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Licensing

Norland has licensed the 'First Steps - An Early Autism Family Support Programme' to the Transforming Autism Project Charity to implement it, as presented in this document, and under the terms and conditions of a Memorandum of Understanding signed between the two parties.

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- Aaliya Mavani Occupational Therapist, Transforming Autism Project
- Sarah McDonald Programme coordinator, Transforming Autism Project
- Dhakshini Patel Integrated Child Psychotherapist, Transforming Autism Project Lead therapist
- Giora Shayngesicht Developmental Therapist and Supervisor, Mifne Center, Israel
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- Jane Yates Integrative Child and Adolescent Psychotherapeutic Counsellor, Transforming Autism Project child therapist

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Conflict of Interest Statement

The authors declare that the research was conducted, and the programme was designed in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

A note on research-informed professional practice

Knowledge and best practice in the field of autism are constantly changing. As new research and experience broaden our understanding, changes in professional research practices may become necessary. Practitioners must always rely on their own experience and knowledge in evaluating and using any information and methods described in this programme. In using such information or methods, they should be mindful of their own safety and the safety of others, including parties for whom they have a professional responsibility.

A note on terminology

In this document, the following terms are used:

- Autism is used to refer to the condition also known as autism spectrum disorder (ASD).
- **Autistic child** is used, rather than **a child with autism**, as this is the preferred term among the community of autistic individuals.



- **Caregiver** is used interchangeably with parent/parents, and caregiver/caregivers to refer to any individual who has the primary caregiving responsibility for the child, including biological parents.
- Child psychotherapist is a qualified and licensed therapist who observes, assesses, and supports children and young people, experiencing psychological and mental health problems.
- Lead therapist is a qualified and licensed child psychotherapist. For the purpose of this programme the lead therapist conducts the initial screening of the child/family, supports and coordinates the work of the other therapists and oversees the therapeutic/clinical aspect of programme implementation.
- Paediatric occupational therapist is a qualified and licensed occupational therapist who
 observes, assesses, and supports young autistic children experiencing sensory-motor
 challenges.
- **Programme** is used to indicate that the support offered is time-bound, aiming to achieve specific outcomes on its completion.
- **Programme manager** refers to the individual who has management and administration responsibilities for the programme.
- **Support** is used to denote the positive stance taken in this programme concerning the child's potential and caregivers' capacities. The programme is not therapy or an intervention, but rather focuses on supporting caregivers to enhance their capacities to enable their child's inherent potential.
- **Therapists** is used as a shorthand to refer to all therapists involved in the programme implementation, i.e., the child psychotherapist, the paediatric occupational therapist.



1. Introduction

The 'First Steps - An Early Autism Family Support programme', hereafter referred to as the programme, is designed for children up to the age of four years who have been diagnosed with autism or their caregivers are concerned that might be autistic. The programme is child-and-caregiver-focused, offering in-home support by a team of therapists consisting of child psychotherapists and paediatric occupational therapists.

The programme is informed by recent scientific evidence concerning autism. It was developed in three phases. In the first phase, a systematic review of recent research concerning autism in young children was conducted and a conceptual framework was developed. In the next phase, the programme was designed with the input of an advisory group, consisting of practising child psychotherapists, autism experts and parents of autistic children. In the third phase, the programme was piloted so that it could be reviewed and refined to its final version, presented in this document. The input of practising child therapists in the design of the programme is a unique element, as it was important to understand and interpret the research findings in the context of the everyday experiences of young autistic children, their caregivers and the therapists supporting them.

This is not a pre-packaged support programme to be universally followed with all children and caregivers, based on preconceived ideas about autism. It is a programme which offers a roadmap for providing personalised support tailored to the unique strengths, capacities and needs of the child and their caregivers. It is a programme which requires *'learning to listen'* for both the therapist(s) and the caregivers.

This document provides an outline of the support programme. The document is for caregivers of young autistic children, and the child therapists involved in the programme implementation. It is intended to be used as a reference to enable caregivers and therapists to have a shared understanding of what is expected from the programme and what will happen during its implementation, so that there is open and transparent communication.

2. A brief note about autism in young children

Autism, also referred to as autism spectrum disorder (ASD), is a complex neurological and brain development condition, which is caused by complex genetic, environmental, and epigenetic factors (American Psychiatric Association 2013). The most noticeable symptoms of autism include social disinterest and lack of or limited affective responsiveness, repetitive or restrictive behaviours, and impaired communication. Severe symptoms may be perceived by and cause concern for caregivers early in children's life, while less severe symptoms might be noticed when children enter the school education system, and their behaviour and interactions affect the teaching and learning process.

Increasingly, research has shown that signs of autism are evident early on in a child's life. Some of the early signs include a child's response to sensory input (such as noise, light, texture, taste, smell, and physical contact) and sensori-motor coordination challenges (Trevarthen and Delafield-Butt 2013, 2020; Walbam 2019). It is argued that the most common and noticeable symptoms of autism, such as social isolation, social emotional and cognitive delays, and language disorders, are secondary consequences of poor early sensori-motor and affective integration (Trevarthen and Delafield-Butt 2013).



Everyday sensory challenges - amplified by their quantity, quality, and intensity - disrupt sensory and motor coordination and regulation and become overwhelming or distressing for an autistic child (Robello et al 2012). When faced with a difficult sensory experience, a young child may appear not to respond, while another may under or over-react in a way that indicates significant distress (Sinclair et al. 2017). The enhanced sensitivity that is characteristic in autism can make this situation feel more intense and devastating for the child concerned (Sahar nd).

If the distress caused to an autistic child from their everyday experiences is not understood by a

Signs of autism can be noticed early on in a child's life, especially concerning sensory sensitivity and motor coordination challenges

parent or caregiver, it may affect their interactions and relationships with their child (Montaque et al. 2017). Parents may find it difficult to be in tune with their child, which will affect the connectedness, attachment, and bond they have with them. Thus, parental awareness of these early signs is crucial in building connectedness with their child and developing the skills to support and strengthen the child's potential.

Autism is a lifelong condition which is not treated or cured, but autistic children can be supported early on to enhance their inner potential and strengths and increase their capacities to lead a fully functioning life (Salazar and Rosello 2021; Sahar nd). Although data about the diagnosis and prevalence of ASD among very young children are limited, there is evidence that, in recent years, the prevalence in this age group has increased with most children receiving an evaluation of ASD between 23-37 months (Christensen et al 2019). Greater awareness about the sensori-motor control and affective regulation as early signs of autism (Trevarthen and Delafield-Butt 2013), which manifest among very young children, might have helped in this aspect. Indeed, sensory impairments are included in the diagnostic criteria for repetitive and restrictive behaviours for autism (APA 2013). Thus, understanding the condition is the starting point.

3. About the programme

In this programme, the child is viewed as a potent, intentional, and goal-oriented individual, inherently wired to seek connection and build trusting relationships with others. Starting from this position, the programme is strengths-based and, while the child is at the centre of the programme, the support offered is primarily aimed at caregivers. The programme is informed by a conceptual framework (discussed in section 8 of this document) which recognises the crucial role of:

- children's early experiences, especially during the first three years of their life, in shaping the brain's architecture and determining its development.
- The caregivers' understanding of the mechanisms of sensory and affective reciprocity in children's everyday experiences, including their interactions with their caregivers
- The caregivers' understanding of the mechanisms of the intersubjective nature of interactions, where the child and caregiver interpret each other's intention in subtle and unconscious ways that guide their responses and actions
- The caregivers' appreciation that their capacity for intentional and reciprocal interactions with their child are subject to their life stresses and challenges.

3.1. The aim and objectives of the programme

The aim of the programme is to reinforce and enhance trusting relationships between the child and the caregiver, building on the strengths and the potential of the child and the capacities of the caregiver.



To achieve this aim, the support programme has the following objectives:

1. To assess and continuously reassess the child's strengths and the caregivers' capacity, while acknowledging the challenges experienced.

2. To assist the caregivers to:

- notice incidents of glimmer and delight in their interactions with their child and work with the therapists to understand and appreciate the triggers and nuanced processes that enable such positive interactions
- appreciate the reciprocity between sensory and affective experiences in playful, intentional, verbal, and non-verbal interactions
- increase their ability to recognise the child's intentions and be in tune with them through joined attention to enhance the connection between them and convey feelings of security
- habitually use and embed new skills, introduced by the therapists, in their everyday life to enhance connectedness, trust and feelings of security with their child.
- 3. To assist the caregivers to recognise and appreciate how their life stresses and challenges impact on interactions and relationships with their autistic child and help them to seek resources and ways of addressing them.

The initial assessment determines the goals to be set out for the child and the caregivers for the duration of the programme, while the end-of-programme assessment details the strengths and needs of the child and the caregivers, summarises key techniques used to support the child, and makes recommendations for future support and/or therapy.

The therapists work with caregivers to break down and analyse second by second instances of delight and glimmer to identify patterns of interaction and communication, verbal and non-verbal, that enable such instances. Becoming aware of such patterns, the caregivers can repeat them and over time habitually embed them in their interactions and communication with the child (Harrison and Tronick 2021).

