GOVERNMENT OF MALTA
MINISTRY FOR INCLUSION
AND SOCIAL WELLBEING

RESPECTING DIVERSITY SAFEGUARDING EQUITY

Malta's 2021 – 2030 National Autism Strategy

An Autism State Support Plan in terms of Article 11 of the Persons within the Autism Spectrum (Empowerment) Act

AUTISM ADVISORY COUNCIL

RESPECTING
DIVERSITY
SAFEGUARDING EQUITY

Malta's 2021 – 2030
National Autism Strategy

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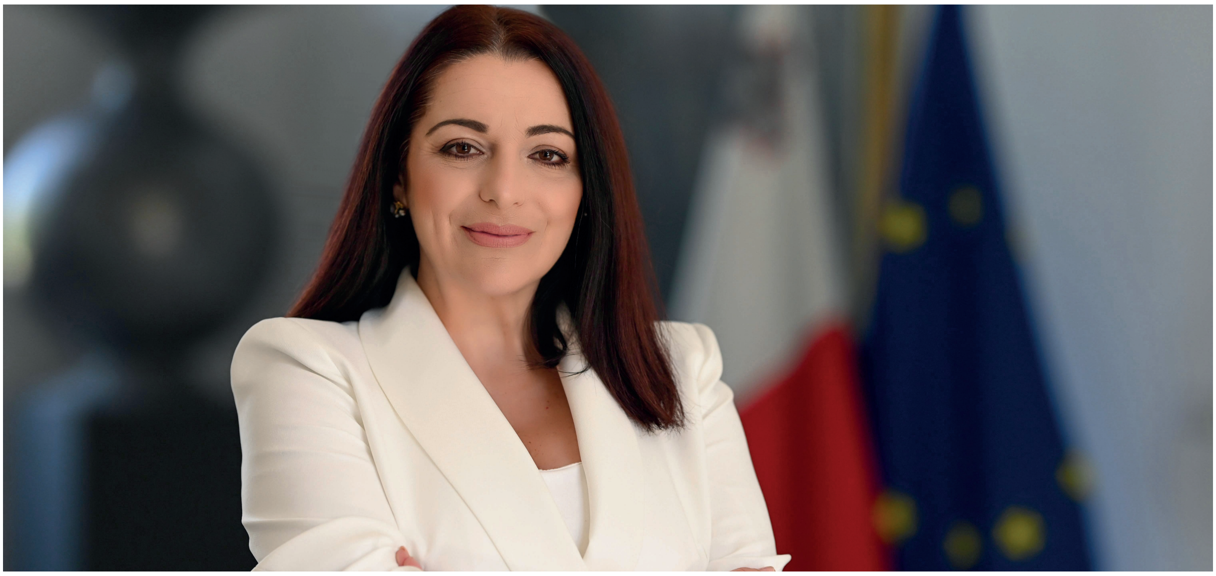

Dear persons on the autism spectrum, family members, professionals and readers,

It gives me great pleasure to present to you Malta's first-ever National Autism Strategy. This is not just any Strategy – it has been years in the making, and has already been commented upon favourably in different circles, both locally and abroad. Furthermore, the document was updated after factoring in feedback from 186 responses received at Public Consultation stage, following the initial exercise carried out by the Autism Advisory Council in preparing the text.

Activists from other countries, in fora such as the European Parliament, have shown their satisfaction that Malta chose to address autism holistically. They commented that it is refreshing that Malta does not look at autism merely from a medical point of view, but instead, as a phenomenon where the social aspect is key, and must be taken into account, if we are really to make a difference, and empower persons on the autism spectrum and their families.

This also makes Malta's Strategy unique – not only is it a lifelong Strategy, but one which seeks to examine how society and persons on the autism spectrum can meet half way, instead of merely looking at the challenges emerging from an autism diagnosis, and how to address those.

The adoption of this Strategy follows another bold step, that Malta took in 2016 – passing the Persons within the Autism Spectrum (Empowerment) Act.

This gave the rights of persons on the autism spectrum recognition in Maltese law, while setting up the Autism Advisory Council, and mandating that it draft and oversee the implementation of a National Autism Strategy. Such legislation also makes Malta a pioneer in the sector.

I would like to take this opportunity to thank all those who have worked and continue to work tirelessly within the autism sector. These persons do not merely work to support persons on the autism spectrum and their families to address challenges they come up against on a daily basis. They work to change lives.

Empowerment is not merely about tackling a perceived problem, or reducing people's suffering. It is about giving both persons on the autism spectrum and their families, and society in general, the necessary tools, in order to be able to make necessary changes, and create a society that leads to the inclusion, acceptance and emancipation of all. That is why, as Minister for Inclusion and Social Wellbeing, I salute you for working to make Malta a better place.

Lastly but most importantly, I salute all those persons on the autism spectrum who have felt different, left behind and disempowered at various stages in their lives. Malta is with you. Malta has recognised the specific challenges being faced by the autistic community, and as we have done over the past years, we will continue to work, to make sure that you – as you deserve – feel part of an inclusive and empowering society too.

