Submission to the National Disability Insurance Agency's *Support for Decision Making* consultation

Children and Young People with Disability Australia
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Recommendations

Recommendations to ensure the decision making framework is not operating in a silo

- The Agency should ensure that the new decision making framework is aligned with existing
 national strategies and frameworks so children and young people are receiving cohesive and
 consistent protections and safeguards across all systems they encounter.
 - This entails the framework adopting the Australian Law Reform Commission's existing National Decision-Making Principles and ensuring its alignment with the next National Framework for Protecting Australia's Children.
- The development of the framework and training of targeted stakeholders should be an iterative process that adapts to incorporate new knowledge and findings that emerges from research and practice learnings.

Recommendation to include an intersectional lens is the framework's development and implementation

The Agency must undertake targeted engagement with members of different communities to
ensure that not only are individuals' cultural and social contexts incorporated in the
framework, but also that it recognises the decision making influences of other's attitudes and
misconceptions towards different community members.

Recommendation to ensure that the framework does not simplify the experiences of children and young and creates resources and outputs that are relevant and appropriate for their needs and strengths

- The Agency must ensure that children and young people are consulted at every stage of the decision making framework so their experiences and needs are represented and accounted for.
 - Particularly, children and young people must be genuinely included in the development and testing of individual capacity building resources and information, as well as resources targeted at stakeholders and decision supporters in children and young people's lives.

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to provide a submission to the National Disability Insurance Agency's (NDIA) *Support for decision making* consultation. By circumstance, in many ways children and young people with disability mature earlier and are confronted with making important and impactful lifestyle and lifechanging decisions that their peers without disability wouldn't have to consider until adulthood – or ever. We hear from our community that from a young age they learn to research their options, navigate complex systems and self-advocate for their own needs.

However, we also know that because of their age and disability, many children and young people are routinely denied their right to dignity of risk and to make the decisions about their own lives that are important to them. We are encouraged that the NDIA is developing a policy framework to support the rights and autonomy of children and young people and hope to keep working closely with the Agency as the project continues.

In September 2021, CYDA held a consultation session with young people with disability on the topic of decision making. With CYDA's support, the session was developed and delivered by young facilitators. Six young people aged between 18-22 participated in the session. There was representation from New South Wales, Queensland, South Australia, and Victoria across the group. The participant group comprised of young people who identify as male, female, and non-binary and one member who identifies as belonging to a culturally or linguistically diverse community. In the session, participants could contribute by answering questions verbally, using the chat function, or directly inputting into interactive activity slides.

The session was delivered as part of the LivedX Consultations Series, which is a component of CYDA's Our Voices Our Visions: Youth Advocacy project. The LivedX Consultations are being conducted to hear from young people with disability about what an ideal future looks like for them, by collecting their ideas and solutions on topics and issues they deem important. The project is funded by a Youth Advocacy Support Grant from the Australian Department of Education, Skills and Employment.

This submission is directly informed by the LivedX consultation on decision making and young people's thoughts, experiences and expertise on the topic. This submission outlines what decisions are important to young people and how their age can impact decision making and their opportunities to make decisions for themselves. As detailed in this submission, young people also shared what practical and social support helps them feel in control of their decision making, as well as what traits

and assistance they want and need from the decision supporters in their lives. This submission highlights the nuanced experiences of young people with disability and calls for the NDIA to create an ongoing engagement strategy with the cohort to ensure the framework and its outputs are relevant their needs and strengths.

Additionally, this submission details CYDA's feedback and concerns on the decision making framework and its background as included in the consultation paper. First, we urge the Agency to build upon existing work and knowledge in developing it, as opposed to creating something entirely new that may not align with existing strategies and frameworks. Specifically, the decision making framework should adopt the Australian Law Reform Commission's National Decision-Making Principles, as well as align itself with the next National Framework for Protecting Australia's Children. The Framework should also be an iterative piece of work, that changes and adapts to incorporate new findings and knowledge.