At the same time, the therapist work with the caregivers to address their own anxieties and stresses. An overanxious caregiver may not be always emotionally available to constructively respond to the child's intentions, disrupting the reciprocity and synchronicity in their interactions and communication. Whereas emotional availability provides a matrix for mutual and reciprocal communication (Alonim et al 2021).

3.2. The interdisciplinary nature of the programme

The programme is implemented by licensed child psychotherapists and licensed paediatric occupational therapists, who work together to:

- assess the functioning of the child and the family
- provide support and guidance for enhancing intentional and reciprocal child and caregiver interactions.

For the duration of the programme, the therapists work with both the child and the caregivers during home visits. Their starting point is the assessment of the strengths of both the child and the



caregivers, while acknowledging their challenges. The therapists work concurrently in three different ways:

- Firstly, they work directly with the child in intuitive and sensitive ways, and, at the same time, guide the caregivers to notice their child's strengths and support them to initiate intentional, playful interactions with their child.
- Secondly, the therapists work together with the caregivers to support the child as experts in their own ways the therapists as experts in providing appropriate support, and the caregivers as the experts who know their child best.
- Finally, the therapists work with the caregivers to enable them to recognise their strengths and capacities, to address their own needs, and to look for solutions that draw on resources and available external networks and make use of existing policies.

While the child is at the centre of the support programme, the therapists work directly with caregivers and support them, considering the family context and circumstances, and external factors (e.g., policies and societal norms, resources, the availability - or lack of - support networks) which have significant direct and indirect impacts on families. As such, the programme is child-and-caregiver-focused (see Figure 1).

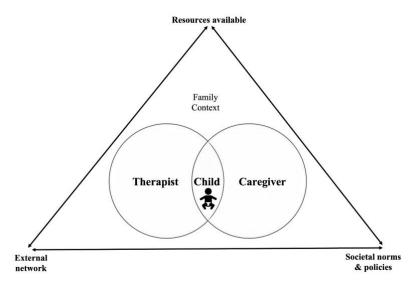


Figure 1: A child-and-caregiver-focused programme

3.3. Duration of the programme

The programme is of the duration of 12 weeks and consists of three phases:

- a preparatory phase of four weeks (detailed in section 4.1)
- the home visits phase, which lasts for six weeks (detailed in section 4.2)
- a concluding phase of two weeks (detailed in section 4.3)

4. Admission to the programme – Screening process

The programme is for young children, up to four years old, who may not have an autism diagnosis, but their caregivers are concerned that they display autistic traits. It is also for children who have an



autism diagnosis but they do not receive any support/therapy or the therapy that they receive is compatible with this programme.

If a child does not have a diagnosis, then an initial screening may take place, followed by an initial exploratory discussion with the programme lead therapist to establish the programme's suitability for the child and their caregivers. The initial screening may involve the completion of the Quantitative Checklist for Autism in Toddlers (Q-CHAT) by the caregivers (Appendix 1). The Q-CHAT is for children 18–30 months old and has been developed by researchers (Allison et al 2008; Allison et al, 2012) of the Autism Research Centre at Cambridge University.

The Q-CHAT is not a diagnostic tool and should not be used as such. It simply indicates if a child has low, average, or high number of autistic traits (The Q-CHAT scoring key is available in Appendix 2). A high score is an indication for further assessment by an appropriate multi-disciplinary team for a diagnosis (The initial screening process is outlined below in Figure 2).

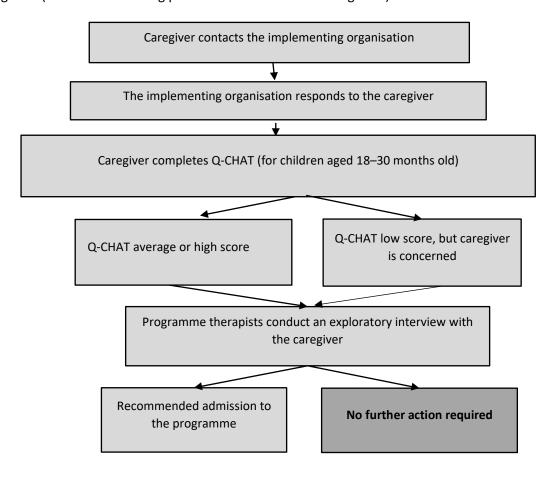


Figure 2: Initial screening process

If the Q-CHAT gives an average or high score, the caregivers may have an initial exploratory interview with the programme lead therapist to establish whether the child and the caregiver will benefit from joining the programme. If there is a low score and the caregivers are still concerned, then they may still have an initial exploratory interview with the programme lead therapist to determine appropriate action.



If a child does not have a diagnosis and they are below the age of 18 months or older than 30 months (up to the age of four years), then the programme lead therapist will have and initial e interview with the caregivers to determine the programme suitability.

Similarly, if a child already has a diagnosis and receives support, then the lead therapist will have an initial exploratory discussion with caregivers to establish whether the programme is appropriate for the child's diagnosis and compatible with any other support that might already be in place. This initial discussion is intended to help the caregiver to make an informed decision about whether to join the programme.

If the programme is deemed appropriate for the child and their caregiver, the programme lead therapist will detail and explain to caregivers the processes and what is expected to happen at each phase of the programme (i.e., the preparatory phase, the home visits phase, and the concluding phase, as detailed below) and allocate the case to the team of therapists who will work directly with the child and caregivers to support them.

5. Programme implementation

5.1. Preparatory phase – initial child and caregiver assessment

During the preparatory phase (which lasts for up to four weeks), the caregivers will provide a range of information to the programme therapist. Caregivers will be asked to complete the caregiver questionnaire (Appendix 3) and the Sensory Profile 2, provide several video recordings of the child's interactions (see Appendix 4), and participate in a joint interview with the child psychotherapist and the paediatric occupational therapist (Appendix 5). The child psychotherapist will also complete the Functional Emotional Assessment Scale (FEAS) based on the video recordings provided.

All the information will be reviewed by the child psychotherapist and the paediatric occupational therapist, who have been allocated to the child/family case, to compile the initial child and caregiver portrait (Appendix 6). This is the initial assessment of the child's, the caregivers', and the family's functioning and summarises their strengths, capacities and needs. The initial child and caregiver portrait will be discussed with the caregivers during the first home visit to set out goals for the duration of the programme.

In the next section, each of these methods of collecting information is discussed briefly.

5.1.1. The caregiver questionnaire

The caregiver questionnaire is designed to gather as much information as possible to help the child psychotherapist and the paediatric occupational therapist to assess the child's potential and needs, the caregivers' capacity, and family functioning, so that the therapists can plan and provide tailored support.

The questionnaire has six parts with questions about:

- the child and the caregiver
- family composition, relationships, and dynamics
- the child's social interactions, communication, sensory sensitivity and motor coordination, developmental history, and medical history
- caregiver and family stresses and challenges



- diagnosis and past/current support
- Information about the services of the implementing organisation.

Caregivers are asked to complete as many questions as they can. If they would rather not respond to any of these questions, that is fine. They should not feel pressurised or obliged to respond to every question. Some of the issues may be discussed with the therapists later during home visits. However, the more information is given, at this stage, the better, as it allows for a more complete portrait of the child and the family situation.

Ideally, the caregiver questionnaire should be completed online. If a hard copy is completed, then this should be submitted to the therapists.

5.1.2. The Sensory Profile 2

The caregivers are also asked to complete the Sensory Profile 2 which, once completed, the paediatric occupational therapist will use it to rate the child's sensory sensitivity and behaviour, such as auditory, visual, touch, movement, oral and behavioural sensitivity. Depending on the score given, the child's sensory sensitivity is assigned to one of four categories (quadrants), based on Dunn's (1997) model:

- seeking/seeker the degree to which a child obtains sensory input
- avoiding/avoider the degree to which a child is bothered by sensory input
- sensitivity/sensor the degree to which a child detects sensory input
- registration/bystander the degree to which a child misses sensory input.

Completion of the Sensory Profile 2 is important, as it provides information about the child's sensory processing and sensitivity concerning the five senses (i.e., taste, smell, hearing, seeing and touch) and the three internal bodily (somato) senses – that is, vestibular function, proprioception and interoception.

The vestibular function involves motor functions that allow, for example, balancing the body, head position and posture, and spatial awareness, and it is responsible for providing the brain with this information. Proprioception is the internal navigation system of the body, which signals the brain to use the information about motion, orientation and balance to facilitate movement and maintain balance. Finally, interoception is the body awareness of how it feels – for example, hunger, thirst, heartbeats, faster breathing, etc. These internal bodily senses are responsible for conveying information to and from the brain about spatial orientation, balance and body awareness of how it feels, determining body responses and actions, as explained by the concept of neuroception (see section 6).

Ideally, the Sensory Profile2 should be completed online. If a hard copy is completed, then a copy should be submitted to the paediatric occupational therapist.

Further Information about the Sensory Profile 2 can be found at: https://www.pearsonclinical.co.uk/AlliedHealth/PaediatricAssessments/Sensory/sp2/sensory-profile-2.aspx.



5.1.3. The caregiver video recordings

The caregivers are asked to video-record the child's everyday life and interactions prior to the home visits commencing.

