



Submission to the Senate Select Committee on Autism

17 July 2020

About the Submitter

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called *Citizenhood*.

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Acknowledgments

JFA Purple Orange would like to thank members of the autism community who contributed to this submission by sharing their experiences with us.

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1. Summary and recommendations

Citizenhood describes a situation where a person is an active and valued member of their local community. The Model of Citizenhood Support is a framework to help a person live a good life where there are perceived disadvantages through investment in four key areas: Personal Capital (perspective), Knowledge Capital (information and skills), Material Capital (tangible physical resources) and Social Capital (connection with other people).

This submission describes each of the four Capitals and uses case studies featuring people living with autism to demonstrate how the actions of agencies can undermine or promote a person's Citizenhood.

By using the Model of Citizenhood Support, case studies and statistics we hope to demonstrate for the Committee how proper investment in the welfare and life chances of people living with autism by agencies can help to support them into involvement in meaningful activities and participation in a network of relationships characterised by acceptance, belonging and love.

In this submission the term 'agency' is used broadly to describe services such as government departments, schools, workplaces and service providers. We have also drawn on statistics produced by the National Disability Insurance Scheme (NDIS) and the Australian Bureau of Statistics (ABS) in relation to the education, employment and social connection of people living with autism to provide further context to the current life chances of this cohort.

We recommend:

Recommendation 1

All agencies working with people living with autism (and their families) should re-visit their mission statements and business practices to ensure they uphold the clients' Personal Capital and do not undermine the person's potential, strengths, self-worth, vision, control and confidence as valued members of mainstream community life.

Recommendation 2

Agencies should discover ways to get to know their clients on that person's own terms, including for example by placing a lesser reliance on formal tools and professional methodologies and a greater reliance on the art of open-ended questioning and active listening.

Recommendation 3

All agencies should conduct an audit of the information they provide to clients to ensure it is accessible by people living with autism and does not make any assumptions of what that person considers is in their best interests.

Recommendation 4

The Australian Government should establish a plan to increase the employment rate of people living with autism in mainstream waged employment, with specified timeframes and designated responsibilities.

Recommendation 5

Workplaces should be encouraged to include information and training for employees about how to create and maintain inclusive working environments for people living with autism.

Recommendation 6

The NDIA review and evolve the planning mechanism so that Scheme participants living with autism have authentic control and choice over how their individual budget is used to maximise their life chances.

Recommendation 7

The Federal Government should provide sustained funding opportunities for peer support networks run by and for people living with autism.

Recommendation 8

An autism inclusion campaign, as well as more training in schools and workplaces about autism and delivered by people living with autism should be rolled out nationally.

Recommendation 9

The Federal Government, through the NDIS and other relevant channels, should strengthen the availability and quality of support to assist people living with autism to make ordinary mainstream connections and take up their rightful place as valued members in community life. This includes strengthening the model of LAC support within the NDIS.

We request the opportunity to appear before the Committee to discuss our submission further.

2. Introduction

JFA Purple Orange is grateful for the opportunity to provide this submission to the Senate Select Committee on Autism.

Given the prevalence and incidence of autism in Australia this inquiry represents an important opportunity to inform and refine the government and society's approach to how we support people living with autism. Recent statistics from the National Disability Insurance Scheme show that autism is the primary diagnosis for 31 per cent of Scheme participants, making it the largest disability cohort represented in the Scheme.¹ In 2018 Autism Spectrum Australia revised its estimate of the prevalence of autism from 1 in 100 to an estimated 1 in 70 people in Australia on the autism spectrum. That is an estimated 40% increase or around 353,880 people.² The Murdoch Children's Research Institute postulates this increase could be attributed to conceptual change, diagnostic substitution, methodological differences and social-cultural influences.³ Significantly, these statistics highlight the prevalence of autism across the Australian community and particularly within NDIS participants; it is therefore essential for the wider Australian community to better understand the experiences of people living with autism.

As the Committee will see from other submissions made by individuals, families and organisations, life for people living with autism can be far from what could be described as optimal. A variety of factors means it is easy for people living with autism to be marginalised, underestimated and discriminated against. These factors include a lack of public education and awareness about autism and inadequate supports available to facilitate the involvement by people living with autism in everyday activities such as school, work and recreation.

¹ National Disability Insurance Scheme, COAG Disability Reform Council, Quarterly Report, 31 March 2020, p 90.

² Autism Spectrum Australia. 2018. Autism prevalence rate up by an estimated 40% to 1 in 70 people. [ONLINE] Available at: <https://www.autismspectrum.org.au/news/autism-prevalence-rate-up-by-an-estimated-40-to-1-in-70-people-11-07-2018>. [Accessed 15 July 2020].

³ The Murdoch Children's Research Institute. 2011. Do more children have autism now than before?. [ONLINE] Available at: <https://www.mcric.edu.au/users/murdoch-childrens-media/blog/do-more-children-have-autism-now>. [Accessed 15 July 2020].

