

**R2D2**  
Mental Health

# **D3.1 – Consensus document on acceptable outcome measures for interventions for NDD**

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# D3.1 – Consensus document on acceptable outcome measures for interventions for NDD

Version V2.0

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## Abstract

This document (D3.1) reports on *Task 3.2: Co-produce consensus on acceptable outcome measures for interventions for neurodevelopmental disorders (NDD)* within the R2D2-MH project. Based on a co-creation process involving established co-creation groups (one composed of adults and another of youth) and project researchers, the initial design was adapted to enhance participation and stakeholder engagement. Through four consecutive phases combining group discussions and questionnaires with both researchers and co-creation groups, 42 dimensions and factors related to the resilience of autistic and ADHD individuals were identified—28 proposed by the co-creation groups and 14 by researchers. Outcome measures were assessed for feasibility, with seven dimensions lacking suitable measures. The prioritisation exercise revealed a strong and consistent consensus among participants, confirming broad agreement on the most relevant dimensions for resilience-focused research and interventions.

## Keywords

Resilience factors; Resilience Dimensions; Outcome measures; Consensus process

## Document revision history

Version	Date	Description of change	Contributor(s)
V1.0	31.10.23	Description of the works and results of the first stages of the consensus process	
V2.0	15.09.25	Description of the works and results of the consensus process	José Miguel Carrasco

## Disclaimer

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R2D2-MH project is based on a co-creation process aiming to incorporate the views and values of autism and ADHD youth, adults and parents. Once the co-creation groups of the project were established (one composed of adults and another of youth), and as a result of the co-creation process itself, the initial design proposed for Task3.2 has been slightly modified/adapted. The modifications adopted, which also imply adjustments to its timeline, are clearly described in the document. Undoubtedly, the acceptance of these modifications is based on and promotes the co-creation process and the participation of the various stakeholders involved in R2D2-MH.

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R

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## Executive summary

The R2D2-MH project is based on a co-creation process aiming to incorporate the views and values of autistic and ADHD youth, adults, and parents. This document (D3.1) provides information on Task 3.2: Co-produce consensus on acceptable outcome measures for interventions for neurodevelopmental disorders (NDD).

Once R2D2-MH was initiated, the co-creation groups were established (one composed of adults and another of youth). As a result of the co-creation process itself, the initial design of Task 3.2 was adapted to make the process more participatory, following suggestions from the co-creation groups. Specifically, instead of designing the Delphi questionnaire independently by the research team, an evaluation questionnaire was developed after gathering inputs from the co-creation groups. In addition, an extra face-to-face group discussion involving all members of both co-creation groups was held during the General Assembly in Paris (November 2023) before the final consensus exercise. These adaptations reinforced the participatory spirit of the project and strengthened stakeholder involvement across all stages of R2D2-MH.

Based on this adapted design, the process undertaken consisted of four consecutive phases:

Phase 1: Group discussions with the co-creation groups to determine the domains and factors relevant to the resilience of people with ADHD or autism.

Phase 2: Questionnaire with researchers (WP1, WP2, and WP4; Annexes I–III) to evaluate the dimensions identified in Phase 1, define additional dimensions relevant for R2D2-MH researchers, and identify potential outcome measures.

Phase 3: Grouping, refinement, prioritisation, and agreement on the dimensions identified in the earlier phases (Annex IV).

Phase 4: Presentation and final discussion of the prioritised dimensions and outcomes with co-creation group representatives and R2D2-MH researchers.

As a result of this process, a total of 42 dimensions and factors related to the resilience of autistic and ADHD individuals were identified: 28 by the co-creation groups and 14 by researchers, who considered them relevant but not previously identified by the groups. Researchers also evaluated the feasibility of identifying outcome measures associated with each of these dimensions, concluding that seven of them currently lack suitable measures, while one or more potential outcome measures could be associated with the remaining dimensions. The grouping, refinement and prioritisation exercise carried out by members of the co-creation groups revealed a broad and robust consensus among participants, with no significant comments recorded that would suggest the need for modifications. Eighteen dimensions reached a median relevance score of 10 points; six dimensions obtained a median of 9 points; one reached a median of 8.5; and four achieved a median of 8 points. Conversely, eight dimensions were not prioritised, as they presented median and mean scores below 8 points, showing a greater variability in the responses. Overall, these results demonstrate a high and consistent level of agreement among participants—both regarding the definitions and the relevance assigned to each dimension—highlighting the strong convergence of perspectives achieved through the co-creation process.

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## 1. TASK 3.2 OBJECTIVE AND METHODS

### 1.1. Objective

Co-produce and reach **consensus on acceptable outcome measures** for interventions targeting people with neurodevelopmental disorders (NDD), providing input for all R2D2-MH work packages, in the form of a consensus statement on acceptable measures to guide the whole project's targets for resilience and outcomes.