Lastly, there is a clear and notable absence of any discussion or inclusion of intersectionality in the framework. As our community have expressed that identity and intersectionality is fundamental in shaping the types of decisions that are important to them, as well as their ability to make the decisions that are important to them, not actively consulting with diverse communities with different experiences and worldviews is a dangerous omission.

Feedback on the decision making framework and consultation paper

Though CYDA is encouraged the NDIA is developing a decision making framework to support participants to have more control at an individual level, the scope of what limits children and young people's ability to have genuine choice and control within the NDIS is beyond just that level. Despite the majority of NDIS participants being aged 25 years and younger, there is no real targeted strategy to ensure their voices are influencing policy and processes – from decisions made at the very top to day-to-day practices.

As advocated by one of the young participants at CYDA's National Youth Disability Summit 2020,¹ "our needs get met the best when we're the ones that get to define what they are." For the NDIS to genuinely respond to the needs of their children and young people, there must be decision making opportunities at all levels with the system. Firstly, there must be representation at a governance and structural level, with concerted efforts to recruit and foster young people into positions of power within the NDIA.

At an operational level, while CYDA acknowledges the development of the Participant First Engagement Initiative to receive direct input from NDIS participants, there is still a clear gap in actively reaching out to young people and providing age-appropriate consultation and decision making activities on their terms. There is also no public framework for what the NDIS is trying to achieve for children and young people and how this is operationalised within the NDIS ecosystem. This is particularly evident for children who have transitioned out of the ECEI program and into the LAC and mainstream system.

While this section details CYDA's feedback on the proposed decision making framework at the individual level, we note that changes are required at all levels within the NDIA to ensure that children and young people's agency and self-determination is upheld.

The NDIS decision making framework should not operate in a silo

Recommendations

- The Agency should ensure that the new decision making framework is aligned with existing national strategies and frameworks so children and young people are receiving cohesive and consistent protections and safeguards across all systems they encounter.
 - This entails the framework adopting the Australian Law Reform Commission's existing National Decision-Making Principles and ensuring its alignment with the next National Framework for Protecting Australia's Children.
- The development of the framework and training of targeted stakeholders should be an iterative process that adapts to incorporate new knowledge and findings that emerges from research and practice learnings.

While we see it as encouraging that the NDIA has recognised a need for the development of a Decision Making Capability Framework and an accompanying Support for Decision Making policy framework (both hereafter referred to as the decision making framework), CYDA urges the Agency

¹ The National Youth Disability Summit was a five-day online conference convened by CYDA in 2020. It was designed by and for young people with disability.

to draw upon existing frameworks and strategies in its development, rather than 'reinventing the wheel.' There are already inconsistencies across the frameworks and safeguards in the systems children and young people intersect with. As result, practitioners are confused as to what their responsibilities are and children, young people and their families and caregivers are forced to navigate complex systems to understand their rights and when they are not being upheld.

Rather than create new principles for its framework, CYDA recommends the NDIA adopt the Australian Law Reform Commission's existing National Decision-Making Principles² (see Figure 1). These principles are consistent with Australia's human rights commitments – namely, the United Nations Convention on the Rights of Persons with Disabilities³ and the Convention on the Rights of the Child⁴ – and can provide an aligned approach across Commonwealth laws and frameworks, inclusive of responsibilities.

Figure 1. The Australian Law Reform Commission's National Decision-Making Principles

Principle 1: The equal right to make decisions. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Secondly, respect and safe environments are pre-determinants for supporting decision making. Currently, the Australian Department of Social Services, in collaboration with the Australian Human Right Commission, is developing the successor plan to the *National Framework for Protecting Australia's Children 2009-2020.* The plan to protect Australia's children is guided by the principle that children and young people are active agents and participate in decision making that affects them. Children and young people with disability and/or parents and carers with disability have been identified a priority group for the successor plan. As consultation work⁵ with children, young people and families has already been completed through the Department of Social Services, CYDA urges

² Australian Law Reform Commission. (2014). *Equality, Capacity and Disability in Commonwealth Laws.* Available at Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124) | ALRC

³ See Articles 3 and 12 of the <u>UN Convention on the Rights of Persons with Disabilities</u>. Article 3 states that the first principle of the Convention is "[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons." Article 12 holds that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and that "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

⁴ See Article 12.1 and Article 13.1 of the <u>UN Convention on the Rights of the Child</u>. Article 12.1 holds that "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. Article 13.1 holds that children "shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds..."