In order to address these issues, to guard against them re-occurring and to prevent new barriers appearing in the future, JFA Purple Orange believes there needs to be proper investment in a person's welfare and life chances. One way to achieve this is by designing and implementing a plan anchored on concepts such as those laid out in the Model of Citizenhood Support.⁴ Broadly speaking, this Model is based on the premise that each of us wants to live a good life, and this can be achieved through investment in four key areas of Capital: Personal Capital, Knowledge Capital, Material Capital and Social Capital.

The purpose of this submission is to explain the key concepts contained in the Model of Citizenhood Support and how they relate to the lives of people living with autism. We use case studies and make recommendations for agencies that will assist them to help their clients achieve Citizenhood. In this way we aim to address the following elements of the inquiry's terms of reference:

- g) the social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people; and*
- k) the social inclusion and participation of autistic people within the economy and community.*

In this submission the term 'agency' is used broadly to describe services such as government departments, schools, workplaces and service providers. However, as one member of the autism community told JFA Purple Orange, agencies are made up of people, and it is the people who are responsible for their actions and hence the actions of the agency. This should be borne in mind by readers, in particular those who may be part of agencies working with the autism community - it is not possible for an agency to change for the better unless the people working there do as well.

When preparing this submission JFA Purple Orange spoke with members of the autism community in South Australia. The experiences they shared with us have been featured in Case Studies where pseudonyms have been used to protect their privacy.

⁴ Williams, R. (2013), *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia.

3. Citizenship

Citizenship describes a situation where a person is an active and valued member of their local community. Their lifestyle is informed by personally defined choices and they are able to grow through their involvement in meaningful activities and by their participation in a network of relationships characterised by acceptance, belonging and love. Citizenship comprises roles that are valued by our communities; family member, friend, neighbour, worker, club member, customer, etc. A summary of the Citizenship concept, and the associated imperative for people living with disability, is outlined in this short animated [media clip](#).

Citizenship is dynamic in that it can rise or fall depending on a person's specific circumstances. For example, a person living with autism who is excluded from the educational and social benefits of mainstream schooling is at risk of having their Citizenship diminished because of insufficient access to valued roles in mainstream community life, in this case the valued role of being a mainstream student.

The concept of Citizenship is not to be confused with the concept of Citizenship, which is a much narrower construct typically referring to membership of a country.

3.1. Model of Citizenship Support

The Model of Citizenship Support is a framework for determining what kind of assistance might be most helpful to a person in circumstances where there are perceived disadvantages such as physical or mental impairment or a lifestyle characterised by a relative poverty of resources and opportunities. By examining how a person can call upon their four key areas of Capital (Personal Capital, Knowledge Capital, Material Capital and Social Capital), it is possible to determine how a person's life chances will enable them to live a good life through exercising life choices. This submission will explain each of the four Capitals and use de-identified case studies from people living with autism to demonstrate how the Capitals can be affected by agencies.

4. The Four Capitals

The Model of Citizenship Support asserts the relative success or failure of systems of personal support in advancing people's life chances can be linked to the degree of attention given to four main elements, called Capitals:

- Personal Capital (perspective)
- Knowledge Capital (information and skills)
- Material Capital (tangible physical resource)
- Social Capital (connection with other people)

4.1. Personal Capital

For a person to advance their chances of living a good life it is important for them to have a sense of who they are, their worth and the vision or dream they are moving towards. There are six important elements of Personal Capital a person may draw upon to advance or uphold a good life: potential, strengths, self-worth, vision, control and confidence.

People may vary in the degree to which they see the inherent worth in themselves, their capacity to take up a life of active Citizenship, and what that might look like. The degree to which we give ourselves permission to do these things may depend on the life experiences we have had. These life experiences will often involve how other members of society perceive us and interact with us. Some people living with autism have told JFA Purple Orange they feel as though their diagnosis puts them "in a box" and they are stereotyped. One interviewee told us:

While autism awareness is growing, I'm not sure acceptance is growing at the same rate. A lot (of us) have internalised ableism from messages we've received which makes it harder for us to disclose we are autistic because we will be stereotyped. There's still a lot of minimising and discounting (of autistic people) and you feel as though you're not free to be yourself.

As the quote above demonstrates, for people living with autism (and their families), their life experiences may mean they have not had the opportunity to believe in their own inherent potential or strengths and have a diminished view of their self-worth. They may not have had the opportunity to imagine a good life for themselves, feel they lack the control they need to make positive change or may lack the confidence to do so.

Case Study 1 – Personal Capital – “Would they have noticed if I hadn’t told them?”

When Jenny* was on a placement as part of her university degree she told her new colleagues she was autistic. After this discussion one colleague would routinely ask Jenny why she didn’t socialise with her work mates more and told Jenny she had to spend more time with others. Jenny told JFA Purple Orange:

“Even when I explained I used my breaks as quiet time to work and that my performance would suffer without this time to prepare, I was still told I should socialise more. This made me regret telling my colleagues about my diagnosis and I wondered, would they have noticed if I hadn’t told them? Once I had the autism label, it was like some of my colleagues were looking for ways I was different.”