Julia Farrugia Portelli
Minister for Inclusion and Social Wellbeing

Introduction

It has been a long journey, but Malta finally has its first National Autism Strategy. We have been collecting input ever since the first formation of the Autism Advisory Council was given its mandate on World Autism Day in 2018.

Expertise from the disability, education and health sectors was guaranteed through representatives of the relevant Government Ministries, and their corresponding Faculties within the University of Malta. The practical experience of Aġenzija Sapport and the regulatory perspective of the Commission for the Rights of Persons with Disability were also present, alongside the experiences of persons on the autism spectrum and their families, representing civil society.

However, it was useless to just discuss matters around boardroom tables, and not go out into the real world, and listen to real people and real issues on the ground. After all, it can be quite easy to write up a strategy document. Other countries have done this, and there is a wealth of information out there. Still, we wanted to make sure that the final document was realistic and implementable. It had to address the status quo in Malta, take a snapshot of where we are at, and chart a course of where we want to get to.

This is why, since 2018, the Council has organised a number of outreach events. We have organised meetings for service providers in the autism sector, we have engaged with schools and gone on University campus, we organised town hall and other sessions for persons on the autism spectrum. We also listened up close to the concerns of persons on the autism spectrum and their families, holding countless one-on-one meetings, to gauge the situation and factor in their experiences and wishes. We also spoke to professionals and practitioners.

While most of this work was done in Malta, we also made sure to factor in a more international perspective, participating in events and discussions abroad, including at European Union and United Nations level, to listen to other views, present our experience, and engage in a mutually beneficial debate.

The result is the document that you have in hand now. We have grouped the concerns put forward through this extensive consultation exercise into 7 main categories, and worked on providing specific action points in respect of each, after laying out a summary of the main concerns raised for every category. What you, the persons we consulted, said, is all laid out, side by side with what we, as the Autism Advisory Council, want to achieve over the next 10 years.

We will work through the National Coordination Mechanism within the Directorate for Disability Issues (DDI), set up in terms of Article 33(1) of the United Nations Convention on the Rights of Persons with Disabilities, to ensure a streamlined implementation process for the contents of this document. This process will also determine more specifically the responsibility of different stakeholders with respect to particular Strategy actions, as well as relevant timeframes for implementation within the Strategy's lifetime.

The Coordination Mechanism allows for inter-entity and inter-Ministerial coordination within the disability sector, and is best placed to be able to bring together different stakeholders that would be involved in implementing the various, far-reaching aspects of this Strategy.

Given that Malta's National Autism Strategy is an all-encompassing, cradle-to-grave Strategy, making it one of the few such documents internationally – although this document focuses much less on the medical side of things, and much more on the social and empowerment aspects – we wanted to use a system that would be fit for purpose, while avoiding duplication by creating even more bureaucracy.

Monitoring and review of the Coordination Mechanism's work on the Strategy would be then performed by the Council itself, further to the mandate given by Article 10(b) of the Persons within the Autism Spectrum (Empowerment) Act.

It will be a long road ahead – however, a journey of a thousand miles starts with a single step. I still remember, back in 2015, in the middle of my doctoral studies, and as an activist, pushing for autism-specific legislation. I was glad to see this initiative take traction, and to have eventually contributed to the resulting Act in 2016.

As an idealist, mainly armchair activist, I wanted change, and drastic measures. The process leading up to the Act, and the last couple of years working on this Strategy, have taught me that the reality on the ground is much more complex, and that things are harder than they seem. However, I am thankful to have been part of a process that is every activist's dream. While I have had a good dose of reality meanwhile, I still believe in achieving the end goals I pushed for initially – those of increased awareness, and total acceptance, inclusion and empowerment of persons on the autism spectrum in Malta. Things may seem hard – but they are not as difficult, if you are all on board. So now, while the Council will continue with its work, we call on you to join us, and let's make real change together.

I would like to thank all of the members of the Autism Advisory Council for their hard work and patience, in making this step a reality, to all those persons who made this initiative possible at both political and technical level and, most of all, to all those who contributed their feedback, shared their expertise, and spilt their heart out, to make sure we could get to this point today.

Alistair de Gaetano
Chairperson
Autism Advisory Council

01

What is Autism?

YOU SAID:

- “ People do not understand what autism is;
- Persons on the autism spectrum are misunderstood and treated unfairly due to this lack of understanding;
- There is too much concern with what other people think when a family member on the autism spectrum is having a tantrum
- Families of persons on the autism spectrum are often seen as troublemakers because businesses and government departments fail to understand their needs;
- Maltese society still maintains a strong culture of shame, and a wrong view of autism, by businesses, government departments, individuals and even some voluntary organisations, hurts persons on the autism spectrum and their families;
- Malta still lacks a culture of trying to understand the other person, whoever that person may be;
- Empowerment should really focus on challenging the stigma – persons on the autism spectrum should all just enjoy whatever activity they are engaging in, as long as it does not cause harm to themselves or to others;
- Malta is also becoming a more multicultural society, so it is important to understand that other cultures might view autism differently, and we need to target them too;
- Autism is not a disease, it is a different way of being – we must ensure that while we are all different, we are all equal – according to the concept of neurodiversity (neurological diversity) mentioned in Maltese law;
- Society should not place limitations on persons on the autism spectrum;
- Not enough awareness exists about the EU Disability Card and its uses, among persons on the autism spectrum, their families, and those providing goods and services;

- Although some persons on the autism spectrum do not speak, this does not mean that they have nothing to say, and we must make an effort to ensure that they can communicate in alternative ways."