⁵ Young people and parents and caregivers from CYDA's community participated in targeted focus group to inform the framework

the NDIA to seek out and incorporate the findings from this work into the new decision making framework. This will help ensure the specific service and safety needs of children and young people – especially considering that 57 per cent of NDIS participants are between 0-25 years old⁶ – are properly considered and incorporated in the plan and that there is consistency across national frameworks.

Lastly, in partnership with UNSW Sydney's Social Policy Research Centre and Inclusion Australia, CYDA is currently undertaking a research project which seeks to better understand how to support young people with cognitive impairment in making the transition from a best interest's decision making framework. This includes exploring how young people in different settings including family, out of home care, and institutional settings can be supported in a way that respects and supports their evolving capacity. This research project is funded by the National Disability Research Partnership and will done by and with people with disability, concluding in mid-2022. We ask that the development of the NDIA's decision making framework is an iterative process and incorporates new knowledge and findings, inclusive of the aforementioned research.

Intersectionality is absent from the framework

Recommendation

The Agency must undertake targeted engagement with members of different communities
to ensure that not only are individuals' cultural and social contexts incorporated in the
framework, but also that it recognises the decision making influences of other's attitudes
and misconceptions towards different community members.

While acknowledging that one of the discussion questions in the consultation papers asks whether there are different things to consider for people with different disabilities or cultural backgrounds, the framework background itself does not reflect on intersectionality or the impact of an individual's cultural or social environment on their decision making. The NDIA must undertake targeted engagement with members of different communities to ensure that not only are individuals' cultural and social contexts incorporated in the framework, but also that it recognises the decision making influences of other's attitudes and misconceptions towards different community members.

For instance, in CYDA's LivedX focus group on the topic of decision making, we asked young people if there are different things to consider for people with different identities and backgrounds, in supporting young people to make decisions. As demonstrated in participants' responses below, it is evident that identity and intersectionality are fundamental in shaping the types of decisions that are important to young people, as well as their ability to make the decisions that are important to them.

"Valid distrust of institutions, specifically legal and medical when you have been otherwise marginalised by those system[s]."

"Complexities of having disabilities related to body parts that people have decided are associated to specific genders. i.e., 'reproductive health' for trans and gender diverse people being specifically harmful and badly handled."

⁶ As at 30 June 2021, NDIA, (2021), Explore data, Retrieved 3 September 2021 from Explore data | NDIS

"Emphasis on preservation of fertility and reproductive health for people with uteruses - this is so confronting, regardless of if you want kids or not, as a young person!!! I want quality of life, not forced 'fertility preservation'??? That's just so not in my mind or universe yet."

"Getting treatment that is queer affirming, culturally safe, etc. (you can't really! or have to wait ages to get in or pay way more)."

"A major thing is celebrating it. I think particularly people going from different backgrounds go through so much already that making sure everything is as a supportive and safe space as possible is the best way to be an ally."

"Extra impacts of medical system and devaluing if you are BIPOC [Black, Indigenous, and People of Colour], trans, queer, and any combination of the above. Both direct interactions with systems, but things like access to location, financial resources, safety."

"Comorbid health conditions and mental health, you aren't just one 'disability'. Though also the homogenisation of disability and experiences being particularly harmful."

"I am autistic. I'm also asexual. And a lot of the doctors I talk to don't think you can be both, because they think I'm just confused because I'm autistic and that I have just not figured out the feeling yet, but I know who I am."

"I find that a lot of people will think a lot of things can't overlap, like say ADHD and autism or being trans and so on, I find that a lot of people think, things can't overlap, what can very likely, very easily overlap."