The video recordings should:

- be taken during the child's and family's daily routine at home and while out and about
- capture the child's interactions in a range of daily activities and their interactions with caregivers (e.g., morning routine, breakfast time, playtime, showing the child playing on their own or with others, abrupt changes to daily routine, etc.) and, if possible, instances when the child and caregiver are out and about (e.g., travelling, shopping, being outdoors)
- clearly show the faces of the people who interact with the child
- capture instances of the child's delight and pleasure during interactions
- focus on positive events and instances that show the child's strengths and potential.

The video recordings should be:

- at least 7–10 minutes long
- taken over a period of three weeks and on different days of the week, the period preceding the programme implementation.

Caregivers are advised, where possible, to:

- use a wide-angle camera on a tripod or kept static for continuous recording
- choose snapshots from continuous recording to upload to TAP's SharePoint.

The video recordings should be made available to the programme therapists at least one week prior to commencing the home-visits to enable the child psychotherapist to complete the FEAS checklist and both the child psychotherapist and the paediatric occupational therapist to inform the completion of the initial child and caregiver portrait.

Video recording can be intrusive and may interfere with the natural flow of a situation. The use of iPhones and tablets can be particularly obtrusive. In addition, by the time an event/interaction is considered important enough to be video recorded, it is often over. Thus, the parents/caregivers should ensure that the recordings are as unobtrusive as possible, using the technology available to them in the best way possible.

NOTE

Caregivers will continue video-recording instances of daily interactions during the period of home visits. Each week, they should upload four video recordings to TAP's SharePoint. These video recordings will be reviewed by the therapists to gain an understanding of the child's functioning throughout the week.

5.1.4. Completion of the Functional Emotional Assessment Scale (FEAS)

The child psychotherapist reviews the video recordings provided by the caregivers and completes the FEAS. This assesses both the caregivers' and the child's functioning across the following domains:

- self-regulation and interest in the world
- forming relationships, attachment, and engagement
- two-way purposeful communication
- behavioural organisation, problem-solving and internalisation
- representational capacity/elaboration.



FEAS is an age-appropriate assessment scale that is used by trained therapists to help children with a wide range of emotional, sensory, motor, regulatory, learning and development challenges.

Further information about the FEAS can be found at: www.icdl.com/research/functional-emotional-assessment-scale

5.1.5. The initial joint interview with the therapists

The child psychotherapist and the paediatric occupational therapist will jointly conduct an initial interview with the caregivers. The interview will focus on three main areas: caregiver stresses; the child's glimmers/potential and their challenges; and resources and support networks available to the child and their caregivers. A draft interview schedule, with indicative questions, is in Appendix 5. This interview schedule is not an exhaustive list of questions or topics to be addressed. Instead, it provides a road map to an informal but informative discussion.

The ordering of questions is not fixed. The caregivers will have the leading role in this discussion, starting the conversation on any issues they would like to address first. It is recommended that the interview schedule is shared and agreed with the caregivers before the interview takes place. The caregivers will decide whether there are questions and issues that they do not wish to discuss at this stage or propose additional topics.

The interview record will be used by the therapists as another source of information to build the initial child and caregiver portrait.

5.1.6. The initial child and caregiver portrait

The child psychotherapist and the paediatric occupational therapist will convene at least one week prior to commencing the home visits to review the information gathered (discussed above in sections 5.1.1 to 5.1.5) and complete an initial child and caregiver portrait (Appendix 6). This document provides an initial assessment concerning:

- the child's potential and capacities, while acknowledging challenges
- the caregivers' strengths and capacities, and any potential challenges
- the overall family functioning
- sources of support available within the family and extended family, as well as from formal statutory services.

In line with the underlying principles of the programme, the assessment takes a positive stance, acknowledging that:

- the child is a potent, intentional, and goal-oriented individual
- the child is biologically wired to seek connection with others to ensure their safety and survival
- the child's and the caregiver's sensory and socio-emotional experiences, real or perceived, determine the way they connect and relate, or not, with each other; this, in turn, affects their interactions, bonding, and sense of mutual security and safety
- the caregiver and family interactions and functioning are crucial to the experiences afforded to the autistic child
- utilising existing inner and external resources (e.g., family, friends, and professional services) can significantly alleviate family stress and improve family functioning.



This assessment will determine the goals that the caregiver and the therapists will agree to work on. It will also provide the basis for the therapists to continuously assess and reassess the child's sensory and socio-emotional functioning and the caregivers' competencies and functioning so that they can produce an end-of-programme child and caregiver portrait (see section 4.3).

The therapists will discuss their initial child and caregiver portrait with the programme lead therapist for feedback, before they present and discuss it with the caregivers in their first home visit.

It should be noted that the assessment conducted as part of this programme is not designed to provide a diagnosis of autism/ASD. Instead, throughout the programme, the child's emotional and sensory-motor functioning, as well as the caregivers' competencies and needs, will be assessed and continuously reassessed jointly by the therapists and the caregivers (The assessment process is depicted in Figure 3)

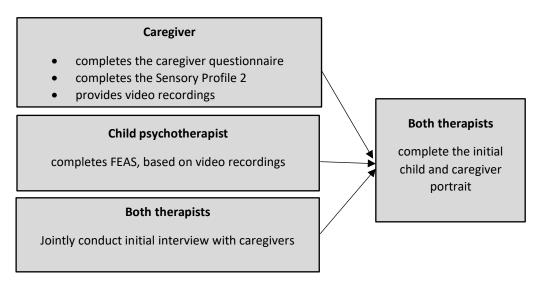


Figure 3: The assessment process for completing the initial child and caregiver portrait

5.2. Home visits

5.2.1. First home visit

Once the initial child and caregiver portrait has been completed, the child psychotherapist and the paediatric occupational therapist will jointly undertake the first home visit. In this introductory home visit, the therapists, the caregivers, and the child will get to know each other. The therapists will also discuss and agree:

- the overall goals that they want to achieve for the child and the caregivers during the sixweek period of the home visits
- the most suitable ways of working together to achieve these goals
- the frequency of home visits conducted either individually or jointly by both therapists
- dates and times when home visits will take place.

It should be noted that the initial assessment, outlined in the initial child and caregiver portrait, will be revisited during the six-week period of the home visits. As the therapists get to know the child and the caregivers better within their family context, they may also readjust the initial goals.



5.2.2. Follow-up home visits

The child psychotherapist and the paediatric occupational therapist will each undertake follow-up home visits, during which they will work directly with the child and the caregivers. The therapists will work with both the child and the caregivers in an intuitive and gentle way that is responsive to the child's and the caregivers' state and level of engagement at the time of the visit to:

- raise their awareness of the importance of reciprocity in playful and intentional interactions between them
- equip them with the skills to notice positive instances in their interactions
- understand the nuanced processes of sensory and affective experiences during interactions,
 which may affect their relationship
- enhance their ability to focus on and strengthen the child's potential and inherent inner capacity for social connection
- strengthen their skills for emulating positive instances, enabling them to become habitual everyday interactions.

Based on the underlying principles of the programme, the therapists work together with the caregivers to review and 'dissect' moments and instances of delight and glimmer in their interactions with their child to find out what the child enjoys and engages with without becoming overwhelmed either by the activity or the environment. The therapists help the caregivers to quickly detect the child's responses, so that they act proactively to offer stimulation or adapt to avoid the child becoming overloaded. Such moments provide the most useful information for the caregivers to better understand how they and the child interact.

The caregivers' understanding of their child's sensory sensitivity enables them to make decisions about the kind of sensory input required. Having, for instance, active stimulation may not be appropriate for a child whose sensory processing needs a calm and quiet environment and vice versa. So, appropriate adjustments are made that are gradually embedded into daily routines to provide consistency and subtle guidance and messages to the child.

At the same time, the therapists work with the caregivers to better understand their own sensory processing during interactions with their child and recognise its impact on how their child reacts, relates to, and interacts with them. Caregivers' understanding of how their sensory processing affects their child can help them to stand back, pay attention to the child's intentions and respond accordingly. The joint intention and attention are key to building connectedness and bonding with each other.

Video recordings taken during the week by the caregivers might also be used to discuss moments of delight and glimmer with the therapist.

5.3. Concluding phase

On completion of the six-weeks home visits, the child psychotherapist and the paediatric occupational therapist review their weekly meeting records and convene to compile the end-of-programme child and caregiver portrait (see Appendix 7 for a suggested template). This document is intended to

- (i) summarise the assessment of the child's and caregivers' functioning at the end of the programme, considering the initial assessment and the goals set out,
- (ii) outline good practices, exemplified during home visits, which should be continued and embedded in the family's everyday interactions and activities



(iii) make recommendations for future ongoing support which could be offered by the implementing organisation and/or other service providers.

The therapists are expected to compile and submit the end-of-programme child and caregiver portrait and give it to caregivers within two weeks of completion of the home visits and invite caregivers for further discussions, if required. Prior to sharing the document with the caregivers, the therapists discuss it with the programme lead therapist for feedback.