### 1.2. Methods

To achieve this objective, our interest is to identify:

- **Health-related dimensions:** health-related domains and factors that people with ADHD and autism consider relevant to their health and resilience.
- **Outcomes:** to evaluate the feasibility of measuring the identified dimensions and to identify available measures for their assessment.

#### 1.2.1. Design

In the proposal presented, this consensus process was designed taking into consideration two phases:

1. **DELPHI technique:** Implementation of a Delphi questionnaire to be completed by both co-creation groups (CCG-adults and CCG-youth) and project researchers.
2. **Consensus exercise:** Conduct a group consensus exercise involving a smaller group with representatives from both co-creation groups (adults and youth) and R2D2-MH researchers.

Once R2D2-MH was initiated, the co-creation groups were established (one composed of adults and another of youth), and as a result of the co-creation process itself, the **initially proposed design and timeline was adapted** considering suggestions from co-creation groups to do it more participative. For instance, by avoiding the design of the DELPHI questionnaire by the research team in charge of this task independently (as was described in the proposal) and instead developing an evaluation questionnaire after gathering inputs from the co-

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creation groups; and including an extra face-to-face group discussion with all the members of both co-creation groups (held during the General Assembly in Paris in November 2023) before the final consensus exercise. Finally, the process undertaken consists of the following phases:

1. **Phase 1:** Group discussions with the co-creation groups to determine the domains and factors that are relevant for the resilience of people with ADHD or autism.
2. **Phase 2:** Questionnaire with researchers (WP1, WP2 and WP4, Annexes I-III) to evaluate the dimensions identified from the co-creation groups in Phase 1, to define any other dimensions relevant for R2D2-MH researchers, and to identify potential outcome measures.
3. **Phase 3:** Grouping, refinement, prioritization, and agreement on the dimensions identified in the earlier phases (Annexe IV).
4. **Phase 4:** Presentation and final discussion of the prioritised dimensions and outcomes with co-creation group representatives and R2D2-MH researchers.

Undoubtedly, the assumption of these modifications is based on and promotes the co-creation process and the participation of the various stakeholders involved in R2D2-MH.

### 1.2.2. Phase 1: Group discussions with the co-creation groups

**Objective:** To collect a pool of health-related domains and factors that people with ADHD and autism consider relevant to their health.

**Participants:** CCG-Adult and CCG-Youth members.

**Technique:** Online group discussions employing consensus dynamics.

**Process:** Three online group discussions were conducted by APLICA, one with the CCG-Adult and two with CCG-Youth. This phase aimed to try to think *out of the box*, identifying different domains and factors that the ones typically used in research in NDD. With that purpose, the co-creation group participants engaged in **open discussions speaking as freely as possible** about what's important for their health and resilience.

At first, the participants were asked "What comes to mind when you hear the word health?", being that the trigger question to start the **discussion about health-related domains and factors related to the resilience of people with ADHD or autism**. After some conversation among the participants, in which they were guided to talk in positive terms about those factors and dimensions that improve their health and contribute to their resilience, they were introduced to the definition of Health by the World Health Organization. This definition has a holistic approach to the concept of health, so it was presented to the participants as a trigger to think and openly discuss the non-biological factors that contribute to their health, which was the last part of the group discussion.

The discussion was led by **two moderators with experience in qualitative data collection and consensus process**. The discussions lasted between 1h and 1h30 and were videotaped with the permission of the participants. The results of these sessions (health-related dimensions and its description), were collected by APLICA in two documents, one for each group. The results report was sent to the members of the CCG-Adult, who had the opportunity to make contributions and improvements. In the case of the GCC-Young, there was availability to hold a second session, in which they were presented with a single document that included the results of their previous session and the results obtained from the CCG-Adult. In this second session, the members of the CCG-Youth had the opportunity to make contributions and improvements to the results of the previous session.

The **final results** of this phase were **processed by APLICA** (summarizing, eliminating duplicates, homogenizing descriptions...) and collected in a single report. This document included the dimensions and factors related to health and resilience proposed by the participants in the co-creation groups and their descriptions (see section 2. Health-related key dimensions).

### 1.2.3. Phase 2: Questionnaire with researchers (WP1, WP2 and WP4)

**Objective:** To assess the **dimensions** identified by the co-creation groups in **Phase 1**, **define** any further dimensions deemed relevant by R2D2-MH researchers, and **identify suitable outcome measures** for their evaluation.

**Participants:** Leaders and researchers involved in R2D2-MH **WP1**, **WP2**, and **WP4**.

**Technique:** An online questionnaire based on **open-ended questions**.

**Process:** The questionnaire was **developed by APLICA** and **reviewed by WP3 researchers and R2D2-MH coordinators**. The questionnaire was sent by email to the leaders of WP1, WP2 and WP4, who were encouraged to consult with researchers in their WP to complete it. The questionnaire used open-ended questions and was **divided into** two sections:

- **SECTION A:** data collection template including all **dimensions identified** as relevant **by the CCGs** and a brief description of them. In this section, R2D2-MH researchers were asked to provide the following information: a) **feasibility of including** each dimension

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in R2D2-MH; and b) **list of related indicators/outcomes** within R2D2-MH datasets/cohorts that could be used to assess/measure the dimensions.