The proposed life stages model is too simplistic

Recommendation

See next section

In CYDA's view, the 'typical' decisions made across the life span underpinning the framework (pages 11-13 on the consultation paper) are too simplistic to represent our community's experiences, because young people with disability must often consider options and make decisions that are atypical to their peers. In our LivedX focus group on the topic of decision making, many young people shared many complex instances of making decisions that related to their health and care. While CYDA agrees that children and young people – whether having disability or not – are entitled to the dignity of risk to make typical decisions across life stages, building a framework based only on 'typical' decisions or theories risks creating something that doesn't factor in the complexities and realities of being a child or young person with disability in our society.

To reflect the strengths, needs, and lived realities of children and young people effectively, it is vital that children and young people are involved in the development, testing and ongoing improvement of the framework and its outputs.

Young people's perspectives on decision making and decision supports

Recommendation

- The Agency must ensure that children and young people are consulted at every stage of the decision making framework so their experiences and needs are represented and accounted for.
 - Particularly, children and young people must be genuinely included in the development and testing of individual capacity building resources and information, as well as resources targeted at stakeholders and decision supporters in children and young people's lives.

Decisions that are important to young people

In our LivedX focus group, we asked young people what sorts of decisions are important to them. The answers varied from being able to choose recreational activities, education options, to treatments and treating professionals. As one young person stated, "*All decisions are important*."

"As a disabled young person, decisions around my health and my treatment and things like that are really important. A lot of the time those are taken away. So, getting to make decisions about, even little things like, 'Am I going to go with the generic or the brand name medication?', to also big things like, "Am I going to change my psychiatrist?" or 'Am I going to do my surgery this year or next year?' and that kind of thing. Things about my body and my brain are really important to me."

"Where I live, who I engage with, what spaces are safe for me, what I do with my money."

"Where I work, where I learn, [or] if I do or don't work/learn."

"Choosing my uni course or whether I am allowed to stay in that course after the wheelchair."

"I think that one of the most important things for me is choosing who ... they [medical professionals] are and their reputation. Sometimes it's important for a doctor to refer you to a specific person, but also having the autonomy to know, 'No, this isn't working for me' or, 'No, I need somebody else's opinion'. I think another significant thing for me is knowing, I dunno, it's like the school and university I go to, and like, having the decision to do that is really significant to me."

"I wanted to just mention financial decisions as being quite important. They are particularly impactful when you're working out, you know, what medical treatment to spend money on, what stuff for yourself to spend money on, that sort of thing."

"I make decision every day of my life like [in] 3 more week[s] time I going to join a soccer team."

Young people also commented on how important it is that they get to determine which decisions they make and who they want involved in that decision making process.

"I know that I go into the chemist or the doctors or something and I will be with my carer and they'll straight away see me in a wheelchair and straight away start talking to anyone else but me. Straight away they think I can't make my own decisions and that's just frustrating in itself. But then I am still able to make my own decisions. Even if it's not about health and stuff, even if I just want to choose what I want to eat for that day, I am getting told what I have to do or what the plan is for that day."

"I think that my decisions that are really important is that just decisions in general when I usually have a chance to do until they find out that I am disabled and then they immediately start talking to my mum who is with me or someone else. I find just having my choice not taken away as soon as they find out that I am disabled is more important to me than the actual decision, because I might want my mum to decide, but I want to be the one to decide that."

"... [J]ust in particular, having carers come in with you [to appointments] and then you could have ... told the carers to go away so you can have everything told to you and then the doctors still just repeat everything back to the carer and I'm like, 'Well, I've just heard everything so why can't I just have that?'. We're still people and we've still got the same brains as everyone else, so I don't get why we can't just make decisions for ourselves?"

Making decisions as a young person

Participants shared how decision making can be or feel different for young people. This included how "infantilisation", cultural differences and feelings of power imbalances can prevent young people to be autonomous and make decisions.