NOTE

The support programme cannot be repeated with the same family. A key component of the support programme is the assessment of the functioning and needs of the child and the family, and this has been summarised in the end-of-programme child and caregiver portrait. If the child and the family will benefit from further support offered by the child psychotherapist and/or the paediatric occupational therapist, then separate arrangements will be made concerning the duration of support, intended goals and outcomes, and how the support will be monitored.

6. Intended programme outcomes

The intended outcomes of the programme are two-fold, i.e., for parents/caregivers and children.

Parents are expected to:

- have better and deeper understanding of their child's experience and what they are attempting to communicate
- appreciate the reciprocity of the child's sensori-motor and affective experiences and how these impact on interactions and family functioning
- enhance their ability to notice enjoyable incidents in their interactions with their child and re-create them in their daily interactions
- have better understanding of how to prevent and reduce stressful situations and experiences
- gain better understanding of how the family environment is conducive to nurturing and trusting relationships between parent/caregiver and their child
- enhance their capacity to create safe, accepting, enjoyable environments that are free of over-stimulation or under-stimulation, as required
- acquire new ways of relating to and enjoying being with their child with deeper emotional connection
- gain confidence in understanding and responding to their child's strengths and capacities and their needs
- embed acquired new skills in their everyday family life
- be empowered to seek support and collaborate with statutory, voluntary and private service providers, and educational institutions, to receive services that meet their child's needs

Intended outcomes for children may include:

- feelings of being understood
- stronger sense of self and other
- enhanced emotional resilience
- greater ability to manage their feelings



- enhanced emotional connection with their parents/caregivers
- a sense of safety in their environment
- improved play, communication and interaction with their parents/caregivers and family members
- more positive transition experience outside the family environment and context

7. Further information about the programme

7.1. Who is the programme for?

To re-cap, the programmes is suitable:

- for children younger than four years old, on programme completion, whose parents are concerned that they may exhibit autistic traits
- for children of the same age who have an autism diagnosis, but do not receive any support/therapy or the support and therapy they receive are compatible with the underlying principles of the *First Steps* programme
- for children who exhibit sensory-motor and affective sensitivity and challenges

It is crucial that the caregivers are ready to engage with the programme implementation or receive appropriate support for doing so.

7.2. Support and supervision of therapists

The child psychotherapist and the paediatric occupational therapist work closely with each other to provide consistent support to the child and the caregivers in the best possible way. They are also mentored and supervised by the programme lead therapist, in weekly meetings. In addition, the therapists have access to external supervisions, offered by licensed therapists, as per the requirements of their professional bodies.

The programme lead therapist also oversees all aspects of the programme work undertaken by the child psychotherapist and the paediatric occupational therapist. The programme lead therapist ensures that the caregivers understand the programme and provides answers to any queries of a therapeutic nature, and they are the first point of contact in relation to these issues.

7.3. Data protection

All records and documents related to the child, caregivers and their family are accessed only by the child psychotherapist, the paediatric occupational therapist, and the programme lead therapist. The programme manager will have access to information gathered for administration and management purposes.

All information will be securely stored, electronically or in hard copies, in compliance with UK GDPR regulations. Information will be used only for the purpose of the programme implementation. If information is intended to be used for other purposes (e.g., research), then the implementing organisation should request additional written consent.

7.4. Programme management and administration

The programme manager oversees the management and administration of the programme, and they are the first point of contact in this regard. The programme manager ensures that all



administrative requirements are complete and information for the family is securely stored, as required.

For management and administrative information and queries, caregivers should contact the programme manager. They will be given a contact address when they are admitted to the programme.

7.5. Raising queries and concerns

For information and queries about the clinical aspects of the programme, caregivers should initially speak to the therapists implementing the programme, or they may contact the programme lead therapist. The caregivers should be given a contact address when they are admitted to the programme.

For any ongoing unresolved issues, caregivers may contact the leadership team of the implementing organisation. The caregivers should be given a contact address when they are admitted to the programme.

7.6. Overall responsibility for programme implementation

The overall responsibility for programme implementation and for accountability to families admitted to the programme lies with the leadership team of the implementing organisation. Caregivers should be given a contact address once they are admitted to the programme.

7.7. About the programme development and document

The programme is informed by the latest scientific evidence about autism in very young children and it has been piloted with a family with a young autistic child to finalise it to its current format. It is the responsibility of the implementing organisation to adhere to programme principles and processes. For further information about the programme development, please, contact: research@norland.ac.uk

8. Sensory and affective reciprocity in child and caregiver interactions

The sections below summarise, in a simplified manner, the key ideas of the conceptual framework that forms the basis of the programme, extensively discussed in a forthcoming paper (Papatheodorou and Prescott, forthcoming).

Currently, there is limited knowledge and understanding of autism especially among infants and toddlers. However, existing evidence from studies which include young children signpost to key issues that are of particular significance for very young autistic children and, thus, form the basis of this programme. These include the excess and/or disruptive neural connections in young children's brain development; the interplay of sensori-motor coordination and affective processing; and the impact of parental experiences of stress and the accompanying emotional (un)availability on children's functioning. Consequently, parental sensitivity and parent-child relationships are key entry points to the support programme.



8.1. Brain development

Autism is defined as a neurological brain condition subject to excessive neural connection/synapses

and/or disruptive of synchronisation between the two hemispheres (Courchesne et al. 2007; Dinstein et al. 2011). Thus, it is useful to understand the brain's structure and development.

The brain consists of billions of neurons that connect with each other in complex and intricate ways. These connections, known as synapses and often described as brain pathways, help neurons to 'talk' to each other (see Figure 4). Neurons convey information from the brain to the peripheral nervous system of the body, via



Figure 4: Neural connections (image attribution: zerotothree.org)

the brain

Liver Spleen Stomach Pancreas Kidney Large intestine intestine

Figure 5: Communication of the peripheral nervous system with the brain (image attribution:

https://biologydictionary.net/vagus-nerve/

stem or vagus (see Figure 5), to coordinate muscle and body movement. Neurons also communicates with internal organs such as heart and lungs (perceiving visceral sensations and emotions) and sensory organs (detecting sound/voice, taste, etc.) to convey information to the brain (discussed in section 8.3).

The synaptic connections in the brain happen throughout life, every time an individual is exposed to new experiences, and they continuously change the brain architecture (Center on Developing Child, Harvard University nd). Existing synaptic connections may be strengthened by being exposed to repeated similar experiences; new connections may be created when exposed to new experiences; and synaptic connections may be repaired by being exposed to appropriate experiences, while old ones may be weakened if they are not used.

Experiences (positive or adverse) that are frequent, repeated, consistent, and intense wire, rewire and change the brain synapses. Positive experiences from

stimulating and encouraging environments have a positive effect by strengthening the synaptic connections. Stressful experiences, on the other hand, have an adverse impact by weakening the

synaptic connections. These synaptic connections can be temporary or permanent, depending on the intensity and reoccurrence of the activities and the signals sent to and received by brain neurons. These changes in the brain are known as neuroplasticity (meaning being malleable) and are crucial in the early years of a child's life.

Experiences (positive or adverse) that are frequent, repeated, consistent and intense wire, rewire and change the brain synapses

8.2. Synaptic pruning

Although the brain architecture can change throughout life, there is a critical period in life where synaptic connections are over-generated and then pruned. Synaptic pruning is happening when active synapses are stabilised, while inactive synapses are eliminated. Synaptic pruning is important



for brain maturation and optimal learning. Too little pruning leaves the brain with many redundant connections, which can be confusing and inefficient and may limit the learning potential. This period is the first three years of life. How synaptic connections and pruning is happening can be seen in the figure 6.

During the first years of life, children's brains form billions of synapses, but gradually unnecessary connections are pruned to enable the organisation of experience and learning. In autistic children, such pruning does not happen as expected, leaving the child unable to organise their everyday experiences. So, too little pruning leaves the brain with too many redundant connections, which can be confusing and inefficient and may limit the child's learning potential. Disruptive neural connections in brain development are related with language, cognitive, social, and sensory behaviours exhibited by autistic children.

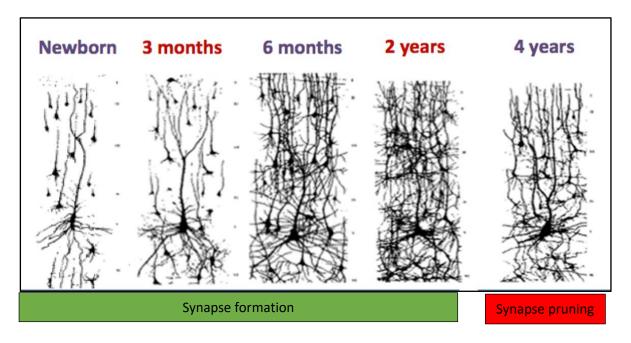


Figure 6: Brain plasticity and synaptic pruning (image attribution https://tinkergarten.com)

Thus, intervention programmes with young children should aim to strengthen, stabilise, and create synaptic pathways that are conducive to learning and eliminate (prune) excessive neural connections. The window of opportunity is up to the age of three years. By the age of four years, the pruning of synaptic pathways has started, and the brain synapses have started to stabilise in whichever way they have learned. After the age of four years, any intervention and support offered has a repairing effect on synaptic pathways. However, this is more challenging than strengthening synaptic connections early on.