In this example Jenny noticed that others interacted with her differently after she told them she was autistic. This had the potential to diminish Jenny’s Personal Capital as she was made to feel different and her behaviours were more closely scrutinised than others’ in the same workplace.

Increased vulnerability resulting from low Personal Capital can lead a person to come into contact with informal and formal supports such as welfare (Centrelink) and the National Disability Insurance Scheme.

Unfortunately, for some people the experience of accessing welfare has resulted in a diminished capacity to see their inherent worth, their strengths, and the possibility of a valued and fulfilling role in the world. This happens because the person is a passive recipient of welfare services: passive in the sense they are not an active partner in the decisions

about how those services happen and recipient in the sense that the person's role is to be the receiver of other people's efforts rather than the giver of their own. This is not to suggest that the financial assistance provided by Centrelink is always unhelpful. On the contrary, thought should be given to how these payments could be used to grow a person's capacity rather than perpetuating the current disconnect between welfare and personal growth.

4.1.1. How agencies can build and uphold the Personal Capital of a client living with autism

Opportunity exists for agencies (including government departments and service providers) to help an individual build their Personal Capital. This can be achieved by the agency recognising it has a fundamental obligation to uphold a person's Personal Capital. This means the agency must carry out its endeavours in ways that do not inadvertently (or intentionally) undermine a person's view of their own potential, their strengths, their personal vision of what might be possible in their life, and their personal leadership as a decider and actor.

Case Study 2 – Personal Capital – Tertiary education setting

Sarah* was an autistic student⁵ in tertiary education in South Australia. She was told by the institution's Disability Adviser she should change her enrolment to part-time because of her autism. After speaking with others, Sarah learned this Disability Adviser would routinely give this advice to other autistic students, regardless of their personal circumstances or preferences.

During her studies Sarah was involved in a group project and on the day of their presentation one of the other group members arrived unprepared and Sarah's group had to present without them. At the end of the presentation the lecturer, who was aware Sarah was autistic, told Sarah in front of the class that she should be really proud to have

⁵ In this submission JFA Purple Orange uses the language "person living with autism". However, we have honoured the individual language used by interviewees in the quotes and case studies. This is why phrases like "autistic student" and "autistic person" have been used in these contexts.

continued on with the presentation and that she should go home and tell her mum about it. None of the other group members were addressed in this way, making Sarah feel uncomfortable and questioning why she was singled out by the lecturer.

In Sarah's case it appears the Disability Adviser and lecturer had lower expectations about Sarah's abilities than she did, which had the potential to undermine Sarah's Personal Capital. Rather than making assumptions about Sarah's ability and potential, the Disability Adviser and the lecturer should have focused on what they could do to help Sarah grow her potential, strengths and view of herself.

Case Study 3 – Personal Capital – Ignored by a service provider

Susan* visited a telecommunications provider with her husband in a busy suburban shopping centre in order to change her internet plan. She explained to the sales assistant that she was starting her own small business and the account she needed upgraded was in her name. Susan then said she was autistic and asked if they could talk somewhere away from the noise and bright lights. As soon as Susan revealed her autism the sales assistant stopped addressing her and only addressed her husband, despite the fact that plan was for Susan and was in her name. Following their visit Susan's husband was sent the survey asking him to rate his experience in the store that day.

In this situation the service provider did not uphold Susan's Personal Capital and actively undermined her by assuming her husband was the more appropriate person to communicate with about Susan's internet plan.

Recommendation 1: All agencies working with people living with autism (and their families) should re-visit their mission statements and business practices to ensure they uphold the clients' Personal Capital and do not undermine the person's potential, strengths, self-worth, vision, control and confidence as valued members of mainstream community life.

Agencies can also consider how they get to know their clients, including their clients' life experiences and the effect of this on their Personal Capital. When assessment tools and other methodologies are driven by an agency's own time and resource constraints, the agency will not get to know their client well.

For example, specific questions generate specific answers and often only derive sufficient information for the agency to calculate a measure of fit within the agency's own offerings. Even though such approaches might be described as individualised planning, or even person-centred planning, they are in fact service-centred planning because the attempts to understand the person are framed in the context of the agency's worldview, not the person's world view.

The risk of service-centred planning exists for any agency that already has ideas in mind (or arrangements in place) for assisting people in similar situations. It is important that an agency does not wholly rely on the assumption that arrangements that proved helpful to one person will prove to be just as helpful for another person with similar issues. For example, a member of the autism community told JFA Purple Orange that some NDIS Planners are making assumptions that people living with autism all require the same types of supports and are including these supports in plans. These assumptions are taking away from the individualised planning approach intended by the NDIS.

Recommendation 2: Agencies should discover ways to get to know their clients on that person's own terms, including for example by placing a lesser reliance on formal tools and professional methodologies and a greater reliance on the art of open-ended questioning and active listening.

4.2. Knowledge Capital

Each individual has a personal store of information and skill which we use to make decisions and take actions. This information also helps us to understand and describe our potential, grow our capacity and exercise personal agency. In the Model of Citizenship Support, this store of information and skill is known as Knowledge Capital.