WE WILL:

1.1 Work, together with you, and with other partners locally and abroad, to produce awareness campaigns showing what autism really is and really is not, and to challenge existing stigma and feelings of shame by family members and persons on the autism spectrum alike, while debunking discredited theories about autism, its origins, and autism interventions.

1.2 Target these awareness campaigns, including, where relevant, in the form of continuing, up-to-date training, to different sectors of society, such as:

- the educational sector;
- the health sector;
- the social care sector;
- persons on the autism spectrum and their families;
- support persons and informal caregivers;
- providers of goods and services in the public and private sectors;
- the general public, through local councils, and social and cultural groups.

1.3 Use different methods to spread our message across, such as:

- in-person visits;
- social media campaigns;
- regular print and audio-visual media.

1.4 Make sure that efforts represent different groups within Maltese society, particular when those groups are currently in more vulnerable situations:

- people from different social and economic realities;
- people from different geographical regions in Malta;
- people from different national and cultural backgrounds;
- people of different genders (since many automatically associate autism with the male gender only).

1.5 Ensure that persons on the autism spectrum, their families and significant others are at the heart of developing and delivering these campaigns.

1.6 Make sure this awareness is a step:

- towards challenging the stigma and judgemental attitudes linked to wrongly-held beliefs about autism, by family members and by any other person;
- towards ending bullying in all its forms, by different persons and in different areas of life, against persons on the autism spectrum and those close to them;
- towards the acceptance of persons on the autism spectrum as equal members of Maltese society, as specified in the law;

- towards the inclusion and empowerment of persons on the autism spectrum and their families, and towards achieving independence for persons on the autism spectrum.

1.7 Make inclusion something that becomes natural for everyone in Maltese society, by working to ensure that when we plan or do anything, everyone can participate, including by implementing the principle of Universal Design – such as by:

- making a child feel included in class and in extra-curricular activities;

- designing a building or public transportation to be accessible for everyone, including people's sensory needs too, and not only their physical needs;

- making public offices, medical facilities, shops and services such as hairdressers, welcoming for everyone;

- increasing awareness of the EU Disability Card and its uses among persons on the autism spectrum, their families, and providers of goods and services, and ensuring its wider use and acceptance;

- ensuring that open spaces and venues for enjoying leisure time can be used by everyone

- while ensuring a commitment to the principle of Universal Design as a general rule, also making reasonable adjustments to service delivery, such as by having autism-friendly hours in shops, and autism-friendly movie screenings.

1.8 Emphasise the need, in such campaigns, to empower persons who make no or little use of spoken language, by:

- also providing them with access to, funding, training and support for using augmentative and alternative communication (AAC) systems and strategies, including:

- unaided AAC such as signing and gestures;

  - aided AAC, including low-tech systems such as PECS (Picture Exchange Communication System), mainstream tablet technology with AAC-specific apps, and dedicated AAC devices, especially when such devices are indispensable for carrying out everyday activities;

  - visual communication strategies such as schedules;

as well as other languages, spoken or otherwise, alongside interventions – as and where appropriate – such as speech and languagetherapy.

- educating family members and persons on the autism spectrum themselves as to the availability of and possibility to use such alternative and augmentative communication methods;

- reaching out particularly to educational establishments and employers, public and private service providers such as businesses, hospitals and government offices, disciplined forces such as the Police, and to voluntary organisations, to be made aware of and equipped to interact with persons using alternative and augmentative communication, to change attitudinal barriers to such forms of communication, and make sure these persons are listened to.

02

Early identification and autism interventions

YOU SAID:

- “Children are not being identified early enough as being on the autism spectrum, and interventions are not commencing early enough;
- The process of early identification is lengthy, can lack dignity, and can also lead to significant costs;
- The methodology used for early identification needs to be revised, and parents demand more clarity;
- How early is early enough or too early for early intervention?
- Girls are being missed by the diagnostic system, or not being served well by current available interventions;
- We are still a long way from having systems in place to reasonably obtain a diagnosis, appropriate interventions and practical supports for adults on the autism spectrum;
- Families and persons on the autism spectrum should be given more guidance when seeking early identification and/ or autism interventions, and also assisted with relevant costs;
- We worry about continuity of services;
- Service providers offering early identification and autism intervention services should be regulated, and follow common standards for the benefit of service users;
- Children on the autism spectrum and their families should be included, as far as possible, in the process of early identification;
- Persons on the autism spectrum and their families, in particular parents and siblings, as well as significant others, should be at the centre of any autism intervention;

- Any autism intervention should be designed specifically around a person on the autism spectrum, and not attempt to change them, but to bring out the best in them;

- Healthcare needs of children and adolescents on the autism spectrum are not being addressed in an autism-sensitive manner;

- There is no appropriate medication that I can find for autism/ one of our biggest problems is overmedication;

- There is not enough information or guidance on alternative interventions for autism;

- It is important that structures and systems are in place to enable persons on the spectrum to receive an accurate diagnosis and the support that they need, thus facilitating their optimal functioning and ability to participate in mainstream activities, within a society that accepts and understands them."