8.3. The interplay of sensory and affective experience

As mentioned, the brain communicates information to the peripheral nervous system via the core stem/vagus and internal organs to activate muscles that coordinate movement. But the core stem/vagus also communicates information from the neurons of the peripheral nervous system to the brain via a process known as neuroception, as explained by the polyvagal theory (Porges 2018). This process is subtle, complex, and intricate and operates at an unconscious level. It is often described as a 'gut feeling' activated at organs such as the heart and lungs when a person encounters new situations. Neuroception is not awareness nor a sensory perception of an



experience that a person is conscious of. It is rather an affect state activated in the internal organs and communicated to the brain via the core stem. The brain, in turn, alerts the peripheral nervous system, which triggers and consciously activates bodily responses.

This undefined affect/'gut' feeling, which precedes any conscious awareness of external experiences, has an adaptive and survival function. The polyvagal theory maintains that human beings are wired to connect with others, and thus to seek connections and relationships with others, to maintain a sense of safety and security, which is vital for survival. This means that when individuals encounter situations and experiences that convey feelings of safety and security, they maintain a state of contentment and calmness. If the gut feeling communicates a level of threat, then the brain may activate bodily responses such as fight, flight, or freeze.

In the case of autistic children, when they encounter a situation and experiences which, at an unconscious level, convey threat (e.g., being exposed to sudden and unpredictable changes, to sensory experiences that they cannot process, or to caregiver stress and anxiety), their responses may vary, depending on the level of threat. The children may:

- respond by over-reacting and showing signs of excessive distress, have meltdowns, and display high levels of disruptive and anxiety behaviours (they get into a mode of fight)
- under-react by withdrawing, and showing disinterest and inhibiting behaviours (they get into a mode of flight)
- appear unresponsive and aloof (they get into a mode of freeze).

In a similar way, and through the same process, if the caregiver senses and unconsciously evaluates the child's emotional state as a threat (e.g., feeling rejected), then this may trigger responses that reinforce and perpetuate the child's existing emotional state. Thus, caregivers are often left in confusion and self-doubt about their parenting, resulting in a state of emotional and physiological arousal that makes it difficult to be in tune with their child (Alonim et al. 2020) Potentially, the difficulties of autistic children and their caregivers may arise

from not being able to infer the intentions behind each other's reactions and behaviours, affecting their interactions and relationship (Trevarthen and Aitken 2001; Stern 1985).

There is reciprocity
between sensori-motor and
affective experiences that
trigger bodily responses
and behaviours

The concept of neuroception intersects with understandings of the function of sensory stimuli and especially the role of proprioception which signals the brain to use information about

motion, orientation and balance (vestibular function) and how the body feels, e.g., hunger, thirst, heartbeats, breathing (interoception) to trigger and facilitate movement and/or maintain a state of balance. The child's sensitivity to sensory stimuli can bring about four different responses, that is, (i) the child seeks sensory input; (ii) the child is bothered by sensory input; (iii) the child detects sensory input; and the child misses sensory input, as per (Dunn's (1997) model.

Caregiver emotional responses are conveyed to their children unconsciously and in subtle ways, eliciting similar responses by their child, creating a vicious (or virtuous) circle

The understanding of how affective feelings triggered by sensory experiences encountered and the way these are communicated to the brain and from the brain to the body demonstrate the interplay and reciprocity between the sensory and affective elements of human experience. They also indicate the significance of sensory challenges as early signs of autism among very young children and the importance of addressing sensory sensitivity in



support or intervention programmes. Trevarthen and Delafield-Butt (2013) note that autistic children differ from typically developing children in their motor coordination, responses and actions and they argue that social emotional isolation and cognitive and language delays are secondary consequences of poor sensory-motor and affective integration.

As with brain development, the autonomic nervous system, which controls and regulates the internal organs without any conscious recognition or effort, is subject to and shaped by prior experiences. Thus, it is crucial to be aware of the experiences to which children are exposed to create an environment that is conducive to positive developmental outcomes.

8.4. Caregiver experience and own emotional state

The caregiver's experiences with their child, combined with their own experiences and memories from childhood (Papaneophytou 2020), and their current mental state and level of stress, may also be directly related to the way they relate to, and connect and interact with, their autistic child. Past experiences and current life stresses may trigger emotional and physiological responses, which lead

the caregiver either to fight (insisting on remediating the situation), or to go into flight mode (give up) or freeze (be unable to respond). The caregiver responses, in turn, may reinforce the initial responses of their child. Autistic children pick up and absorb parental stress and react accordingly. This reciprocal interactional process can become a vicious circle that impacts on the child's level of sensitivity and security, which determines the way they engage and respond, or not, to their environment and experience.

With appropriate early support, young autistic children can enhance their inherent potential and increase their capacities to lead a fully functioning life

Thus, it is important that caregivers acknowledge the stress factors in their life and potentially their previous attachment history and understand how these impact on their emotional and mental state when interacting with their child. It is also important to consider how their previous life experiences (for example, being hurt, upset, ignored, told/feeling not being good) and current experiences (e.g., the autistic child having consistent, positive, and appropriate stimulating interactions) may influence the caregiver's responses and interactions with their child beyond the realm of awareness. Thus, it is crucial that any support programme addresses caregiver stress and their mental state alongside working with the child.

8.5. Caregiver and autistic child interactions

The interplay between affective and sensory experiences is particularly important during infancy and toddlerhood, when children's experience is largely sensory and non-verbal. This is evident in early

expressive non-verbal communication and reciprocal playful interactions between the child and the caregiver, whereby their shared experience impacts on the experience of the other (Trevarthen and Aitken 2001; Stern 1985; Salazar 2020; Center on Developing Child, Harvard Universityb nd-b;). Such interactions are characterised by the caregiver's intuitive understanding of the child's feelings and intentions during playful routines and their joint attention in carrying such

It is crucial that caregivers
acknowledge the stress factors
in their life and are aware of
how these may impact on their
interactions and relationship
with their child

routines by being in tune with the affective state of their child. The shared reciprocal interactions between the child and the caregiver through playful and expressive (non-verbal and verbal)



communication are key to supporting young autistic children. The integration of feelings with the sensory and bodily experience of the child plays a crucial role in developing their core self and identity.

Thus, the integration of the sensori-motor and affective experiences of both the autistic child and their caregivers is a fundamental key principle of the programme. This requires that caregivers are aware of and able to notice the early sensori-motor signs of autism and provide support to their autistic child early on to enable them to utilise their inner capacities and potential to lead a functional life.

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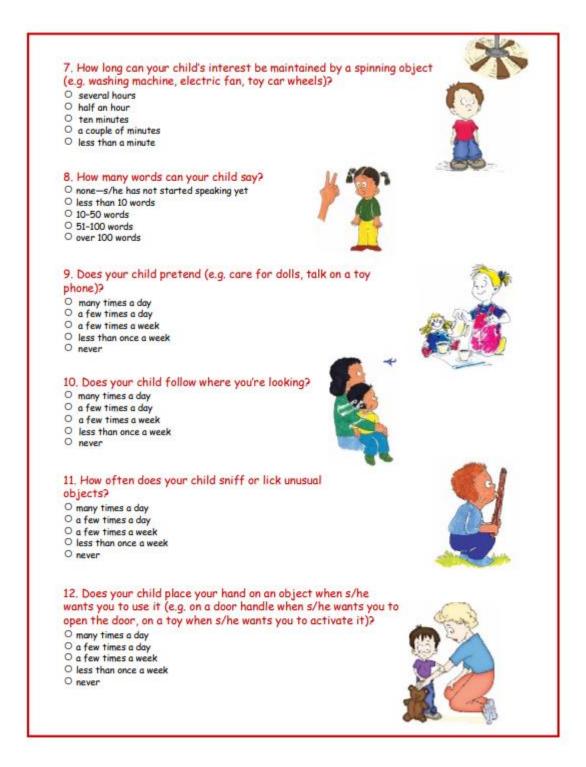
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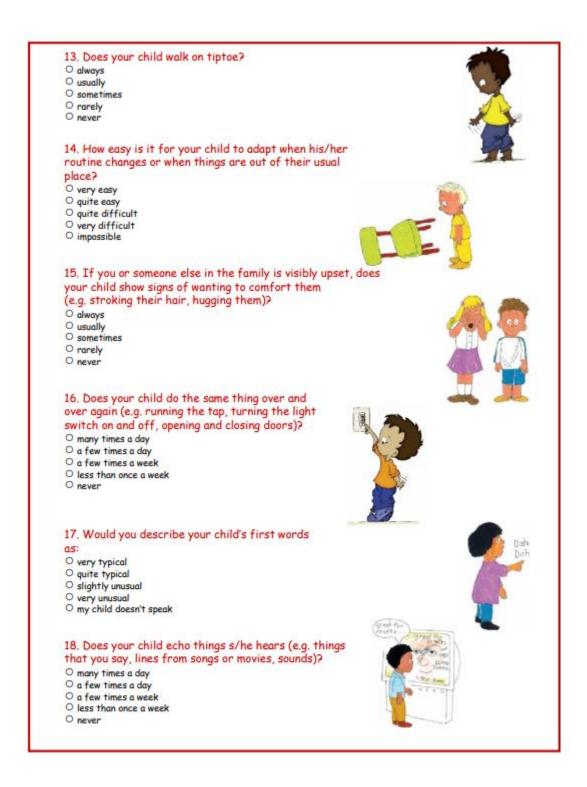
Appendix 1: Quantitative Checklist for Autism in Toddlers (Q-CHAT)

https://docs.autismresearchcentre.com/tests/QCHAT.pdf (Accessed 25 April 2022).