Knowledge Capital has two important considerations: how we make the best use of what we know and can do, and how we acquire new knowledge and skill. For people living with increased vulnerability, which can include people living with autism, issues with access to information, and filters applied to information before it is received by the person, can impede that person's Knowledge Capital.

It is important to understand what filters have been applied to information before it is provided to a person so that one might assess the relative value of that information. In the context of people living with autism, filters can take a variety of forms including family members, friends, teachers, government agency staff and employers. Where assumptions are made about the capacity of a person living with autism to understand information (or their potential level interest in the information being provided), this can act as a filter which has an impact the six elements necessary for a person to uphold a good life: potential, strengths, self-worth, vision, control and confidence. It is therefore necessary for agencies as well as family members to understand how they might be underrepresenting or misrepresenting information in their exchanges with people living with autism.

Case Study 4 – Knowledge Capital – The doctor's phone call

Samantha* was in her early twenties and living with her parents when her doctor called the house. Rather than discussing Samantha's medical issues with her directly, he instead spoke to Samantha's mother, a clear breach of Samantha's privacy as an adult. Samantha believes this would not have occurred if she was not autistic.

In this situation the doctor undermined Samantha's Knowledge Capital by requiring her private information to be communicated to Samantha through the filter of her mother.

4.2.1. How agencies can build and uphold the Knowledge Capital of a client living with autism

In the Model of Citizenship Support, when seeking to help a person, an agency (or individual agent) has a fundamental obligation to uphold a person's Knowledge Capital and to build on it. This means the agency must carry out its endeavours in ways which do not inadvertently undermine the person's access, understanding and use of their Knowledge Capital.

In order to ensure an agency is not inadvertently undermining a person's access, understanding and use of their Knowledge Capital, they may need to engage in deeply thoughtful and highly intentional steps to assist the person to access information that may eventually prove meaningful, especially in the context of advancing the person's life chances. In order to achieve this, an agency should consider how it makes information available by conducting information audits on a regular basis. This audit should identify where an agency is prioritising their own interests over the interests of the people it claims to serve and should consider what role the agency plays in facilitating access to information possessed by others.

Recommendation 3: All agencies should conduct an audit of the information they provide to clients to ensure it is accessible to people living with autism and does not make any assumptions what that person considers is in their best interests.

4.3. Material Capital

The Model of Citizenship Support asserts two main types of Material Capital: Personal Material Capital and Public Material Capital, and both need to be addressed to advance a person's life changes towards a good life.

Personal Material Capital is the tangible assets owned or controlled by a person themselves, such as money, housing and personal effects. Public Material Capital are tangible assets within our communities, both publicly and privately owned, which are available for the broader population to use. Examples of Public Material Capital include public transportation, shopping malls, telecommunication networks and outdoor spaces like the beach. These assets are instrumental in a life of active Citizenship as they are typically the platform for a person to connect with others.

4.3.1. Personal Material Capital

Where a person experiences low Personal Material Capital, otherwise known as poverty, this typically translates to poor or no housing, difficulties with costs of food and utilities, and less involvement in community life because of the difficulties meeting the costs of public transportation, entertainment and so on. The experience of poverty dramatically reduces the range of choices available to a person, because many choices in life are dependent on people having money. Fewer choices mean fewer opportunities, and few opportunities means less Citizenship.

Low Personal Material Capital makes it harder for a person to access Public Material Capital; it's much harder to get to the beach, the shopping mall or the concert if you can't afford the bus fare to get there. People can experience difficulties accessing Public Material Capital separate from financial means, particularly where these assets are not accessible. For example, a person living with autism or their family member may find noisy, bright and busy supermarkets inaccessible due to the sensory challenges they pose. If in its design the bulk of Public Material Capital is inaccessible to sections of the community, many of those people will be less able to engage in community life on the same basis as others, and this cuts

people off from an almost incalculable range of possibilities – for growth, for work, for love, for belonging.

People need to be able to access Material Capital in support of active Citizenship. This includes maintaining current Material Capital and also growing Material Capital. If a person needs assistance because of increased vulnerability, the formal agency (or individual agent) has a fundamental obligation to uphold that person's Material Capital. This means the agency must carry out its endeavours in ways which help maintain, and do not inadvertently undermine, the person's ownership or control of personal material resources, or the person's access to publicly available amenities.

In order to achieve this, the agency must provide assistance in a way that demonstrates they respect and show care for that person's belongings. They must also take care to avoid practices which diminish a person's access to mainstream Public Material Capital and instead should assist a person to take advantage of this capital. A powerful example of this is the creation of 'special' services for people living with disability, such as segregated schools and workplaces. While often well-intentioned, the creation of 'special' settings for people living with disability mean this part of our population are less visible to the broader community which could lead to some people believing that public amenities and other mainstream community resources are not suitable for people living with disability.

4.3.2. Meaningful paid work

In order for a person to advance their Personal Material Capital, two elements are required: finding meaningful paid work and creating personalised budgets. Earning a living wage is the primary way most people maintain and grow their Material Capital; therefore meaningful paid employment is a powerful way to advance a person into a life of active Citizenship. As one person living with autism told Purple Orange:

"being able to maintain paid employment has increased my wellbeing massively. It's helped me be more resilient when I'm dealing with people discounting and minimising me (because of my autism) and when systems are being inflexible".