WE WILL:

2.1 Work, together with you, service providers, the voluntary sector and relevant government bodies, to ensure a holistic reform of current State and private services in the area of early identification and autism interventions, for persons of different ages, by:

- building upon and strengthening already existing State structures, both in terms of clinical area and specialised human resources and training, such as the Child Development Assessment Unit (CDAU), the Children and Young People's Services (CYPS), the School Psychologist Service and the school Autism Spectrum Support Team, and related services, to ensure timely and effective intervention and support;

- working to:

- continually enhance the pool of resources, including human resources, available with respect to services, including those related to psychosocial and practical support, soft skills such as socialisation and safe internet use, and including through the use of support animals, therapies such as mindfulness and music therapy, and augmentative and alternative communication (AAC) technologies;

- ensure continuity of service;

- making sure that services are not only available to persons on the autism spectrum, but also specifically for the benefit of their family members and of those close to them, including through family-friendly measures, and especially in respect of issues such as coping with grief, struggles and parental alientation;

- ensuring regular monitoring and review of methods used, to keep them in line with the best international standards, and to make sure that delivery of services such as counselling and psychological support are not treated as purely medical interventions, but instead are delivered in a humane and socially holistic manner, in line with the social model of disability;

- developing further existing genetic services, both in terms of capacity building and health service development and training, focused on identifying the underlying aetiology of neurodevelopmental disability, while ensuring that data gleaned from such services is used towards appropriate ends;

- Understanding:

- That many individuals may not present with pronounced or stereotypical manifestations of expected autism symptoms, such as challenges in social communication or interaction, or specific interests, behaviours or activities, but might still qualify for an autism diagnosis, or otherwise for support to address the challenges they face;

- That diagnostic procedures should be carried out using a transdisciplinary approach, informed by evidence-based practice, and that even the best of such practices are only as good as the competence of those administering them;

- Understanding:

  - That many individuals with pronounced or stereotypical manifestations of expected autism symptoms, such as challenges in social communication or interaction, or specific interests, behaviours or activities, may exhibit certain key expected symptoms while failing to exhibit others, which could lead diagnosticians to not issue them with a formal diagnosis, and;

  - That individuals in whom such expected symptoms are not pronounced, or those who otherwise present in very different ways to expected stereotypical norms, might also similarly be excluded from formal diagnosis, and;

  - That every effort must be made to ensure that such factors do not impede a person from receiving a diagnosis, as early as possible, in line with the most current best practice guidelines, to ensure that a person has access to all necessary supports to address the challenges that they face, including those stemming from factors such as anxiety, sensory processing differences and emotional regulation, and those resulting from co-occurring conditions;

- Understanding that the medical model of investigation, formal diagnosis and treatment should never exclude or replace ongoing functional, social and educational supports, and that ensuring these supports should be the primary focus for early identification and/ or intervention, as distinct from striving to produce a dogmatic, permanent, diagnostic label.

2.2 Propose draft legislation that will appropriately regulate the provision of professional services in the autism field, and the registration and conduct of service providers, to:

- ensure peace of mind for persons on the autism spectrum and families using these services;

- support regulated service providers who in turn want to support persons on the autism spectrum, their families and significant others;

- put a stop to any negative practices that are not in line with the best international standards.

2.3 Work closely with Government, following the adoption of this legislation, to ensure mechanisms for financial support to persons on the autism spectrum and their families making use of regulated early identification and autism intervention services, including through tax rebates, while also making sure that there is no duplication of services covered by said financial support.

2.4 Maintain an open dialogue with service providers in the field of early identification and autism intervention, including:

- to promote the concept of holistic, person-centred interventions, with a focus on a transdisciplinary approach, bringing together different professionals from across disciplines;

- securing guarantees for continuity and coverage of services, in general, and especially when services are offered by the State, or through the partnership of a private provider with the State;

- ensuring that services are not offered merely to children, but are available across a person's lifespan;

- reaching negotiated agreements to tackle the issue of waiting lists.

2.5 Work with you, relevant government entities, and public and private service providers, to ensure that early identification and autism intervention services are more broadly gender-sensitive, and use an inclusive, intersectional approach, with a particular focus for professionals being aware of gender-related subtle yet significant discrepancies in presentation of autism in females and non-binary persons when compared to males, with therapy and support being tailored to these differences.