"Some things you just know. It doesn't matter how young you are, sometimes you just know. But when it comes to say surgeries and something you might know, 'Hey, ... I know myself, I've done research on this, I've looked it up. I know this is what I want' and a doctor will be like, 'No, you are only young, you don't know what you want'."

"I think something I'm thinking about a lot is how often young people in our like, you know, expansive coolness ... is like inherently challenging to a lot of like what medical, educational, like financial institutions, expect for people. ... So, like, recognising that in the, you know, all of the excellence that is young people, people who aren't in our community, view that in a really negative way, and then our treatment, and our, you know, support and capacity to make decisions is negated by that."

"Reflecting on an experience that very much took away my control and decision making, when I was in hospital and I was also realising that my home environment wasn't safe, so I needed to look for a new place to live and I told this to my doctor in confidence expecting them to support me and they continued to misgender me and also demean me and say, 'You're just a little girl, you don't know what you're doing'."

"[A factor for young people is the] power imbalance and age difference in practitioner to young person."

One member also commented on how legal restrictions for those under 18 years old can prevent younger people to have control and that even if they have good decision supports in their lives, a parent or carer – who might not be their preferred decision supporter – generally has the ultimate say.

"...[T]here is a very clear division on what young people's power of decision making is if you're under 18. And that makes it particularly difficult in situations where malpractice is happening by adults that ultimately have the final say over you. So, fundamentally, being restricted because of your age, which has some reasonable things, but some unreasonable things. While you should be able to make your own decisions, the law often says that you can't."

Many participants shared how it can be hard for young people to have confidence and capability to make decisions for themselves, as it can be a skill they're still developing.

"Young people can tend to have their opinion easily swayed by those in authority and by their peers. There needs to be more training for young people with disability to be assertive and believe in themselves – we want to avoid them censoring what they say because they have impostor syndrome or think they're 'just a kid'.

"Identity and self-confidence is a bit wobbly generally for young people"

"We are still learning how to 'adult', so we need clear, engaging information and resources on how to navigate making decisions. ... Role models are big."

Access to resources, such as finances, and community or age-appropriate services were also identified as a barrier or enabler for decision making.

What helps young people feel in control

Young participants in the LivedX focus group shared with us what makes them feel in control. Many young people emphasised the importance of the people in their lives listening to and respecting their choices (see next section). In addition, young people also highlighted that access to clear information and feedback processes is essential to help them understand their options. The need for multiple methods of information provision was also raised by the group as being important.

Young people's responses to what helps them feel in control of their decision making:

"Understanding the information. I have to get a carer to read things if it has to be read fast"

"Privacy"

"Being given multiple options and second opinions"

"I find that also what helps me make decisions is not just having multiple choice, but having multiple ways to explain it. Because I usually don't understand a lot of things the first time. If you just explain it the same way again, I'm still not going to understand it. So, a different way of explaining things is, I find, very helpful for decision making."

"Info you can take away and read/look at on our own time. Not being rushed to make decisions, being given time."

"Information online! Reviews available to look at!"

"Affirming complaints and feedback processes. the feedback processes need to be accessible and ideally have fast, empathetic responses."

A young person elaborated that information needs to be timely, and how not having information provided to them at the right time impacted their decisions.

"... [A]fter I got my diagnosis, it took me about like six months of being in like relevant Facebook groups and following things on Instagram to work out that I would be able to access a ... chronic health plan, which gets you stuff cheaper so like physio, nutrition — that sort of stuff cheaper. And I also didn't know that I could get a mental health care plan through my GP as a part of my diagnosis as well. So, I think if I knew those things that would have saved me a lot of money. So yeah, if there's a way to make that just accessible to people because I don't think GPS even realised that you don't know, and it's just something that sort of missed."

One group member commented on how young people are particularly savvy online and how it can be a good avenue to provide information about clinicians and support options.

"I think that young people have been really good at this idea of spreading information online and things like that and shopping around until you find medical practitioners that fit. So maybe an easier way for you to find doctors that will work with you and your specific case."

In addition to practical resources and support, group members also shared how safe environments are conducive to supporting young people make decisions for themselves.