According to the Australian Bureau of Statistics, the labour force participation rate for working age people living with autism in 2018 was 38 per cent, compared to 53.4 per cent of all working age people living with disability and 84.1 per cent of people without disability. The unemployment rate of people living with autism was 34.1 percent, which was more than three times the rate for people living with disability and eight times the rate for people without disability.⁶ In 2018, 65 percent of NDIS participants aged 25 and over living with autism were employed in an Australian Disability Enterprise, with a further 13 percent in open employment at less than award wages. Only 16 percent of NDIS participants aged 25 and over living with autism were in open employment with full award wages, compared to 33 per cent for all disability types.⁷

JFA Purple Orange spoke with people living with autism about their employment experiences which are described in Case Study 5 below.

Case Study 5 – Material Capital – Employment experiences

When asked about her experience revealing her autism diagnosis to colleagues, Tina* told JFA Purple Orange:

I thought disclosing at work would free me up because I wouldn't have to camouflage anymore, but it's put me more in the spotlight. I get questioned a lot. If I talk about feeling anxious, that gets focussed on by others. Colleagues advocate for me when I don't need it or want it. For example, they will contact my manager saying, "we think Tina is stressed", when really they are the ones who are stressed about a situation. Revealing my autism has limited me in workplaces. I have not been given opportunities for higher roles. People treat you as though you are less capable or skilled. They won't invite you to social gatherings and it changes the way you are spoken to. I once told an interviewer about my diagnosis and you could feel the level of respect drop in the room.

⁶ Australian Bureau of Statistics. 2019. Autism in Australia. [ONLINE] Available at: <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018>. [Accessed 9 July 2020].

⁷ National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018, p 75.

Bianca* explained her frustrations about the lack of education and awareness of autism in workplaces:

You feel like you have to establish yourself and prove yourself before anyone knows you have a disability so you're not automatically stereotyped. People don't know how to cope if I am having an escalation. They don't know how to support me but they don't have discussions about how to support me either. Workplaces don't have Access and Inclusion Plans or mentors and there are few peer networks for autistics in paid employment. There's not much education for workplaces around autism. This has impacted my career aspirations.

Julia* revealed how the working from home arrangements imposed as a result of COVID-19 were beneficial for her:

Working from home has been great. I don't have to worry about what I look like to other people. I don't have to go through driving an hour to and from work and all the concentration that requires. It's meant I'm free to be creative and sit in solitude which I need to concentrate for long periods of time. I've been able to escape into hyper-concentration phases without being interrupted – I've at least doubled my productivity since working from home. COVID-19 has given me opportunities to participate in more things because they are being held online. I'm worried about 'returning back to normal' because this new normal has been better for me. I'm nervous workplaces will reduce these online opportunities for external engagement.

The experiences described in Case Study 5 together with employment statistics demonstrate the challenges many people living with autism face when trying to find and maintain a job, particularly in open employment at full wages. Given the importance of a living wage to a person's life chances, the challenge for agencies is how to maintain a strong focus on assisting people into authentic employment paying a living wage, and to firmly resist the temptation to conclude such a goal might not be possible for people with certain types of vulnerabilities, including autism.

Recommendation 4: The Australian Government should establish a plan to increase the employment rate of people living with autism in mainstream waged employment, with specified timeframes and designated responsibilities.

Recommendation 5: Workplaces should be encouraged to include information and training about how to create and maintain inclusive working environments for people living with autism.