2.6 Work with you, relevant government entities, and public and private healthcare providers, to ensure that healthcare interventions offered to children and adolescents on the autism spectrum:

- are both disability and age-appropriate;
- are delivered in autism-sensitive settings, primarily in familiar environments such as home/ school/ occupational settings;
- are delivered by staff sensitised to the needs of these children and adolescents;
- are twinned with awareness and information measures aimed at these children and adolescents and their families, both at the place of intervention, such as the use of clear signage, and outside of it, such as the use of accessible websites.

2.7 Work with you, relevant government entities, and public and private service providers, towards ensuring better availability of and access to age and gender-appropriate and sensitive diagnosis and autism intervention services for adults on the autism spectrum, with a particular emphasis on psychosocial and practical support services;

2.8 Work closely with relevant government entities and other stakeholders involved, including the National Statistics Office, towards collating anonymised statistics relevant to the number of persons on the autism spectrum in Malta, with the specific purpose of using such data:

- in line with applicable obligations found in international and national laws;
- disaggregated following best practice guidelines established by the United Nations' Washington Group on Disability Statistics;
- to be able to better map the need for services and supports for persons on the autism spectrum, and deliver such services and supports in line with feedback received.

2.9 Work with you, relevant experts, government bodies and regulatory authorities, to properly examine the issue of medication and autism in Malta, and, in particular:

- Examine the current and possible use of medication, factoring in the rights and input of persons on the autism spectrum, to improve quality of life in relation to specific complaints;
- Look into the issue of overmedication, and tackle any concerns as necessary;
- Ensure that appropriate awareness efforts are made in respect of persons on the autism spectrum and those who support them, including professionals, concerning issues relating to medication, including the short and long-term effects of such medication, and of different options available;
- Examine the issue of alternative medicine and other interventions, offered both locally and abroad, in relation to specific complaints experiences by persons on the autism spectrum, and work to evaluate possible evidence-based benefits and risks should there be evidence for possible effectiveness, and also specific regulation.

2.10 Work to ensure that the input and voices of persons on the autism spectrum, their families and significant others are given utmost consideration, against the backdrop of this Strategy, when planning any further action taken in respect of early identification and autism intervention.

03

Education

YOU SAID:

- “Students on the autism spectrum are still not enjoying the same treatment as their neurotypical peers, in both the private and public education systems, at all levels;
- While there are many committed educators, such as Administrators, Teachers or Lecturers, Learning Support Educators, and other professionals or practitioners from specialised fields, autism sensitivity still varies largely from school to school at the primary and secondary level, and also in different tertiary-level institutions;
- At the primary and secondary level, the school and classroom environment should be adapted to ensure that children on the autism spectrum are not triggered by elements such as clutter, while rendering the environment also more pleasant for neurotypical children;
- Designing lessons or lectures in a way that better includes both students on the autism spectrum, and neurotypical students, will allow students on the autism spectrum to benefit more widely from mainstream education;
- Further efforts to include children on the autism spectrum into mainstream education, such as support classrooms or units, and further supplementary programmes, should be developed and used as necessary;
- Ensuring that a student’s statement of educational needs is not concept available only to primary and secondary school students, but also to students in post-secondary education;
- We should work closely with educational institutions, at all levels, to make sure autism knowledge is shared with all students – on the autism spectrum and otherwise, families, and educators;
- Support structures should be set up or strengthened in public and private educational institutions, at different levels, following a common design, and with the input and participation of persons on the autism spectrum and their families;

- We should take note of the benefits that e-learning has brought with it, and not forget about this once the COVID-19 pandemic is over;

- Transition planning should happen in a more structured manner, particularly between the home or childcare and the educational system, within the educational system, and between the educational system and the world of work."

WE WILL:

3.1 Work, together with you, and with relevant government bodies and education providers, to:

  - ensure an updated, streamlined and holistic framework for establishing, reviewing and meeting the educational needs of students on the autism spectrum;

  - build upon processes, such as the work of the Statementing Moderating Panel, policies such as the National Inclusion Policy, and toolkits such as the Autism Spectrum Support Toolkit, that are currently in place;

  - ensure that Individualised Education Plans (IEPs) also extend to students in tertiary education, while complementing existing schemes such as Course Access Needs (CAN) reports used by the University of Malta,and involve students in the process of their drafting and follow-up, while measures would be taken to ensure that IEPs are implemented and adhered to in the best way possible;

  - strengthen existing and develop new support structures across educational institutions, and eventually a common plan for such structures at the primary, secondary and tertiary levels;

  - further explore and harness the benefits of e-learning.

3.2 Work, together with you, and with relevant government bodies, education providers, and potential or prospective employers, to:

- build upon and consolidate existing schemes, and develop a holistic framework for providing students on the autism spectrum with career guidance and support;
- create internship and work placement schemes for students on the autism spectrum, and encourage potential employers to join such initiatives;
- create a system, based on best practice experiences in other countries, that would ease students on the autism spectrum from educational institutions into the world of work.

3.3 Work, together with you, and with relevant government bodies and education providers, to:

- increase content related to autism, including exposure to real-life situations involving autism, in initial and follow-up training, which is delivered to educational professionals, and constantly updated;
- ensure that continuing autism awareness is provided both to all students, and to parents where applicable.