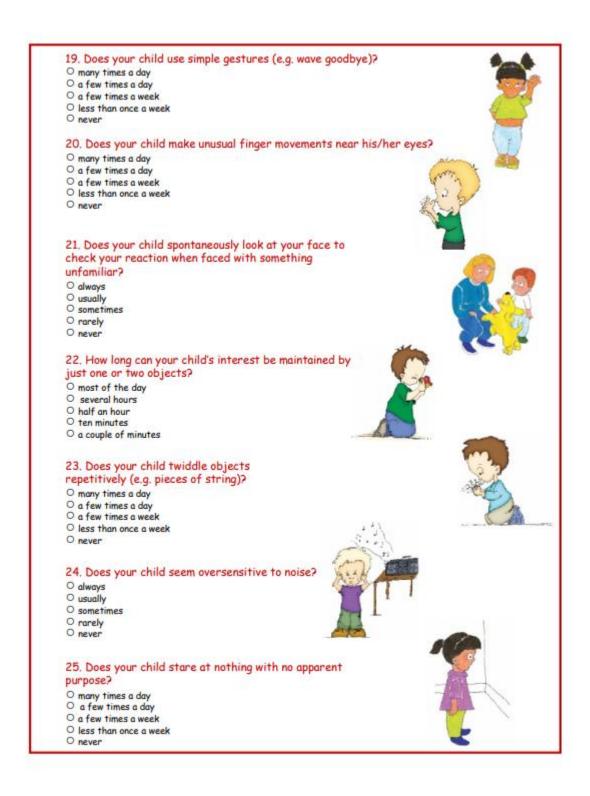














Appendix 2: Q-CHAT Scoring Key

https://docs.autismresearchcentre.com/tests/QCHAT_scoringkey.pdf (Accessed 25 April 2022)

		Always	Usually		Sometin	nes	Rare	ly	Ne	ver
1.	Does your child look at you when you call his/her name?	0	1		2		3		4	
		Very easy	Quite ea	asy	Quite difficult		Very		lm	possible
2.	How easy is it for you to get eye contact with your child?	0	1		2		3		4	
		Always	Usually		Sometin	nes	Rare	ly	Ne	ver
3.	When your child is playing alone, does s/he line objects up?	4	3		2		1		0	
		Always	Usually	Sor	netimes	Rar	ely	Never		My child does not speak
4.	Can other people easily understand your child's speech?	0	1	2		3		4		4
		Many times a day	A few times a	day	A few times a week		Less once week	a	Ne	ver
5.	Does your child point to indicate that s/he wants something (e.g a toy that is out of reach)?	0	1		2		3		4	
		Many times a day	A few times a	day	A few times a week		Less once week	а	Ne	ver
6.	Does your child point to share interest with you (e.g pointing at an interesting sight)?	0	1		2		3		4	
		Several hours	Half an		Ten minutes	;	A cou	uple of ites		ss than a nute
7.	How long can your child's interest be maintained by a spinning object (e.g washing machine, electric fan, toy car wheels)?	4	3		2		1		0	
		None – s/he has not started speaking yet	Less tha 10 word		10 – 50 words		51 – word			er 100 ords
8.	How many words can your child say?	4	3		2		1		0	
		Many times a day	A few times a	day	A few times a week		Less once week		Ne	ver
9.	Does your child pretend (eg care for dolls, talk on a toy phone)?	0	1		2		3		4	



		Many times a day	A few times a day	A few times a week	Less than once a week	Never
10.	Does your child follow where you're looking?	0	1	2	3	4
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
11.	How often does your child sniff or lick unusual objects?	4	3	2	1	0
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
12.	Does your child place your hand on an object when s/he wants you to use it (e.g on a door handle when s/he wants you to open the door, on a toy when s/he wants you to activate it)?	4	3	2	1	0
		Always	Usually	Sometimes	Rarely	Never
13.	Does your child walk on tiptoe?	4	3	2	1	0
		Very easy	Quite easy	Quite difficult	Very difficult	Impossible
14.	How easy is it for your child to adapt when his/her routine changes or when things are out of their usual place?	0	1	2	3	4
		Always	Usually	Sometimes	Rarely	Never
15.	If you or someone else in the family is visibly upset, does your child show signs of wanting to comfort them (e.g stroking their hair, hugging them)?	0	1	2	3	4
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
16.	Does your child do the same thing over and over again (e.g running the tap, turning the light switch on and off, opening and closing doors)?	4	3	2	1	0
		Very typical	Quite typical	Slightly unusual	Very unusual	My child doesn't speak
17.	Would you describe your child's first	0	1	2	3	4



		Many times a day	A few times a day	A few times a week	Less than once a week	Never
18.	Does your child echo things s/he hears (e.g things that you say, lines from songs or movies, sounds)?	4	3	2	1	0
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
19.	Does your child use simple gestures (e.g wave goodbye)?	0	1	2	3	4
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
20.	Does your child make unusual finger movements near his/her eyes?	4	3	2	1	0
		Always	Usually	Sometimes	Rarely	Never
21.	Does your child spontaneously look at your face to check your reaction when faced with something unfamiliar?	0	1	2	3	4
		Most of the day	Several hours	Half an hour	Ten minutes	A couple of minutes
22.	How long can your child's interest be maintained by just one or two objects?	4	3	2	1	0
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
23.	Does your child twiddle objects repetitively (e.g pieces of string)	4	3	2	1	0
		Always	Usually	Sometimes	Rarely	Never
24.	Does your child seem oversensitive to noise?	4	3	2	1	0
		Many times a day	A few times a day	A few times a week	Less than once a week	Never
25.	Does your child stare at nothing	4	3	2	1	0



Appendix 3: Caregiver questionnaire

Dear Caregiver,

This questionnaire is designed to gather as much information as possible to help the child psychotherapist and the paediatric occupational therapist to assess your child's potential and needs, and your capacity as a caregiver and family to support your child in the best possible way. Please complete as many questions as you can. If you find that you would rather not respond to any of these questions, that is fine. You should not feel pressurised or obliged to respond to every question. You will have time to discuss them later with the child psychotherapist and/or the paediatric occupational therapist during home visits. However, the more information you provide at this stage, the better, as it allows for a more complete portrait of your child and the family situation.

For open ended questions you will be able to expand the space given to include as much information as you wish to provide.

Please note that in this questionnaire, the terms parent, parents, caregiver and caregivers are used interchangeably.

The questionnaire is completed by (please state your name):

Υοι	Your legal relationship to the child:				
Dat	Date:				
PAI	RT 1: About your child and yourself				
1.	What is your child's name?				
2.	How old is your child?				
3.	What is your child's biological sex?				
4.	Are you currently married/cohabiting? • Yes • No • Other (please describe if you wish to do so)				
5.	If applicable, how long have you been together as a couple?				
6.	How would you describe your relationship? Do you feel that you have a stable and secure relationship? • Yes				

7. Are you both (if together) the biological parents of the child involved?

Please give further details if you wish to do so

Yes



 No Other (please describe if you wish to do so)
8. What are your ages? [Please specify the age of all caregivers]
9. How would you identify yourselves racially or ethnically? [Please specify for all caregivers]
10. If you are employed, what is your current occupation? [Please specify for all caregivers]
11. If you are not employed, what is your current source of income? [Please specify for all caregivers]
 12. Have you had to leave your place of employment or take time off because of issues related to your child's health or needs? No Yes
 Yes If yes, how often has this occurred in the last six months?
13. Have you recently moved house, or is this the home your child has always known?
14. Have you experienced any traumatic experiences that have affected your lives?No
Yes If yes, please give details
PART 2: Family composition, relationships and dynamics
 15. Do you have any other children? No Yes – please give age and gender
16. Would you describe your other children's development as 'typical'?
Yes No
 Not sure If No/Not sure, please give more information
17. Are there any other members in your household? Please specify
18. How would you describe your relationship with your child?



