with sensory/processing issues and be able to look at these issues as attempts at communication. As one of our service users mentioned "Trying to integrate somebody who's very much in the kind of mental space where they respond to going outside of their comfort zone with aggression is going to make it more difficult to figure out how it's going"

As mentioned above accessibility of these services, and their ability to meet the service users where they are at, is key to breaking down barriers. To fully implement the UNCRPD services must adapt their services to meet the needs of potential service users and ensure that easy reads etc are available. Access to these services should be on a needs basis, an assessment of need/capacity should be completed at an early stage and if necessary this information should be shared with other similar services to avoid duplication.

Services should have an identifiable pathway for persons with disabilities to meaningfully impact on service provision. This pathway should be supplemented by ancillary services mentioned above (ISL etc). As one of our service users mentioned "The society that we live in is used to having every form of communication available for people to use and be able to find communication in terms of their own body". This will hopefully alleviate some of the isolation/marginalisation of a growing and increasingly more diverse. Service delivery and outcome measurement should have a clear input from service users. In addition any such services should also be accessible to all potential service users, whether that is a transport issue or a building accessibility issues. It is also an attitudinal one, services should have effective complaints system, that is accessible to all service users, to ensure that services are as effective as possible.

Service users should also have an input into key governance pieces, such as policy development, this should be meaningful and measurable.

Any service user who wishes to play a part in their society should be supported to do so. Approximately 1 in 7 Irish people have a disability of some sort however there is little to no evidence of this in the political field for example. In the time honoured tradition of "you can't be it if you can't see it" this lack of diversity is impacting on society as a whole.

- **Question 3: What would a successfully implemented strategy look like? For example, how do you think life should have improved for disabled people in Ireland at the end of a five-year strategy?[1] (Maximum 500 words)**

  The progression of recent domestic legislation such as the passing of the Assisted Decision-Making (Capacity) (Amendment) Act 2022, has paved the way for the commencement of the Assisted Decision-Making (Capacity) Act 2015 and the operationalisation of the Decision Support Service will have a direct impact on the lives of service users we support. The improved outcomes for service users in relation to their autonomy and individual choices will allow for people with disabilities to be included in areas of adult life that they would have been traditionally excluded from such as sex and relationships.

  The sexuality of individuals with an intellectual disability produces ambivalent feelings among society and is often overlooked as a problem rather than a human condition. Promoting a sexual identity for clients or family members with an intellectual disability will be a challenge for service providers but the decision support services will be key in changing the lives of service users in the coming years.

  The recent focus on equality diversity and inclusion amongst employers and education providers will create a diverse and inclusive work and education environments for individuals with disabilities. The focus will move beyond the expectation for reasonable accommodations and look for education providers and employers to create bespoke roles and courses that are designed to meet the needs of service users.

  Recent trends in areas of life such as retail outlets having ASD friendly times to shop should be welcomed also. This wasn't necessarily triggered by legislative change, it came from an understanding that services need to adapt. It also highlighted the importance of a united disability community and the power it could yield should it be harnessed.

  From a legislative perspective we do need to frame the discussion as a rights based one. We are aware of the importance in other areas of life of key articles in the constitution, and how this frames the debate.

- **Question 4: If you have any other views that are relevant to the new National Disability Strategy please tell us? (Maximum 300 words)**

  Ensure that the consultation is as wide as possible and that people with disabilities are key components in drawing up a new strategy. For a strategy to be effective it must also be reviewed and have teeth in the implementation of same. Services must have measurable outcomes that they need to achieve and must have meaningful input from service users in establishing how to measure them.

As mentioned above the discussion has to be framed as a rights based one, there needs to be an acknowledgement that all members of society have access to the same set of rights.

Discrimination, and exclusion should be defined. Discrimination can be passive as well as active, if services are tasked with delivering services to the public then they should be accessible to more members of the public. We should also recognise that some members of the disability community are more at risk of exclusion than others. Older members of the community, women and girls etc are more at risk than others may be and services should be set up to reflect this.

The end goal of any society, or indeed service, should be that all people with disabilities should be able to live as independently as possible, in their own community.

Interview notes:

Introduction: "So, Cormac, thank you for siexternal service user community in Limerick. I'm Kevin Heffernan, a project worker and a key worker with Cormac. Cormac has agreed to sit down with us and go through some points that we're going to submit to our senior management at the end of the day. So, the first question is:

Question 1: (KH) **What changes do you see as important to ensure that disabled people in Ireland are fully included in society?**

(CF) There are quite a few things that we're behind on, to be frank with ourselves. There's a fair number of people being left behind, and this manifests in different ways across age groups. For example, younger people with disabilities find difficulty integrating themselves into the working society, or if they do, many have difficulties coping with it. When it comes to elderly people who are disabled, the degree of isolation you already see in the elderly population worsens as they progress through the years. And of course, this comes along with the issue that generally speaking, as people get older, they are more likely to have disabilities in and of themselves. We see this with conditions like Alzheimer's or dementia, just as an example off the top of my head. Integrating these people in line with the UNCRPD is going to take more than just implementing the recommendations of those policies. It's going to take accounting for how one's disability affects their integration. We're worried about one-size-fits-all systems as they currently stand, but as long as our attitudes lean towards simply

striving for a better perspective rather than what will cover as much as possible in a very basic manner, it will never really match up to what people need.

(KH) So, do you think it's not a funding issue as such, but rather how it's allocated, and these are a lot of very nuanced cases, and is that where the difficulty lies?

(CF) That would certainly be one way to put it. Now, attitudes are going to impact regardless of funding, which is what I'm getting at. So, the thing is, you could risk throwing a lot of funding at something, only for it to end up being misplaced because you misunderstood how you were actually going to be spending that funding. And it's the sum of that that leads some to take the attitude that it's very much impossible to trust direct state bodies, and I can hardly blame anyone for coming to that conclusion. Like I said, addressing the attitudes and issues like how you're going to resolve those is going to take a fair bit of research.