- **SECTION B:** open-ended questions to collect **any other dimensions and outcomes identified as relevant by researchers**. It was suggested to the WP leaders to consider sharing this section with the rest of the WP researchers. In this section, R2D2-MH researchers were asked to provide the following information: a) **name**; b) **description**; c) **relevance**; d) **feasibility of its assessment** with the context of their WP/R2D2-MH; d) **indicators/measurements** for its assessment if available.

The **results** obtained from the questionnaires of the three WPs (WP1, WP2, WP4; Annexes I-III) were **compiled and processed by APLICA** (eliminating duplicates, homogenizing descriptions, summarizing...).

#### 1.2.4. Phase 3: Grouping, refinement, prioritization, and agreement

**Objective:** The objective was to **group and further specify the dimensions identified** in the previous phases, and to **prioritize them according to the relevance** assigned by the co-creation group members.

**Participants:** CCG-Adult and CCG-Youth members.

**Technique:** **Group discussion** and a prioritisation **online questionnaire** designed in a format similar to a Delphi survey (Annexe IV) to facilitate structured feedback and consensus building.

**Process:** Following the **face-to-face meeting** held in Paris and the subsequent **online exchange of information** with and among the members of the co-creation groups to specify and finalise the work conducted during the in-person session, an **online questionnaire** was designed to assess the **level of relevance assigned** to each dimension by the group members. For each dimension, co-creation group members were asked to rate its relevance on a scale from 1 to 10, while also having access to a free-text field to provide comments on the assigned score or on the definition of the dimension itself. The questionnaire was **completed by all members** of the co-creation groups, and the results were analysed by APLICA, revealing a **broad and high level of consensus** among participants, both **on the definitions and on the relevance assigned to each dimension**, with no significant comments suggesting any need for revisions

## 2. HEALTH-RELATED KEY DIMENSIONS

Based on the process described above, a **list of health-related dimensions and factors contributing to the resilience of people with autism and ADHD** was compiled and is presented below, including the assigned name and its description. Some of these dimensions were identified by the co-creation groups in Phase 1 of the consensus process, while others were identified by the R2D2-MH researchers in

Phase 2, which is why this section of the report is divided into **two sections**: *Co-creation groups' health-related dimensions* and *R2D2-MH researchers' health-related dimensions*.

## 2.1. Co-creation groups' health-related dimensions

The following table lists health-related dimensions that people with ADHD or autism, and parents, from the co-creation groups consider relevant to their health.

Name	Description
<b>SELF-CONTROL</b>	To limit yourself and control the social interaction when it could be beneficial (e.g. not exaggerating in a passion).
<b>SELF-CONFIDENCE</b>	To have the feeling that it is okay to be who you are, not having the need to control any part of yourself.
<b>PERSONAL DEVELOPMENT</b>	To be able to meet your needs and desires and accomplish your aspirations.
<b>INDEPENDENCE</b>	To be able to cope with your problems having a feeling of control.
<b>TO PLAN</b>	To have a predictable day, to know what is going to happen and have control over situations, as it's a nice feeling to know that things have gone as expected.
<b>SAFE ENVIRONMENT</b>	To have a place to be calm and self-regulated without unexpected changes.
<b>ADAPTED ENVIRONMENT</b>	To live in an adapted environment to your needs (e.g. descriptive signs, self-checkout at shops, etc.).
<b>TRUSTED PEOPLE/PERSON</b>	To develop as a person in an environment in which you trust, knowing that you are trusted too.
<b>COMMUNITY INVOLVEMENT</b>	To be connected to people (physically or virtually), sharing activities within a group, socializing and feeling their support.

<b>SOCIAL RELATIONS</b>	To hang around with friends or people that make you feel good, connected and not to feel lonely (meaning to have people surrounding you that have the ability to think in the same way or at the same pace).
<b>FAMILIAR RELATIONS</b>	To have a caring and supportive family.
<b>EDUCATION</b>	To acquire knowledge, skills, and understanding through formal or informal learning processes.
<b>EDUCATIONAL SUPPORT (INSTITUTIONAL)</b>	To have additional support specialized for individuals with ADHD or autism at educational institutions (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).
<b>EDUCATIONAL SUPPORT (FAMILIAR)</b>	To have help with school homework or to mediate with school if you have problems (e.g. with teachers, with schoolmates).
<b>ECONOMIC SITUATION</b>	To be able to ensure financial security for present and future needs.
<b>OCCUPATION</b>	To find and choose a paid or unpaid job, maintaining and achieving advancement at work and being able to leave a job in an appropriate manner.
<b>COGNITIVE ACTIVITY</b>	To make mental connections (e.g. between memories, facts, knowledge you've gathered through the years...), letting your mind work at its highest level, being absorbed in your passions.
<b>TO PLAY</b>	To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.
<b>TO READ</b>	To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.
<b>PETS</b>	To spend time with domestic animals kept for companionship or pleasure.
<b>NATURE</b>	To connect with the environment in natural spaces (go to the forest, mountains, sea,...).
<b>CREATIVE ACTIVITIES</b>	To involve in imaginative activities as handicraft, painting, writing, listening or playing music, etc.