3.4. Work with relevant government bodies and education providers, to further establish the principle of Universal Design for Learning – design that works for everyone – as a core educational value, while promoting positive attitudes and further awareness in this respect.

3.5 Work, together with you, and with relevant government bodies and education providers, to:

- encourage the development and implementation of support classrooms or units for students on the autism spectrum, within mainstream education;
- review and encourage the development of new supplementary programmes,

responding to general need, also in collaboration with non-governmental entities and private providers.

3.6 Work, together with you, and with relevant government bodies and education providers, to:

- out when children are still as young as possible, and that the State is empowered to take necessary steps in the best interests of the child as part of this process, in order that children would be able to access the most appropriate services and supports as early on as possible, and without delay;

- make further efforts to ensure the inclusion of certain students on the autism spectrum into mainstream education, to ensure they receive their academic entitlement, rather than resorting to methods such as extensive use of withdrawal rooms;

- review the programmes offered by schools, and make recommendations concerning updates to existing programmes, and new programmes.

3.7 Work, together with you, and with relevant government bodies and education providers, on appropriate transition planning strategies at all levels:

- from the home and childcare to compulsory schooling;

- from primary to middle school, middle to secondary school, secondary school to post-secondary education, and post-secondary to tertiary education;

- between formal education and employment.

04

Employment

YOU SAID:

- “ We are worried that our children will not be able to find a job anywhere;
- The employment services are not autism-friendly, so there is no way that I can get a job, if I cannot even get through the process that will help me to get one;
- Employers do not know what autism is, or else do not want to employ persons on the autism spectrum;
- I am afraid of disclosing that I am on the autism spectrum at work, because they will fire me on the spot;
- There is no way I will get a serious job if I am on the autism spectrum, I was only ever offered simple tasks because of the way I am, but I know I am capable of doing much more;
- Employers prefer to pay a fine if they do not meet the 2% quota for employing disabled persons, rather than offering proper employment to persons on the autism spectrum that would benefit both sides;
- We just wish some people could help us with on-the-job coaching;
- There are job training programmes, but it is impossible to continue in full-time employment with a company after a period of training;
- My employer is refusing to make necessary adjustments I am entitled to due to being on the autism spectrum, or else is threatening to fire me for being difficult;
- We don’t know where or who to turn to for assessment, training or support concerning employment;
- Trade unions should be there to defend the rights of all workers and jobseekers, including those on the autism spectrum.”

WE WILL:

4.1 Work, together with you, relevant government entities, and public and private sector employers, to:

- ensure an updated, streamlined and holistic framework for establishing, reviewing and meeting the employment needs of persons on the autism spectrum, including by ensuring accessibility, specifically sensorial accessibility of workplaces, in line with the principle of Universal Design, thereby also benefitting autistic and non-autistic employees alike;

- ensure awareness and implementation of person-centred reasonable adjustments, such as teleworking arrangements, provision of assistive technologies, and greater awareness and understanding in respect of balancing work and leave, particularly sick leave;

- devise and deliver presentations highlighting the benefits of employing persons on the autism spectrum;

- encourage effective and mutually beneficial employment of persons on the autism spectrum, as an alternative to employers paying prescribed fines for not meeting employment quotas for disabled persons;

- devise training on autism at the workplace, for employers and co-workers.

4.2 Further work, together with you, relevant government entities, and public and private sector employers, to:

- strengthen existing programmes offered by the State or by private employers, in areas such as pre-employment training, including job interview preparation, and job placements, aimed at persons with disability, to specifically better include persons on the autism spectrum;

- create proper channels of communication, for persons on the autism spectrum and their families to be made aware of, and be able to reach out to these programmes;

- ensure outreach to persons on the autism spectrum in respect of employment in niche areas that bring out their abilities;
- make sure that access to employment is not only targetted at certain persons on the autism spectrum, but to different persons having differing support needs.

4.3 Engage with relevant government entities and educational institutions, and external researchers as necessary, to:

- continue strengthening the national system of job coaching and mentoring, while ensuring regular monitoring and review of said system;
- create partnerships with foreign entities to address the shortage of job coaches and job mentors in Malta;
- work towards a job retention strategy for Malta, in collaboration with both private and public sector employers.

4.4 Work, together with relevant government entities, to:

- encourage new firms, particularly foreign firms with a track record in the autism field, and local startups, to operate in an autism-friendly manner;
- offer guidance, financial incentives and people on the ground to these firms, including job coaches and job mentors;
- explore a system for certifying and acknowledging autism-friendly employers;
- encourage the use of social enterprises in the field of autism, both for the benefit of persons on the autism spectrum, and especially with the involvement and even the direction of persons on the autism spectrum.

4.5 Engage with relevant government entities, to ensure that tax incentives offered to employees on the autism spectrum are also extended to persons on the autism spectrum who want to become self-employed.