20.	If applicable, how would you describe the relationships between siblings?
	If applicable, do you, as a family, have a close relationship with extended family members?
•	Do other members of your extended family or friend network help with the care of your child, when you are unable to? No Yes – and how often?
PAR'	T 3: About your child

Section 3.1:. social Social interactions

23. How would you describe your child and their social interactions? Please tick appropriate characteristics:

- Happy
- Friendly
- Outgoing
- Cooperative
- Impulsive
- Seeking approval
- Sensitive
- Crying often
- Shy
- Fights often
- Destructive
- Separates easily
- Fearful
- Needs reminders
- Repeats sounds or words over and over
- Strong reactions to changes in routine or environment
- Displays sense of humour
- Severe temper tantrums and/or frequent minor tantrums
- Gets along well with others

Section 3.2: Communication

- 24. How does your child communicate?
 - Pre-verbal
 - Facial expression
 - Gestures
 - Sign language
 - Communication device
 - Vocalisations/sounds
 - Single words



 Two-word sentences Three-word sentences Speech stopped for a period None of the above
25. Does the child understand what you say to him or her?
26. Can your child follow simple instructions?NoYes
27. What is the language spoken at home?
 28. Has your child ever received a developmental or speech/language evaluation before? No Yes – please state recommendations given
Section 3.3: Sensory sensitivity and motor coordination 29. Does your child show any sensory sensitivity? Please tick, below, all those that apply • Visual • Auditory • Smell • Touch • Taste • Body balance • Body awareness • Spatial awareness • Other – please specify
 30. Has your child ever had their vision or hearing tested? No Yes – please state the results
 31. How would you describe your child's energy level? High Average Low
 32. How would you describe your child's small muscle coordination? Good Average Poor
 33. How would you describe your child's large muscle coordination? Good Average Poor

34. Is there anything unusual about your child's gait? If so, please explain _____



35. Does your child have any specific physical needs? If so, please describe
Section 3.4: Developmental history
36. Was your child born:
full term
• premature
37. What was your child's weight at birth?
38. Were there any complications during birth?
• No
Yes – please explain
39. Were there any feeding problems?
• No
Yes – please explain
40. At what age did your child do the following? (Please give approximate age by months or years)
Held head up:
• Crawled:
• Sat alone:
Walked alone:
Fed self with spoon:
Potty-trained:
Started self-dressing:
Spoke first word:
Spoke sentences:
Section 3.5: Medical history
41. Has your child had:
Mumps: No/Yes
Measles: No/Yes
Rubella: No/Yes
Meningitis: No/Yes
Encephalitis: No/Yes
Ear infections: No/Yes
High fevers: No/Yes
• Seizures: No/Yes – If <i>yes</i> , when was the last seizure?
42. Does the child have any medical condition or illness, or have they had any accidents? Please tick
and give further details
Cerebral palsy
Diabetes
Asthma
Head injuries
• Serious accidents



Other – please list				
43. Is your child currently on any medication?				
• No				
Yes – please give details about the medication and dosage:				
PART 4: Caregiver and family stresses and challenges				
44. How much of your attention does your child require on a daily basis? Please describe				
45. Do you worry about whether you are doing enough for your child?				
• No				
• Yes				
• Sometimes				
Please give further details				
AC Barrer and the late to the all the sections and the section 2				
46. Does your child's behaviour in public embarrass you or bring you stress?				
NoYes				
• Sometimes				
Please give further details				
 47. Do you ever feel judged about your parenting by family or strangers? No Yes Sometimes Please give further details 				
48. Have you ever felt that you were treated differently in public or in social situations because of				
your child's reactions and interactions? Please explain				
• No				
• Yes				
• Sometimes				
Please give further details				
 49. Would you agree that your child's autism is a major source of stress in your life? No Yes 				
• Sometimes				
Please give further details				
50. What other factors contribute to feelings of stress? Please explain				
51. Do you enjoy spending time with your child?				
No No				
• Yes				
• Sometimes				
Please give further details				



 52. Do you feel that your child is a source of affection for you? No Yes Sometimes
Please give further details
 53. Do you feel optimistic about your child's future? No Yes Sometimes Please give further details
 54. Do you feel that your child leaves you little time and flexibility in your life? No Yes Sometimes Please give further details
 55. Do you feel that your child's condition is a financial burden? No Yes Sometimes Please give further details
 56. Do you feel that it is difficult to balance your responsibilities to your other children because of your child's condition? No Yes Sometimes Please give further details
 57. Do you ever feel overwhelmed by the responsibility of being a parent? No Yes Sometimes Please give further details
 58. How stressed do you feel on a daily basis? Hardly stressed at all A little bit stressed Very stressed
59. From everything that is happening right now in your life, what are the three major factors in your stress? Please state: 1 2 3



PART 5: Diagnosis and support

60.	 Has your child been assessed for or given a formal diagnosis of autism/ASD? Yes Still waiting No If Yes/Still waiting, who provides the service? If No, what has made you suspect that your child might be on the autism spectrum? Ple describe 	ase
61.	 Have you had any support or therapy before? No Yes – please state the therapy you have had access to and who provided it 	
	. Describe in your own words your concerns about your child	
63.	. When did your concerns start?	
64.	. What changes, if any, have you observed in your child since then?	
65.	. Do you have any thoughts about what might have caused these changes?	
66.	. What concerns you most about your child?	
67.	. What pleases you most about your child?	
68.	. What would you say are your child's strengths?	
69.	. Details of your GP (i.e., name and address)	
70.	 Do you consent to TAP contacting your GP, if required? Yes No 	
	RT 6: About TAP's services . How did you come to find out about TAP?	
72.	. Why have you decided to use TAP's services?	
73.	. What do you hope to achieve from this intervention?	
74.	Are you currently in contact with other services?No	
	Yes – which services?	

Thank you for completing the questionnaire



Appendix 4: Video recordings

Video recordings – guidance for parents/caregivers and therapists

The caregivers are asked to video-record the child's everyday life and interactions prior to and during the period of home visits.

The video recordings should:

- be taken during the child's and family's daily routine at home and while out and about
- capture the child's interactions in a range of daily activities and their interactions with
 parents/caregivers (e.g., morning routine, breakfast time, playtime, showing the child
 playing on their own or with others, abrupt changes to daily routine, etc.) and, if possible,
 instances when the child and caregivers are out and about (e.g., travelling, shopping, being
 outdoors)
- clearly show the faces of the people who interact with the child
- capture instances of their child's delight and pleasure during interactions
- focus on positive events and instances that show the child's strengths and potential.

The video recordings should be:

- at least 7–10 minutes long
- taken over a period of three weeks and on different days of the week.

Caregivers are advised, where possible, to:

- use a wide-angle camera on a tripod or kept static for continuous recording
- choose snapshots from continuous recording to upload to TAP's SharePoint.

The parents/caregivers should upload to TAP's SharePoint

- at least six video recordings a week prior to the home visits commencing, taken during the previous three weeks
- at least four video recordings during each week of home visits

Note: Video recording can be intrusive and may interfere with the natural flow of a situation. The use of iPhones and tablets can be particularly obtrusive. In addition, by the time an event/interaction is considered important enough to be video recorded, it is often over. Thus, parents/caregivers should ensure that the recordings are as unobtrusive as possible, using the technology available to them in the best way possible.



Appendix 5: Therapists' initial interview with caregivers

Suggested schedule for therapists' initial interview with caregivers¹

Child psychotherapist's name:
Paediatric occupational therapist's name

Organisation:

Caregivers' names:

Child's name:

Child's age:

Child's gender:

Interview date:

Interview conducted (delete as appropriate):

- Telephone
- Face to face via online platforms
- Face to face in person

Interview was (delete as appropriate):

- Audio-recorded
- Video-recorded
- Handwritten notes taken

The interview focuses on three main areas: parental stress, child challenges and glimmers/potential, and resources available, with further questions inviting the caregivers to provide additional information and/or elaborate further on key issues raised.

The interview focuses primarily on strengths, while acknowledging challenges

How are you? How do you feel? How does the world look for you?

- How do you feel in relation to your child and his/her care in terms of the responsibilities and demands made upon you?
- How do you feel in relation to other family members in terms of the responsibilities and demands made upon you?
- How is your spousal relationship (if question is relevant)?
- What is your relationship with extended family and/or friends?
- In general, how do you feel being in the world at this moment in time?
- Do you think that the way you feel impacts on your child (state name) and other family members? If this is the case, how? In what ways?

¹ This is only a suggested interview schedule, aiming to give the therapists and caregivers some structure for their discussions. The interview schedule should be shared and agreed with caregivers before the interview takes place.



- 1. What are the triggers in your child's interactions and behaviour that concern you? What are the things in your interactions with him/her that have brought you joy?
 - When did this happen? What time of day? Was it at home or while out and about?
 - What exactly happened?
 - Who was there?
 - How did it make you feel?
 - What challenged you?
 - What gave you joy and/or satisfaction/hope?
 - How did you respond?
 - What was the child's response?
 - How did the situation end/how was it resolved?
- 2. What is the outlook for the child, yourself, the family? What do you want to achieve?
 - What do you think are your strengths?
 - What are the strengths of your family?
 - What can you do on your own or within the family's resources and capacities?
 - What can you do with support from others?
 - What support do you have from extended family and friends?
 - What regular professional support do you have?
 - Is there any support available that you would like to access but do not know how to do so?
- 3. Would you like to add anything else, which we have not discussed but is significant and of importance to you?
- 4. Do you have any questions for us?

Thank you for your time



Appendix 6: Initial child and caregiver portrait

Initial child and caregiver portrait

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goal setting

Report by:
Name of child psychotherapist:
Name of paediatric occupational therapist:
Date of the report:
Section A
Child's name:
Date of birth:
Names of parents/caregivers:
Reasons for referral:
Section B – Brief information about the therapists
Child psychotherapist:
Paediatric occupational therapist:
Lead therapist (if applicable):



Section C – Purpose of the report (template text – do not remove)

- 1. To provide an assessment of the child's and family's strengths and areas requiring strengthening
- 2. To set out goals for the home visits

Section D – Aim of the support programme (template text – do not remove)

The aim of the programme is to reinforce and enhance trusting relationships between the child and the caregiver, building on the strengths and potential of the child and the capacities of the caregiver.