<b>PHYSICAL EXERCISE</b>	To engage in any bodily activity that enhances or maintains physical fitness and overall health.
<b>TO REST</b>	To be able to get enough rest along the days and to sleep well.
<b>HEALTHY LIFE-STYLE</b>	To adopt and maintain habits and behaviours that promote overall well-being and optimal physical and mental health.
<b>SENSORY STRATEGIES</b>	To find isolation, stimming (e.g. putting things in order, moving legs, rocking back and forth, using fidgeting toys to play with hands when stressed, headphones, etc.)...
<b>PSYCHOTHERAPY</b>	To have professional treatment to improve mental and emotional well-being.
<b>SERVICE DOG</b>	To have a service dog to carry out daily activities.

## 2.2. Researchers' health-related dimensions

The following table presents the health-related dimensions that R2D2-MH researchers from WP1, WP2, and WP4 consider relevant to explore and measure in resilience-focused research and interventions. After being presented with the health-related dimensions proposed by the co-creation groups (listed in the previous section), the researchers were invited to assess whether any additional dimensions or factors might be important for resilience-focused research and interventions. The results of this process are presented below, including the proposed name, the corresponding WP, and the description provided.

Name	WP	Description
<b>SYMPTOMS IMPROVEMENTS</b>	1	Symptomatology associated with autism spectrum disorder.
<b>BIOPHYSICAL HEALTH</b>	1	Presence of physical health conditions.
<b>COGNITION</b>	1	The ability to process and understand information, think critically, solve problems, make decisions, and effectively use cognitive skills.
<b>SOCIAL BEHAVIOUR</b>	1	Questionnaire and genetic measures of social behaviour.
<b>DEVELOPMENTAL MILESTONES</b>	1	Age at which individuals master important developmental milestones such as sitting, crawling, standing.

LANGUAGE PERFORMANCE AND COMMUNICATION	1	Measures to describe the production and perception of language and the ability to communicate efficiently.
MOTOR PERFORMANCE	1	Measures to describe the motor skills.
INTIMATE RELATIONSHIPS	2	The ability to maintain healthy intimate relationships, with clear boundaries and in which both people's needs and preferences are prioritised. Equally, the ability to exercise necessary distance and/or end relationships if they are not going well.
FRIENDSHIPS AND PEER RELATIONSHIPS	2	The ability to interact with peers and form peer relationships.
COMMUNICATION STRATEGIES	2	The access to and support through verbal or non-verbal communication strategies in order to be able to express ones needs, desires and oneself to others.
IDENTITY DEVELOPMENT	2	The freedom and support to explore and develop one's own interests, preferences, values, world views and attitudes towards oneself.
EMOTIONAL AWARENESS	2	To identify and be able to describe one's emotions/feelings, and generally be aware of their possible causes or triggers.
NURTURING/ENRICHING HOME ENVIRONMENT	2	Childhood factor. The extent to which parents provide stimulating, educational, or otherwise developmentally favourable home environments, activities, and experiences which encourage learning and the development of skills, interests, and hobbies.
POSITIVE PARENTING	2	Childhood factor. The extent to which parents behave in a warm, involved, and consistent way towards children, and avoid negative parenting behaviours such as overreactivity/anger, hostility and criticism, and negative discipline practices such as corporal punishment.
AFFECTIVE EMPATHY	2	Caring about and/or being emotionally affected by the feelings and needs of others.
---	4	In our opinion the dimensions are sufficient, however efforts should be made in order to make for some dimension relevant outcomes to be measured for: Preschool; School; Adolescence; Adults.
	4	This is extremely important since we should make efforts to make sure we are measuring relevant outcomes along the circle of life and not measuring it only on adults, thus missing the opportunity to evaluate early interventions.

## 3. FEASIBILITY AND OUTCOMES

### 3.1. Feasibility and Outcomes of Co-creation Groups' Identified Dimensions

The following table lists the **evaluation of R2D2-MH researchers from WP1, WP2 and WP4 of the feasibility and assessment of the dimensions identified by the co-creation groups and the outcomes** they propose for measuring them. The feasibility of measuring a dimension has been recorded in the table with “Yes/No/X”, representing X those dimensions in which the question about feasibility has not been answered by the researchers in the questionnaire. As for outcomes, those in which the researchers specified that no measures were available in their cohorts, were recorded as “None”; those in which the researchers proposed measures explicitly stating that they were not precise enough for measuring the dimension, were recorded as “Alike”; and those for which no response was available from the WPs, were recorded as “X”.