(KH) **So, I'll move us on to our next question, which is what needs to happen for these changes to be achieved? So, when they're talking about these changes, they're talking about the national disability strategy.**

(CF) I suppose it's broad, and I think we have discussed this in the past. It's a very broad subject; we're talking about a big population across the whole country, and a population that for quite a few people, their views are growing, with the concern that clearly what the responses of some policies then put forward. I've already discussed the attitudinal issues. Yeah, like when it comes to funding, it's all too easy to say, "Okay, we need to increase funding" in a very broad way. But on that top level, where that's always going to impact how they're going to get about, if that's where they've been kind of put... is probably the wrong word. If they worked in place, it's going to be difficult to access the actual building itself if you have a wheelchair. Yeah, how much of that spend is going to be spent getting stuff like that sorted out? It's going to be difficult to do that in every building, and quite a few, especially the older buildings, you know, the regulations came in probably over 20 years ago now that the door jambs had to be a certain width, etc. And how we said, no specs, but it's all buildings, right? Don't even have a service center there !!! If I was going to a meeting in People's Museum, there's a good chance I'm not going to get a meeting on the ground floor. Going up and down, that's just one example. On the mental health side of things, I kind of wonder what it would take in a sense, like, in terms of integration. Not everyone is like referring to all those spectrums for a reason. Yeah, there's people who... it's going to take a lot

of standing in for. I know that's not necessarily the money aspect. n, more difficult to figure how they can just fit in because the very way they see the world can't fit in one vision of the world. (KH)That's a great point, and it's one that's very difficult to fix because, like you said, it's such a broad spectrum. Could you explain that a bit more?

CF The society that we live in is used to having every form of communication available for people to use and be able to find communication in terms of their own body. Yeah, like these are complicated, these are boundaries that have been surmountable around circumstances for those with hearing difficulties, for those with vision impairment, for those who can't perceive in the same way, or it was weird, like all these things, like even someone trying to interpret gestures. Anybody who's limited on any of those already finding it difficult to integrate into society. And for somebody who has multiple of those at once, the task seems to grow exponentially. So, like integrating into a society that expects people to be able to deal with all these modalities of communication is going to be kind of impossible if people in most society aren't up for being able to communicate in sign language for someone who needs that, if someone who's being left behind because they can't see the PowerPoint presentation that's being given to them in their work place, there's no easy way to fix any of that. And when I said attitude problems, these are automatic problems from state bodies, or that's a far bigger issue than a problem with state bodies' consideration of actually expanding groups who are gay or of different cultures or religions if also another priority for government, and which is the bigger priority ? stuff like that's going to be needed if we are truly going to bring people... I'm not even saying bring equity or equality here, I'm saying trying to bring them up to par, trying to reduce the handicap, and I mean that in the broadest sense that is put on people with disability. And I think with the previous sentence, I was just going out of that, like that model makes more sense to me, you know, just societal model, like the societal society, the social model kind of discusses society as a barrier to the same people rather than disability, (KH) Could you expand in depth? I think I have an idea what you're saying, just to expand on it, (CF) like it is that these people are disabled by the society around them more so because it "I think I have an idea what you're saying, just to expand on it. It's that these people are disabled by the society around them, more so because it doesn't account for the difficulties they're having. (CF) You know, I feel like I've mastered that discussion. I haven't made that mistake to whoever is, no, no. And come here, any ideas or suggestions at the hotel that would be comparable to societal issues? You know, how... I don't know, is it promoting more awareness in schools?(this is about the migrant issues, CF larger point is the impact that far

right ideas on social media can impact the youth of today) That's the thing. Like we talk about awareness, and like they had to do a whole thing for my year in Secondary school when I first came in. Like, 'Oh yeah, this person, is this away...' and I don't know how that worked. I don't know if I could say that worked well. Like these kinds of things can end up equipping people with militant tenacity maybe, but I wish I could recall how the actual discussion went in the first year. So, I don't want to pin the blame on that or anything. Yes, some people will find ways to be unkind, unfortunately."

(KH) Nearly there, what would a successful implemented strategy look like? (CF) For example, how do you think life should be improved for disabled people in Ireland at the end of a five-year strategy? I know that's a broad question, and success is also probably the broadest part of that sentence in my mind because is success to implement the policy or is success to see particular changes? The two are not the same, exactly. Depending on what's in said policy, it might end up being very counterintuitive to those who are being affected by it. But if it reaches these particular parameters, then tackling the policy was a success. And success as well, getting it was it like to succeed if it's truly to be a success, I would say that it takes more than just people being made more aware of it. True success would agree that the grave, or less extent, it isn't visible. Not in the sense that people are hidden, not in the sense that we don't have to worry about this kind of problem because this person just won't show up. It's that they aren't even thought of, the issues that they're kind of actually gone on with this pedal course. A day for talking about impacting physically now, whereas success comes from beyond stuff like that. For people like myself, it is going to take... it's going to take a lot. Success in terms of integration is more than just throwing people at the problem and seeing if they stick, okay?

KH "**Last one, have you any other views that are relevant to the new national disability strategy?** This can be, article, whatever you think. Right, there's no barriers here. So, the question from the top is if you have any other views that are relevant in the new disabilities strategy model, what would they be?(CF) I wonder how they're going to be handling... how we're going to be handling this employment strategy. This is something that has been kind of discussed in other areas, particularly prepaid round payment on disability payment reform, but it doesn't really go into much detail. And it's something that I haven't seen mentioned much in the record now." KH (C thank you for your time.