"Being talked to, rather than talked about/around."

"Having the vocabulary/ environment to say no to proposed decisions."

"Trust building."

What young people want from decision supporters

CYDA asked the LivedX focus group members what an ideal decision support looks like to them. A resounding theme in the answers, for this question and the consultation discussion more broadly, was that young people want to be respected and feel heard. They felt that too often their lived experience, agency, and knowledge of what it best for them is diminished or disregarded. Young people also want to be viewed as being "independent [and] not tied to a disability."

"Just because it is in my head, doesn't make it invalid."

"I think something that I always found quite important in like supportive family and friends, but in medical professionals too is believing invisible stuff that's going on, regardless if it's convenient for them or not. I'm sure people understand a bit, but it does become a little more difficult if you've become a bit more of an inconvenience, or perceived to be an inconvenience, so yeah, just someone that's incredibly understanding whether or not it's convenient is really important."

"I find doctors don't listen very well to you. Especially when you coming in with something more invisible than physical. I found that I'm listened to more if I have a physical problem, like I sprained my ankle. ... So I find that listening is the most important thing and understanding that I know you can see it better if I have a broken leg, but my leg isn't broken right now, it's my head and I need more help than that."

"For me, my ideal decision maker is often someone who is older than me, but has had experience working with people with similar needs as me but also respects the fact I am an individual person with different experiences and different viewpoints. So essentially, you know, they know the basics and they know how to properly communicate and effectively understand some problems that I have, but also that they know I am a different person."

"[An ideal decision supporter] is willing to do their own research, but trusts my opinion over google."

The group also discussed what boundaries that wanted decision supporters to stay within, and when to offer support and when to pull back.

"I think a decision supporter, in my view, is different from someone who supports my mental health and I think them knowing that line and when to refer."

"[They] follow my lead, [and] only enter spaces when I ask them to."

"Is okay when I ask them to step back, no ego."

"Regular check-ins with me about what I need and how they support me."

Other desirable traits in decision supporters as raised by the group include "patient", "no agenda", "non-judgmental", "good memory" "share lived experience", "reliable", "a good sense of humour", "flexible", "good listener", and people who hold themselves accountable and who are genuine.

Finally, we would like to highlight the following case study provided by a young person in our community, which demonstrates good practice; in particular, it shows a good decision support and the effort she went through to support the young person's autonomy.

"Yes, I did have this one really lovely nurse who, she realised I was a bit awkward with eye contact, so she made sure that she wasn't always looking at me. Say, we were playing a card game ... she realised I was better when I had something else to interact with, so we played cards a lot and ask questions very genuinely, but she also didn't sugar coat everything. So if I was being a bit whinier than usual she'd be like, 'Oh, c'mon. Stop that now'."

But she could also tell if I was in genuine pain and once a doctor was basically telling me to suck it up and she fully raged at him, was like, 'No, you don't know what's going on in her head' ... because I was having voices in my head at that time and I was having a moment and the doctor came in and thought I was faking it and [she] got really angry at him and helped me find a new doctor.

So I liked that she listened to what I had to say and helped me figure out the problem, but also helped me solve the problem on my terms.

She was like, 'Hey, I think this is going on. What do you think? Would you like me to help? This is how I can help', but I was involved in every step and I was involved in everything I was doing and she also told me what she was thinking.

It was very helpful, because I'm not very good at guessing what people are thinking. So ... every now and again when she said it [it] also meant that I could correct her if I was in a better place and be like, 'No, I'm actually not that bad today. I'm actually pretty good' if she thought I was in a worse place ... and then she's say, 'Oh, well okay, then I can help this other person' and I was like, 'Yeah, I'm okay today you go help them.' So she would also explain to me what she was doing so I could also help her to help more people if they needed it.

And building the trust that I had lost from those doctors. So it meant when she said, 'I think you should try this new medication' that I wasn't sure about, I had trusted that she had done the research on it and she also leant me her own research and said, 'Hey, this is what I think if you want to do your own."