Name		Description			
<b>SELF-CONTROL</b>		To limit yourself and control the social interaction when it could be beneficial (e.g. not exaggerating in a passion).			
Feasibility		WP1	WP2	WP4	
Yes		Yes	Yes	Yes	
Outcomes		WP1	WP2	WP4	More than 1 WP
Effortful control subscale of Emotionality, Activity, Sociability Temperament Assessment; Child Behaviour Checklist (CBCL); YCBCL; BRIEF-A; ABC-C, hyperactivity/noncompliance subscale; CANTAB cognitive subscale; NEPSY-II tasks of inhibition	Cognitive Emotion Regulation Questionnaire (CERQ), ECBQ Inhibitory Control, impulsivity subscale; CBQ Inhibitory Control, impulsivity subscale	Brief Self-Control Scale; Social responsiveness Scale (SRS-2)		BRIEF-2 (WP1 + WP2); Strength and Difficulties Questionnaire (SDQ) (WP1 + WP4)	

<b>SELF-CONFIDENCE</b>	To have the feeling that it is okay to be who you are, not having the need to control any part of yourself.					
<b>Feasibility</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>				
Yes	Yes	Yes				
<b>Outcomes</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>			
Self-esteem Questionnaires; Harter scale	ASD-adapted version of the Stigma Scale; Stigma Scale	Alike				
<b>PERSONAL DEVELOPMENT</b>	To be able to meet your needs and desires and accomplish your aspirations.					
<b>Feasibility</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>				
Yes	No	Yes				
<b>Outcomes</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>			
Life course interview; Education/Vocational training, Romantic Relationships and Sexuality, Reproduction; WHO-QOL-BREF; Background History Questionnaire	None	Mental Health Continuum Short Form (MHC-SF), Psychological well-being subscale; Strength and Difficulties Questionnaire (SDQ)				
<b>INDEPENDENCE</b>	To be able to cope with your problems having a feeling of control.					
<b>Feasibility</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>				

Yes	Yes	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Childhood-effortful control; Adulthood Economically active; Independent live; ADHD Child Evaluation (ACE) medical; Daily living skills: Personal and domestic	WHOQoL	Psychological Wellbeing Scales, Autonomy subscale; Generic sense of ability to adapt (GSAAS); Developmental milestones; Parenting Self Efficacy questionnaire; Parental Stress Index	Vineland-II, coping skills subscale (WP1 + WP2)
<b>TO PLAN</b>	To have a predictable day, to know what is going to happen and have control over situations, as it's a nice feeling to know that things have gone as expected.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	Yes	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Alike	X	Alike	
<b>SAFE ENVIRONMENT</b>	To have a place to be calm and self-regulated without unexpected changes.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	No	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP

HOME; WHOQoL, environment scale; Living situation: have a bedroom/living room/children's room/hobby room	None	None	
<b>ADAPTED ENVIRONMENT</b>	To live in an adapted environment to your needs (e.g. descriptive signs, self-checkout at shops, etc.).		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	X	X	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
London Handicap Scale: environmental factors	X	X	
<b>TRUSTED PEOPLE/PERSON</b>	To develop as a person in an environment in which you trust, knowing that you are trusted too.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	Yes	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
WHO-QOL-BREF; Child Behaviour Checklist (CBCL); Social communication questionnaire (SCQ-40); Social	Multidimensional Scale of Perceived Social Support (MSPSS): special person/friend subscales	No	

responsiveness Scale (SRS-2); social behaviour polygenic scores			
<b>COMMUNITY INVOLVEMENT</b>	To be connected to people (physically or virtually), sharing activities within a group, socializing and feeling their support.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	Yes	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Parent interview; Life Course Interview; Vineland-II: play and leisure subscale; WHO-QoL-BREF; social behaviour polygenic scores	WHO-QoL	Mental Health Continuum Short Form (MHC-SF): Social-relational wellbeing subscale; Child Behaviour Checklist (CBCL)	Vineland: play and leisure and interpersonal relationship subscales (WP1 + WP2)
<b>FAMILIAL RELATIONS</b>	To have a caring and supportive family.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	No	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Dyadic Adjustment Scale; Parent-Child Relationship; Sibling relationships; Family	None	EPDS	

constellation; Cognitively stimulating parenting			
<b>EDUCATION</b>	To acquire knowledge, skills, and understanding through formal or informal learning processes.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	No	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Education history and further education; GPA; type of school; Vineland-II: ask level of education of parents, and individuals' education/highest grade completed; Background History Questionnaire	None	Education level; Type of school; Support needed	
<b>EDUCATIONAL SUPPORT (INSTITUTIONAL)</b>	To have additional support specialized for individuals with ADHD or autism at educational institutions (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	X	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>

special school; additional support in/outside school provided; treatment/therapy; Family history interview; Background history questionnaire	X	Questionnaire about school: Type and intensity of support; ADHD Child Evaluation (ACE)	
<b>EDUCATIONAL SUPPORT (FAMILIAL)</b>	To have help with school homework or to mediate with school if you have problems (e.g. with teachers, with schoolmates).		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	X	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Private lessons; Parenting: critical, warmth, coping; Family history interview; Background history questionnaire	X	ADHD Child Evaluation (ACE)	
<b>ECONOMIC SITUATION</b>	To be able to ensure financial security for present and future needs.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	No	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Employment; Income/Welfare; Housing Situation; WHO-QOL-BREF; ADHD Child	None	Alike	