4.6 Make it a priority to work closely with regulatory authorities, to ensure a crackdown on discrimination, by proactively identifying and addressing issues related to:

- employers acting in a discriminatory manner in the pre-employment phase, such as with respect to job interviews;
- employees disclosing that they are on the autism spectrum;
- employers not providing reasonable adjustments or an appropriate work environment, as required by law, to employees on the autism spectrum;
- employers under-tasking, or bullying or infantilising employees, due to these employees being on the autism spectrum;
- employers threatening employees with negative consequences or loss of employment, for reasons related specifically to an employee being on the autism spectrum.

4.7 Initiate a constructive dialogue with national trade unions, with the participation of persons on the autism spectrum and their families, to:

- make trade unions and their officials at all level aware of autism, and the needs of persons on the autism spectrum in the labour market;
- ensure that trade unions become drivers for promoting equity and non-discrimination for persons on the autism spectrum, in all areas related to employment and industrial relations.

05

Advocacy, Self-Advocacy and Outreach

YOU SAID:

- “We do not have a voice (persons on the autism spectrum);
- What about the South?;
- What about Gozo?;
- What will happen to our children when we are gone?;
- Why won’t they listen to us, as parents?;
- How will they listen to us, if persons on the autism spectrum are not taken seriously?;
- If only we were listened to or included, we would not be in this situation right now;
- ‘Having a voice’ and ‘being listened to’ are two different things;
- I want my children to be able to stand up for themselves, and tell their teacher how they feel, the next time around;
- We want to go out there and show Malta who we really are, but it is impossible to do that right now.”

WE WILL:

5.1 Continue working with the Autism Advisory Council working group, set up in terms of the law, for persons on the autism spectrum, to:

- give persons on the autism spectrum the encouragement and necessary support, along with the platform, to seek real empowerment;
- acknowledge that persons on the autism spectrum are different but definitely not less, in the spirit of neurodiversity, allowing them to cultivate a sense of identity and share it with others;
- enable persons on the autism spectrum to coordinate and direct their efforts at the national level, as agents for change, including through the formation of self-advocacy organisations led by them;
- work with persons on the autism spectrum so that they would become true advocates, using their voice (through whatever means) in the way they want to be heard, rather than only when they feel heard.

5.2 Create one or more similar working groups for family members of persons on the autism spectrum, paying particular attention to the voices of parents and siblings, to:

- give family members a more unified platform within the Autism Advisory Council;
- be operated in coordination with established, reputable stakeholders already in existence.

5.3 Continue organising the annual Service Providers' Meeting, while exploring further avenues for dialogue with them, recognising:

- the need for their services;

- the role and contribution of these entities;
- the importance of open and constructive dialogue with them.

5.4 Engage with all relevant stakeholders, to address the needs and challenges of specific regions in the country, in particular Gozo, as well as other regions and areas that would particularly benefit from such an exercise, through:

- commencing a dialogue with the Ministry for Gozo, to implement the law and this Plan in a more focused manner in that region, while replicating, as far as possible, at the regional level, elements and mechanisms described in this Plan;
- engaging with regional councils representing Malta's other regions, as well as with local councils, as a means to better reach out to the communities that they represent, and devise more targetted ways in which to implement this Plan at the regional and local levels.

5.5 Cooperate with non-governmental organisations and, in particular, organisations of students and young people, including the National Youth Council (KNZ), to:

- ensure that advocacy and self-advocacy are not merely actions limited to activists or self-advocates in the autism field, but are streamlined into the daily activities of these organisations, which would be structured on the principle of Universal Design;
- empower all their members through ensuring that the organisation practises inclusion in all its processes and activities;
- encourage participation by and empower actual and potential members on the autism spectrum, including by supporting and encouraging them to hold positions of responsibility within said organisations, such as becoming board members, having fostered an autism-friendly environment;
- also prepare persons on the autism spectrum for effective participation in political and public life.

5.6 Reach out further to education authorities and specific educational institutions (including at tertiary level), in the private and public sectors, to include advocacy, in particular self-advocacy, and empowerment, as part of school curricula – such as in Personal and Social Development classes, alongside efforts at autism and peer awareness discussed earlier in this Plan.

06

Autism and Adulthood

YOU SAID:

- “Why does everyone just talk about children, but not about adults?;
- Just because I am an adult on the autism spectrum, I am expected to ‘grow up and act normal’;
- What about women? What if I do not otherwise identify as a male?;
- The Maltese system leaves you alone once you turn 16, unless you are really ‘severe’;
- Navigating the healthcare system is extremely daunting once children on the autism spectrum start to grow up;
- Police, employment services, businesses – they are not trained or equipped to interact appropriately with adults on the autism spectrum;
- Adults on the autism spectrum should be involved in efforts for change – as eye-openers, and eventually even role models and success stories;
- As adults on the autism spectrum, we would like to see further initiatives that will support us with socialisation;
- Unless we get Maltese society to understand autism, how can it integrate us? If kids on the autism spectrum are ‘naughty troublemakers’, then what about adults seeking jobs and having sensory overloads?;
- It is impossible to access appropriate services and supports – or even diagnosis – for adults on the autism spectrum, or else information is very well hidden;
- We are infantilising adults on the autism spectrum, and as a result, denying them their legal capacity because we presume they are incompetent to make any decisions about their lives;

- Why does the institution I live in not allow me to enter into a relationship, just because I am on the autism spectrum?;

- Why do my children have to end up in institutions when they grow up, instead of receiving services and supports within the community?;

- Society is holding my children, who will transition to adult life in a couple of years, away from the opporunity of accessing employment, other services, and rights, on an equal basis with non-autistic peers;
- I want to be independent;

- If we don't even talk about autism and adulthood properly, how can we even start to address the existing (but hidden) phenomenon of adults growing old on the autism spectrum?."