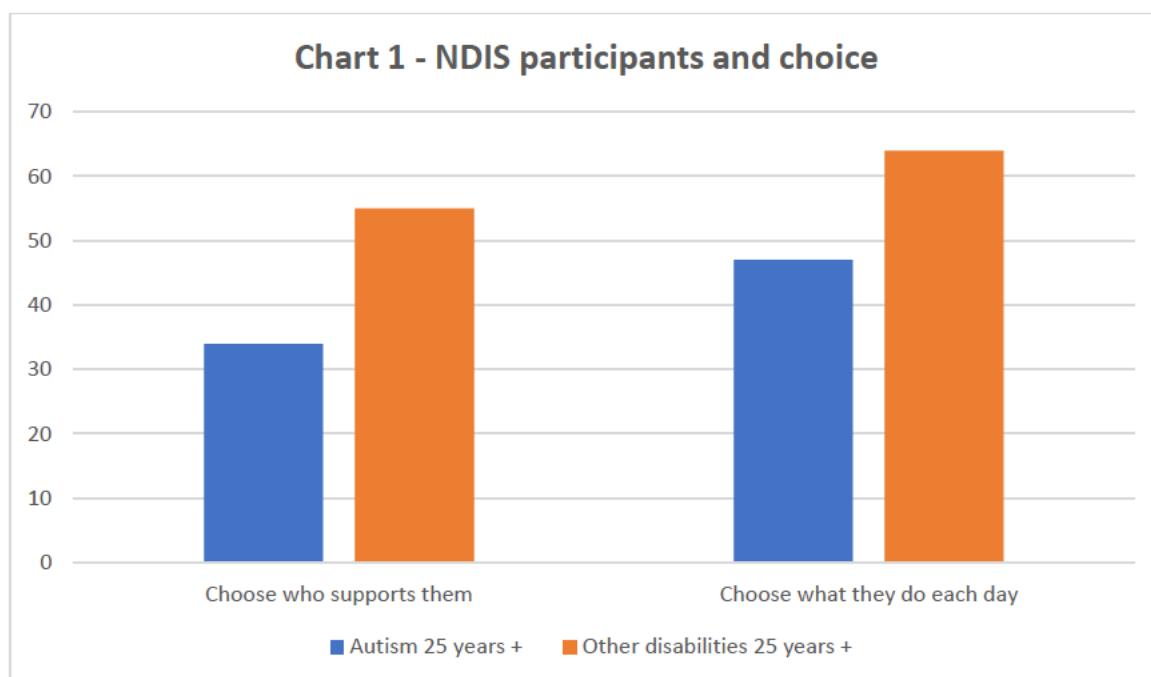
4.3.3. Personalised budgets

The availability of a personalised budget advances a person's Material Capital because the person has control over additional material resources, which can result in improvements to the person's circumstances.

Creating personalised budgets means a person has choice and control over how to spend funding provided to them. An example of this in Australia is the National Disability Insurance Scheme. According to the most recent Quarterly Report (2019-2020 Q3) released by the NDIS, 31 per cent of Scheme participants had autism as their primary diagnosis, the largest disability cohort represented in the Scheme.⁸ However, participants living with autism were less likely to choose who supports them and what they do each day than participants with other disability types. Only 34 percent of participants aged 25 and over reported they choose who supports them, and 47 per cent choose what they do each day (compared to 55 per cent and 64 percent respectively for other disability types).⁹ These statistics suggest that the increase in Personal Material Capital provided by the NDIS is not necessarily translating into improvements in the person's circumstances where they are a Scheme participant living with autism.

⁸ National Disability Insurance Scheme, COAG Disability Reform Council, Quarterly Report, 31 March 2020, p 90.

⁹ National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018, p 71.



Recommendation 6: The NDIA review and evolve the planning mechanism so that Scheme participants living with autism have authentic control and choice over how their individual budget is used to maximise their life chances

4.4. Social Capital

The nature and extent of our connectivity to other people represents Social Capital, and is an asset that can be used to advance a person's life chances. The Model of Citizenship Support proposes two main aspects of Social Capital: Connection and Fellowship.

Connection refers to the transactions that happen between people. Fellowship on the other hand refers to the depth of those transactions. Fellowship can range in depth from the pleasant familiarity of chatting to the same checkout operator during our weekly shop, or a regular cuppa with the neighbours, acquaintanceships, friendships, and close relationships. But none of these fellowships can grow or be sustained without the initial and subsequent connections shared by the people involved. Social Capital can be considered to be low if the person has few connections and relationships. The consequence of low Social Capital is isolation and loneliness.

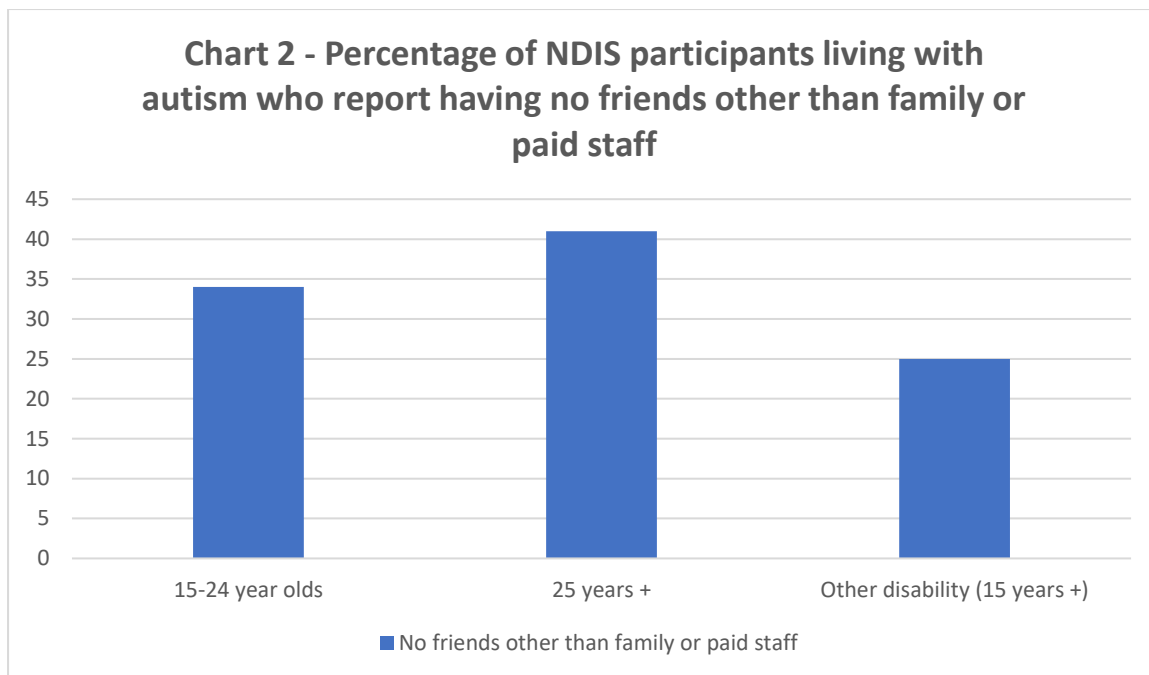
Unfortunately for many people living with increased vulnerability, daily life is characterised by the receipt of services and not much else; as though the goal of service delivery seems to be to get people clean, dressed, fed, moved and “therapied” with the rest of the time being “filler”. In this way, people are at risk of being trained to see their life goals in terms of service reciprocity rather than growing social networks.