Evaluation (ACE), Medical; Area Deprivation Index			
<b>OCCUPATION</b>	To find and choose a paid or unpaid job, maintaining and achieving advancement at work and being able to leave a job in an appropriate manner.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	Yes	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Employment; ADHD Child Evaluation (ACE); Brief-A	WHOQoL	Child Behaviour Checklist (CBCL)	
<b>COGNITIVE ACTIVITY</b>	To make mental connections (e.g. between memories, facts, knowledge you've gathered through the years...), letting your mind work at its highest level, being absorbed in your passions.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	No	No	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Alike	X	None	

<b>TO PLAY</b>	To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.					
<b>Feasibility</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>				
Yes	Yes	Yes				
<b>Outcomes</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>			
Parent interview: garden/playground, playmate; Life course interview: physical activities, social activities, hobbies, and chores; ADOS; Vineland-II: Play and Leisure subscale	WHOQoL; CBQ, High Intensity Pleasure subscale	VABS-II: Domain on "Play and leisure"; Social responsiveness Scale (SRS-2); Child Behaviour Checklist (CBCL)	Vineland: play and leisure subscale (WP1 + WP2)			
<b>TO READ</b>	To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.					
<b>Feasibility</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>				
Yes	Yes	Yes				
<b>Outcomes</b>						
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>			
Alike	None	None				
<b>PETS</b>	To spend time with domestic animals kept for companionship or pleasure.					

<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
No	X	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
X	X	None	
<b>NATURE</b>	To connect with the environment in natural spaces (go to the forest, mountains, sea,...).		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	X	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Parent interview. living conditions-garden/green space in neighbourhood where child can play?	X	SAIL-SF (Spiritual Attitude and Involvement List – Short Form): Connectedness with nature subscale; SAIL; Mayer's scale on connectedness to nature	
<b>CREATIVE ACTIVITIES</b>	To involve in imaginative activities as handicraft, painting, writing, listening or playing music, etc.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	X	Yes	

<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Family Environment Scale: Intellectual-cultural orientation	X	Alike	
<b>PHYSICAL EXERCISE</b>	To engage in any bodily activity that enhances or maintains physical fitness and overall health.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	Yes	No	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Life course interview: physical activities; Actometer assessment; Family Environment Scale: Active recreational orientation; WHO-QOL-BREF	WHOQoL	X	
<b>TO REST</b>	To be able to get enough rest along the days and to sleep well.		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	Yes	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>

Sleep quality/problems; Pittsburgh Sleep Quality Index; Family history interview: report of sleep problems	Alike	X	Child/Adolescent Sleep Habits Questionnaire (CSHQ) (WP1 + WP4)
<b>HEALTHY LIFE-STYLE</b>	To adopt and maintain habits and behaviours that promote overall well-being and optimal physical and mental health.		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	X	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
WHOQoL-BREF: sleep, physical environment, leisure activities	X	Alike	
<b>SENSORY STRATEGIES</b>	To find isolation, stimming (e.g. putting things in order, moving legs, rocking back and forth, using fidgeting toys to play with hands when stressed, headphones, etc.)...		
<b>Feasibility</b>			
WP1	WP2	WP4	
Yes	Yes	Yes	
<b>Outcomes</b>			
WP1	WP2	WP4	More than 1 WP
Alike	Alike	Alike	
<b>PSYCHOTHERAPY</b>	To have professional treatment to improve mental and emotional well-being.		

<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
Yes	Yes	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
Mannheimer Parent Interview: Treatment/therapy	Alike	Alike	
<b>SERVICE DOG</b>	To have a service dog to carry out daily activities		
<b>Feasibility</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	
No	X	Yes	
<b>Outcomes</b>			
<b>WP1</b>	<b>WP2</b>	<b>WP4</b>	<b>More than 1 WP</b>
X	None	None	

### 3.2. Feasibility and Outcomes of R2D2-MH Researchers' Identified Dimensions

The following table lists the **health-related dimensions identified by R2D2-MH researchers**, as well as **their opinions on the feasibility of assessing them and outcomes** from the R2D2-MH cohorts they propose for this purpose. The feasibility of measuring a dimension has been recorded in the table with "Yes/No/X", representing X those dimensions in which the question about feasibility has not been answered by the researchers in the questionnaire. As for outcomes, those in which the researchers specified that no measures were available in their cohorts, were recorded as "None"; those in which the researchers proposed measures explicitly stating that they were not precise enough for measuring the dimension, were recorded as "Alike"; and those for which no response was available from the WPs, were recorded as "X".