To achieve this aim, the support programme has the following objectives:

- To assess and continuously reassess the child's strengths and the caregivers' capacity,
 while acknowledging the challenges experienced. The initial assessment will determine
 the goals to be set out for the child and the caregivers for the six-week period of the
 home visits, while the end-of-programme assessment will detail the strengths and needs
 of the child and the caregivers, outline the support offered, and make recommendations
 for future therapy and support.
- 2. To assist the caregivers to:
 - notice incidents of glimmer and delight in their interactions with their child and work with the therapists to understand and appreciate the triggers and nuanced processes that enable such positive interactions
 - increase their ability to recognise the child's intentions and be in tune with them through joined attention in order to enhance the connection between them and convey feelings of security
 - appreciate the reciprocity between sensory/motor and affective/emotional experiences in playful, intentional, verbal and non-verbal interactions
 - habitually use and embed new skills, introduced by the therapists, in their everyday life to enhance connectedness, trust and feelings of security with their child.
- 3. To assist the caregivers to recognise and appreciate how their life stresses and challenges impact on interactions and relationships with their autistic child and help them to seek resources and ways of addressing them.



The underlying principles of the support programme (template text – do not remove)

the programme is underpinned by the following ideas:

- Children's early experiences, especially during the first three years of their life, shape the brain's architecture and determine its development. At this age, the brain has great plasticity and capacity for development.
- The crucial role of sensory and affective reciprocity in child and caregiver interactions. The subtle and unconscious sensory stimuli are communicated to the brain, through the nervous system, which in turn guides the reactions and actions of both the child and the caregiver.
- The subjective and intersubjective nature of interactions, where the child and caregiver
 interpret each other's intention and attention in subtle and unconscious ways that guide
 their responses and actions.
- The caregivers' understanding of the sensory and affective reciprocity and the subjective and intersubjective nature of their interactions with their children is crucial in enabling them to create everyday situations for intentional and reciprocal interactions.
- The caregivers' capacity for intentional and reciprocal interactions is subject to their life stresses and challenges. Thus, addressing parental anxieties and stresses and having access to support networks and services are equally important.

In this programme, the child is viewed as a potent, intentional, and goal-oriented individual, inherently wired to seek connection and trusting relationships with others. The child is viewed in relation to and in connection with others. Thus, while the child is at the centre of the programme, the support offered is primarily aimed at the caregivers.

Section E – Evidence for building the initial child and family portrait (template text – do not remove)

- The caregiver questionnaire, including developmental history
- The caregiver video recordings
- The Sensory Profile2 scoring given by the paediatric occupational therapist
- Therapists' joint initial interview with the family
- FEAS (Functional Emotional Assessment Scale) completed by the child psychotherapist

Section F – Introduction and background information

Provide an overview of the family, detailing information about:

- the child
- the family situation and current stressors
- favourite moments with the child
- strengths of the child and family



- previous therapy support received
- wishes and goals from the support programme.

Section G – Sensory assessment

Provide information about the child's sensory processing (e.g., visual, auditory and tactile processing; proprioception; vestibular function; and interoception). Please state **strengths and areas for improvement**.

Section H - Functional emotional assessment

Provide information about the child's socio-emotional functioning (e.g., the child's self-regulation and their interest in the world; social engagement and enjoyment; and reciprocal communication). Please state *strengths and areas for improvement*.

Section I – Setting goals for the six-week period of the home visits

- Sensory functioning
- Social emotional functioning

Review date:

State a date, within two weeks of completion of the home visits, to provide an end-of-programme child and family portrait.



Appendix 7: End-of-programme Child and Caregiver portrait

End-of-programme child and caregiver portrait

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recommendations

Report by (names of the therapists):					
Date of the report:					
Section A					
Child's name:					
Date of birth:					
Names of parents/caregivers:					
Reasons for referral:					
Section B – Brief information about the therapists					
Name of child psychotherapist:					
Name of paediatric occupational therapist:					
Name of lead therapist, if applicable:					
Section C – Purpose of the report (template text – do not remove)					

- 1. To provide an assessment of the child's and family's strengths and areas requiring strengthening
- 2. To outline key recommendations for future support and therapy



Section D – Aim of the support programme (template text – do not remove)

The aim of the programme is to reinforce and enhance trusting relationships between the child and the caregiver, building on the strengths and potential of the child and the capacities of the caregiver.

To achieve this aim, the support programme has the following objectives:

- To assess and continuously reassess the child's strengths and the caregivers' capacity,
 while acknowledging the challenges experienced. The initial assessment will determine
 the goals to be set out for the child and the caregivers for the six-week period of the
 home visits, while the end-of-programme assessment will detail the strengths and
 needs of the child and the caregivers, outline the support offered, and make
 recommendations for future therapy and support.
- 2. To assist the caregivers to:
 - notice incidents of glimmer and delight in their interactions with their child and work with the therapists to understand and appreciate the triggers and nuanced processes that enable such positive interactions
 - increase their ability to recognise the child's intentions and be in tune with them through joined attention in order to enhance the connection between them and convey feelings of security
 - appreciate the reciprocity between sensory/motor and affective/emotional experiences in playful, intentional, verbal and non-verbal interactions
 - habitually use and embed new skills, introduced by the therapists, in their everyday life to enhance connectedness, trust and feelings of security with their child.
- 3. To assist the caregivers to recognise and appreciate how their life stresses and challenges impact on interactions and relationships with their autistic child and help them to seek resources and ways of addressing them.

The underlying principles of the support programme (template text – do not remove)

the programme is underpinned by the following ideas:

- Children's early experiences, especially during the first three years of their life, shape the brain's architecture and determine its development. At this age, the brain has great plasticity and capacity for development.
- The crucial role of sensory and affective reciprocity in child and caregiver interactions. The subtle and unconscious sensory stimuli are communicated to the brain, through the nervous system, which in turn guides the reactions and actions of both the child and the caregiver.
- The subjective and intersubjective nature of interactions, where the child and caregiver
 interpret each other's intention and attention in subtle and unconscious ways that guide
 their responses and actions.
- The caregivers' understanding of the sensory and affective reciprocity and the subjective
 and intersubjective nature of their interactions with their children is crucial in enabling
 them to create everyday situations for intentional and reciprocal interactions.
- The caregivers' capacity for intentional and reciprocal interactions is subject to their life stresses and challenges. Thus, addressing parental anxieties and stresses and having access to support networks and services are equally important.

In this programme, the child is viewed as a potent, intentional, and goal-oriented individual, inherently wired to seek connection and trusting relationships with others. The child is viewed in relation to and in connection with others. Thus, while the child is at the centre of the programme,



Section E – Evidence for the assessment and recommendations provided (template text – do not remove)

- The initial child and family portrait, as agreed at the beginning of home visits
- Records of home visits by the therapists
- The FEAS to be completed by the child psychotherapist to assess the child's social and emotional functioning after the completion of the home visits
- The Sensory Profile 2 to be completed by parents/caregivers again for the paediatric occupational therapist's to rate the child's sensory sensitivity after the completion of the home visits
- Video recordings taken by the therapists, during home visits, if applicable
- Any further recorded discussions the therapists might have had with parents

Section F – Introduction and background information

In this section, provide a summary of the initial child and family portrait, detailing information about:

- the child
- the family situation and current stressors
- · favourite moments with the child
- strengths of the child and family
- previous therapy support received
- initial wishes and goals from the support programme.

Section G – Sensory assessment

On completion of the support programme, please provide a sensory assessment – e.g., visual, auditory and tactile processing; proprioception; vestibular functioning; and interoception. Please state *strengths and areas for improvement*.

Section H - Functional emotional assessment

On completion of the support programme, please provide information about the child's socioemotional functioning – e.g., the child's self-regulation and their interest in the world; social engagement and enjoyment; and reciprocal communication. Please state **strengths and areas for improvement**.

Section I - Recommendations

Recommendations must be prioritised and limited. They should not be overwhelming for the family or beyond their means, and the family should have the capacity to take full advantage of them.

- 1. Summary of good practices, exemplified during home visits, that should continue:
- 2. Additional support required from:



Ш	A child psychotherapist
	A paediatric occupational therapist
	Other (specify):
3.	Services available to the family (from other statutory service providers):
4.	Additional resources available to the family (community and free-of-charge resources and sources of information):
5.	Services available from TAP (tick one box only):
	Both the child psychotherapist and the paediatric occupational therapist
	The child psychotherapist only
	The paediatric occupational therapist only

Please note that the support programme cannot be repeated with the same family. A key component of the support programme is the assessment of the functioning and needs of the child and the family, and this has been summarised in the end-of-programme child and caregiver portrait. If the child and the family will benefit from further support offered by the child psychotherapist and/or the paediatric occupational therapist, then separate arrangements will be made concerning the duration of support, intended goals and outcomes, and how the support will be monitored.