According to the 2019 NDIS report ‘Outcomes for participants with autism spectrum disorder’, 34 per cent of Scheme participants living with autism aged 15 years to 24 years old reported having no friends other than family or paid staff, and 41 per cent of participants aged 25 and over reported having no friends other than family or paid staff.¹⁰ This compares to 25 per cent of other disabilities in those age ranges reporting they have no friends other than family or paid staff. Only 36 percent of over 25 year old’s living with autism reported being involved in a community, cultural or religious group in the last 12 months, which while low, is on par with other disability types.¹¹ The prevalence of social isolation in the autistic community was affirmed in a 2018 survey conducted on behalf of Amaze which found that 52 per cent of autistic people reported feeling socially isolated.¹² These statistics suggest that people living with autism are more likely to have Connection than Fellowship with other people in their lives and that as the person living with autism enters adulthood they are less likely to have friends outside of family and paid staff.

¹⁰ National Disability Insurance Scheme, COAG Disability Reform Council, Quarterly Report, 31 March 2020, pp 67 and 71

¹¹ National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018, p 71

¹² Amaze, Talking About Autism, Guidelines for Respectful and Accurate Reporting on Autism and Autistic People, p 10.



Case Study 6 – Social Capital – “Autistic people can get lonely”

While discussing the concept of Social Capital with Tina*, she told JFA Purple Orange:

It's vitally important for people to know the idea that autistic people don't want friends is so wrong. Some of us love seeing people and are very social. Others say they feel as though they use up all their energy at work and they just want to relax. But because people make assumptions that we don't want to socialise, autistic people can get lonely.

When the NDIS statistics pertaining to social connection were discussed with a person living with autism, they looked at the information from a different perspective. They advised that for some people living with autism, lots of social connection with others may not be something this is actively sought or wanted. It is important then noting that while the NDIS statistics provide an indication of the level of social connectedness, they do not necessarily reflect whether the Scheme participants with autism who were surveyed *want* to be more socially connected. Consideration must therefore be given to how we can better support people living with autism who want to be more socially connected achieve this. Where a person's circumstances are significantly challenging enough to be disabling, we must contemplate how we can support them to make new connections in mainstream community life.

The Model of Citizenship Support asserts that where a person lives with increased vulnerability it may be more difficult for them to move into opportunities that build connection, which has an impact on their Social Capital. A typical system response to this has been to set up special opportunities or services for the person, albeit with hopefully good intentions. However, these special opportunities typically involve grouping people living with disability, or where one-on-one support is dominated by the worker being the main conversation holder with community members. The result of these sincere but misjudged efforts is that the person's Social capital is not grown, and is often actually diminished. By their nature, special services present narrower opportunities to access and build ordinary social connections. This inhibits the advancement of the person's Social Capital, giving rise to the need for more special services. This becomes a vicious circle, where a person with lower capacity to build social connections is referred to special services, whose efforts only serve to make the issue entrenched, which in turn results in more special services.

While school students living with autism enjoy a higher rate of participation in mainstream schools (60 per cent compared to 53 per cent of other disability types), this inclusion does not carry over into weekends or after school, with only 34 per cent of children with autism spending time with friends or participating in mainstream programs during those times.¹³ Even more concerning is that children living with autism feel less welcomed and actively included in those activities compared to children with other disability types.¹⁴ This separation from mainstream activities at a young age risks entrenching segregation as the child grows older, inhibiting the advancement of their Social Capital and potentially giving rise to the need for more special services, thus perpetuating the vicious circle described above.

¹³ National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018, p 61.

¹⁴ 71 percent of children living with autism reported feeling welcomed or actively included compared to 82 percent of children with other disability types. National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018, p 61.

4.4.1. How agencies can build and uphold the Social Capital of a client living with autism

If a person needs assistance because of increased vulnerability, the formal agency (or individual agent) has a fundamental obligation to uphold and advance that person's Social Capital. This means the agency must carry out its endeavours in ways which help maintain, and do not inadvertently undermine, the person's social connections. The agency should also be mindful of the role it can play in supporting a person to advance their Social Capital by organising its supports in ways which continuously present opportunities for the person to make new connections in mainstream community life, and to maintain and deepen connections so that true mutual fellowship emerges.