WE WILL:

6.1 Work with adults on the autism spectrum, through the Autism Advisory Council's specific working group, and through events and initiatives organised, to:

- continue determining the needs and challenges faced by adults on the autism spectrum, while working together to ensure empowerment as a path to independence;

- increase awareness as a way of increasing acceptance and inclusion;

- specifically focus on the issue of masking, performed for different reasons, by adults on the autism spectrum;

- create safe spaces for socialisation and peer support, including by further developing the working group into a free-standing entity;

- reach out to relevant stakeholders, to contribute to specific initiatives for change.

6.2 Engage families – also emphasising the role of siblings – and significant others, to obtain feedback on needs and challenges, and to act as allies in initiatives aimed at reaching out and making a change.

6.3 Focus particular efforts on targeting decision-makers and providers – including through updating relevant laws and policies where necessary, and through providing continuing, up-to-date training – in the areas of:

- Employment;
- De-institutionalisation, alternatives thereto, and measures to prevent institutionalisation;
- Social support and care, including within the community;
- Independent living within the community;
- Healthcare;
- Education;
- Leisure and culture, including outreach to voluntary organisations;
- Sports;
- Justice and law enforcement.

6.4 Contribute, working in particular with adults on the autism spectrum and their supporters, to the discussion on reforming the law, to ensure that:

- adults on the autism spectrum are allowed to be legally capable to make decisions concerning their lives, in line with relevant legislation;
- adults on the autism spectrum are guaranteed the support of appropriate and trusted persons, where relevant;

- adults on the autism spectrum are not denied relevant supports allowing them to exercise their personal autonomy and live independently, including reasonable adjustments and acceptance of alternative communication methods in areas such as employment and leisure, with relevant sensitisation efforts engaging all involved.

6.5 Work, in particular, to ensure that adults on the autism spectrum are not:

- denied the right to explore and express their sexuality, sexual orientation, gender identity and gender expression, in respect of which relevant efforts should include the Gender Wellbeing Clinic's Multi-Disciplinary Team, as and when necessary;
- denied the right to make legally available choices about their relationships, sexual health and reproductive rights, including about contraception;
- given contraception without their consent;
- forced into medical procedures that violate their bodily integrity, self-determination and privacy, such as by not allowing them to have children, or otherwise interfering with their sexual and reproductive development;
- denied the right to have a family and be parents, including the right not to have their children taken away from them, and the right to appropriate support mechanisms;
- denied access to age-appropriate sex education, tailored to their learning needs throughout their lifespan, and with a particular focus on issues such as consent and navigating social cues.

6.6 Work with you to ensure that due importance is given to addressing transition planning:

- in all areas already discussed elsewhere in this Plan;
- from paediatric health services, through adolescence, to health services for

adults, through adulthood and old age, including geriatric services specific to the needs of persons on the autism spectrum.

6.7 Start a discussion, working with you and with all relevant stakeholders, in Malta and abroad, on the topic of autism and ageing, to eventually also explore specific needs and challenges in this area, and start working towards addressing them.

6.8 Work with you and all relevant stakeholders, to make sure that a gender-sensitive and inclusive perspective is ensured concerning all areas covered by this Chapter.

07

The Autism Advisory Council

YOU SAID:

- “We want a centralised focal point to deal with autism in Malta;
- We would like the Autism Advisory Council to be more involved in the day-to-day work of particular sectors e.g. education or health;
- We would like to see the Autism Advisory Council play a larger role in advocacy;
- We want the Autism Advisory Council to involve our particular group e.g. persons on the autism spectrum/ families/ service providers, more regularly/ deeply in its work;
- We would like to see Gozitan representation on the Autism Advisory Council;
- We want the Autism Advisory Council to establish a social media presence and provide online resources;
- We would like to see the Autism Advisory Council organise more meetings and events for us.”

WE WILL:

7.1 Continue working with you:

- throughout the process of implementing this Plan, through the National Coordination Mechanism within the Directorate for Disability Issues (DDI);
- throughout the process of monitoring the implementation of this Plan, and reviewing it at regular intervals, through the Council and its structures;
- to create terms of reference for reviewing and monitoring the progress achieved through the implementation of this Plan, including through the use of a social impact assessment process and analytical indicators.

7.2 Enter discussions with Government, as a result of the consultations that led to the drafting of this Plan, with a view to the possible redimensioning of the Council and of its role, including by amending the law in respect of the Council's composition, structures and role.

GOVERNMENT OF MALTA
MINISTRY FOR INCLUSION
AND SOCIAL WELLBEING