Name	Description
<b>SYMPTOMS IMPROVEMENTS (WP1)</b>	Symptomatology associated with autism spectrum disorder
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Social communication questionnaire (SCQ-40)
<b>BIOPHYSICAL HEALTH (WP1)</b>	Presence of physical health conditions
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Health Utilities Index (HUI): Prenatal and neonatal health, Disability; WHOQoL; SF-12; ADHD Child Evaluation (ACE) medical
<b>COGNITION (WP1)</b>	The ability to process and understand information, think critically, solve problems, make decisions, and effectively use cognitive skills
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Harter scale: cognitive competence; Wechsler Adult Intelligence Scales (WAIS): executive functions, attention, memory; WASI-II; CANTAB: attention, working memory, social cognition, executive function; NEPSY-II: response inhibition, theory of mind; Mullens scale of early learning (MSEL)
<b>SOCIAL BEHAVIOUR (WP1)</b>	Questionnaire and genetic measures of social behaviour
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Social behaviour GWAS for a spectrum of different social outcomes (peer problems and prosocial behaviour, different developmental stages, parent (home), teacher (school) and self-assessments; Social communication questionnaire (SCQ-40); ADOS-II; ADI-R; Vineland-II
<b>DEVELOPMENTAL MILESTONES (WP1)</b>	Age at which individuals master important developmental milestones such as sitting, crawling, standing
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Age of walking; Age of sitting; Age of crawling; Age of smiling; Age of self-feeding; ADHD Child Evaluation (ACE) medical: age of walking, and first words; ADI-R: age of walking, and first words
<b>LANGUAGE PERFORMANCE AND COMMUNICATION (WP1)</b>	Measures to describe the production and perception of language and the ability to communicate efficiently
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Language level; Language age level; Cognitive age level; Language disorder; Diagnostic Evaluation of Articulation and Phonology: Phonology subtest; Children's Communication Checklist (CCC); Communication Checklist-Adults (CC-A)
<b>MOTOR PERFORMANCE (WP1)</b>	Measures to describe the motor skills
<b>Feasibility</b>	Yes

<b>Outcomes</b>	DCDQ; Vineland: motor skills subscale; Mullens scale of early learning (MSEL): measure of motor skills
<b>INTIMATE RELATIONSHIPS (WP2)</b>	The ability to maintain healthy intimate relationships, with clear boundaries and in which both people's needs and preferences are prioritised. Equally, the ability to exercise necessary distance and/or end relationships if they are not going well.
<b>Feasibility</b>	Yes
<b>Outcomes</b>	None
<b>FRIENDSHIPS and PEER RELATIONSHIPS (WP2)</b>	The ability to interact with peers and form peer relationships.
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Strength and Difficulties Questionnaire (SDQ): prosocial; Peer Problems; Vineland: Interpersonal Relationships
<b>COMMUNICATION STRATEGIES (WP2)</b>	The access to and support through verbal or non-verbal communication strategies in order to be able to express ones needs, desires and oneself to others.
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Alike
<b>IDENTITY DEVELOPMENT (WP2)</b>	The freedom and support to explore and develop one's own interests, preferences, values, world views and attitudes towards oneself
<b>Feasibility</b>	X
<b>Outcomes</b>	None
<b>EMOTIONAL AWARENESS (WP2)</b>	To identify and be able to describe one's emotions/feelings, and generally be aware of their possible causes or triggers
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Toronto Alexithymia Scale (TAS-20) (reversed)
<b>NURTURING/ENRICHING HOME ENVIRONMENT (WP2)</b>	Childhood factor. The extent to which parents provide stimulating, educational, or otherwise developmentally favourable home environments, activities, and experiences which encourage learning and the development of skills, interests, and hobbies
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Alabama Parenting Questionnaire (APQ)
<b>POSITIVE PARENTING (WP2)</b>	Childhood factor. The extent to which parents behave in a warm, involved, and consistent way towards children, and avoid negative parenting behaviours such as overreactivity/anger, hostility and criticism, and negative discipline practices such as corporal punishment
<b>Feasibility</b>	Yes

<b>Outcomes</b>	Alabama Parenting Questionnaire (APQ)
<b>AFFECTIVE EMPATHY (WP2)</b>	Caring about and/or being emotionally affected by the feelings and needs of others
<b>Feasibility</b>	Yes
<b>Outcomes</b>	Alabama Parenting Questionnaire (APQ); Child Empathising Quotient and Systemising Quotient (CEQSQ); Empathy Quotient (EQ)

### 3.3. Dimensions with no associated outcomes

This section lists all those dimensions that were identified as having no associated measures at least by one WP, whether or not they have been considered as feasible to assess by the researchers. On some occasions, researchers proposed outcomes explicitly stating that they are not precise enough for measuring a particular dimension. There are dimensions in which only these types of imprecise measures are proposed by the researchers for evaluation. These dimensions are also listed below as dimensions with no associated outcomes.