Case study 7 – Social Capital – Women's social group

Beth* was in her 20s when she was strongly encouraged by a disability service provider to join a social group for autistic women. The members of the group had no say in the activities that were organised for them. On one occasion they went to an arts and crafts event where they were told to make pom poms, an activity the women felt was not age appropriate for them. This group did not provide opportunities for the women to build connections with the wider community and the members were not empowered to take ownership of the group and determine what activities were to be arranged. In this situation the organisers of the social group were not advancing the Social Capital of the group's members.

One of the frustrations people living with autism told JFA Purple Orange about was the need to take up the role of educator due to the lack of community awareness and understanding about autism. We were told how it can be "frustrating and tiring" explaining your diagnosis to another person and there is a tension between wanting to act on 'teachable moments' and a reluctance to do so due to the frequency with which these moments present themselves. However, when a person living with autism connects with another autistic person, the pressure to play the role of educator is removed. As a result, members of the autism community also told JFA Purple Orange about the importance of making connections with other people living with autism.

Case Study 8 – Social Capital – Building connections with the autism community

Julia* described for Purple Orange why building connections with other autistic people was important for her:

It took a long time for me to work out what friendship is, what work friends are, what romantic intentions look like. The beginning of the journey was meeting my husband and him being so relaxed and open about who I was. Then having the (autism) diagnosis and deliberately seeking out my community and discovering there was a whole world of people like me, people with similar life experiences who enjoyed shorter periods of contact and online friendships. I have friends now, people I can call if I need to talk about things. People who I can have conversations with and not have to worry about making eye contact. Autistic people assume we are all competent in every area to start with.

As demonstrated by Case Study 8, peer support for people living with autism is an important way to find fellowship and mutual support. Relationships with other people living with autism were described as “safe” by interviewees, and provided opportunities for them to be themselves. Greater investment should be made by the Federal Government in establishing and maintaining peer support networks run by and for people living with autism, for example through Individual Capacity Building grants.

Recommendation 7: The Federal Government should provide sustained funding opportunities for peer support networks run by and for people living with autism.

The peer support provided through connecting with other people living with autism is important, however, this should not lead to an assumption by society that these connections are the only relationships people living with autism need or want. Furthermore, peer support does not replace the importance of our mainstream communities becoming more welcoming and inclusive of people living with autism as part of a diverse community.

The lack of community awareness and understanding about autism may be acting as a barrier for people living with autism developing connection and fellowship with the broader community, and thus advancing their Social Capital. More capacity-building in schools,

workplaces and other agencies would assist in bridging that knowledge gap and remove the need for people living with autism feeling as though they need to adopt the role of educator when they are confronted with ignorance or naivete. This training should be delivered by people living with autism. A national campaign to increase autism inclusion (not just basic awareness) would help to ensure a broad reach of information about autism into the community and make it easier for people living with autism to access opportunities for connection and fellowship to the extent they want.

Recommendation 8: An autism inclusion campaign, as well as more training in schools and workplaces about autism delivered by people living with autism should be rolled out nationally.

Recommendation 9: The Federal Government, through the NDIS and other relevant channels, should strengthen the availability and quality of support to assist people living with autism to make ordinary mainstream connections and take up their rightful place as valued members in community life. This includes strengthening the model of LAC support within the NDIS.

5. Conclusion

The Model of Citizenship Support provides a framework for assisting people experiencing vulnerability to advance into a life characterised by engaging in meaningful activities and genuine, respectful relationships. JFA Purple Orange hopes that by providing case studies demonstrating how an individual's Personal, Knowledge, Material and Social Capital can be affected by agencies we have provided the Committee with insights into how agencies can assist people living with autism achieve a good life.

We request the opportunity to appear at a public hearing for this inquiry in order to discuss our submission further.

6. References

Amaze, Talking About Autism, Guidelines for Respectful and Accurate Reporting on Autism and Autistic People

Australian Bureau of Statistics. 2019. Autism in Australia. [ONLINE] Available at: <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018> [Accessed 9 July 2020]

Autism Spectrum Australia. 2018. Autism prevalence rate up by an estimated 40% to 1 in 70 people. [ONLINE] Available at: <https://www.autismspectrum.org.au/news/autism-prevalence-rate-up-by-an-estimated-40-to-1-in-70-people-11-07-2018>. [Accessed 15 July 2020]

National Disability Insurance Scheme, COAG Disability Reform Council, Quarterly Report, 31 March 2020

National Disability Insurance Scheme, Outcomes for participants with Autism Spectrum Disorder, 30 June 2018

The Murdoch Children's Research Institute. 2011. Do more children have autism now than before?. [ONLINE] Available at: <https://www.mcri.edu.au/users/murdoch-childrens-media/blog/do-more-children-have-autism-now>. [Accessed 15 July 2020].

Williams, R. (2013), Model of Citizenship Support: 2nd edition, Julia Farr Association Inc, Unley South Australia