#### 3.3.1. Dimensions with no associated outcome for all the WPs

- **SELF-CONFIDENCE**
  - WP1: no outcomes
  - WP2: imprecise outcomes
  - WP4: imprecise outcomes
- **PREDICTABILITY AND CONTROL**
  - WP1: imprecise outcomes
  - WP2: imprecise outcomes
  - WP4: no outcomes
- **TO READ**
  - WP1: imprecise outcomes
  - WP2: no outcomes
- WP4: no outcomes
- **SENSORY STRATEGIES**
  - WP1: imprecise outcomes
  - WP2: imprecise outcomes
  - WP4: imprecise outcomes
- **COGNITIVE ACTIVITY**
  - WP1: imprecise outcomes
  - WP2: imprecise outcomes
  - WP4: not feasible to assess
- **PETS**
  - WP1: no answers
  - WP2: not feasible to assess
  - WP4: no outcomes

- **SERVICE DOG**
  - WP1: no answers
  - WP2 considered this dimension not feasible to assess
  - WP4 didn't propose any measures

### 3.3.2. Dimensions with no associated outcome for two of the WPs

- **PSYCHOTHERAPY**
  - WP2: imprecise outcomes
  - WP4: imprecise outcomes
- **SAFE ENVIRONMENT**
  - WP2: not feasible to assess
  - WP4: no outcomes
- **ECONOMIC SITUATION**
  - WP2: not feasible to assess
  - WP4: imprecise outcomes
- **CREATIVE ACTIVITIES**
  - WP2: no answers
  - WP4: imprecise outcomes
- **HEALTHY LIFE-STYLE**
  - WP2: no answers
  - WP4: imprecise outcomes

### 3.3.3. Dimensions with no associated outcome for one of the WPs

- **INDEPENDENCE**
  - WP2: imprecise outcomes
- **COMMUNITY INVOLVEMENT**
  - WP2: imprecise outcomes
- **TO REST**
  - WP2: imprecise outcomes
- **INTIMATE RELATIONSHIPS**
  - WP2: no outcomes
- **COMMUNICATION STRATEGIES**
  - WP2: imprecise outcomes
- **PERSONAL DEVELOPMENT**
  - WP2: not feasible to assess
- **EDUCATION**
  - WP2: not feasible to assess
- **NATURE**
  - WP2: no answers
- **EDUCATIONAL SUPPORT (INSTITUTIONAL)**
  - WP2: no answers
- **EDUCATIONAL SUPPORT (FAMILIAL)**

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- WP2: no answers
- **IDENTITY DEVELOPMENT**
  - WP2: no answers
- **FAMILIAL RELATIONS**
  - WP4: imprecise outcomes
- **PHYSICAL EXERCISE**
  - WP4: no outcomes
- **TRUSTED PEOPLE/PERSON**
  - WP4: no outcomes
- **ADAPTED ENVIRONMENT**
  - WP4: no answers

## 4. PRIORITIZED DIMENSIONS, AGREEMENT LEVEL, AND OUTCOME MEASURES

The following section presents the **results of the analyses** conducted on the **prioritisation questionnaire** (Annex IV), completed by all members of the co-creation groups, including both adult and youth participants. The questionnaire followed a format similar to that commonly used in Delphi surveys, allowing for structured feedback and consensus building. Prioritisation and the degree of consensus were assessed using the median and mean of the individual relevance ratings assigned to each dimension, based on a ranking scale from 1 (minimum relevance) to 10 (maximum relevance).

The analysis of the responses revealed a **broad and robust consensus** among participants, with no significant comments recorded that would suggest the need for modifications. Eighteen dimensions reached a median relevance score of 10 points; six dimensions obtained a median of 9 points; one reached a median of 8.5; and four achieved a median of 8 points. Conversely, eight dimensions were not prioritised, as they presented median scores below 8 points and showed greater variability in the responses.

The tables below present the results regarding the **relevance assigned** to each dimension, the corresponding **level of agreement** (mean and median), and the **availability of outcome measures** for their evaluation, based on the information provided in the questionnaires completed by R2D2-MH researchers. Dimensions for which no outcome measure could be identified are highlighted in orange

### PRIORITISED DIMENSIONS (n=29)

PRIORITISED DIMENSIONS (n=29)	Median	Mean	Available	Outcome name	Domain/Subscale
APPROPRIATE SUPPORT	10	9,82			
SAFE ENVIRONMENT	10	9,73	Yes	HOME	
			Yes	World Health Organization Quality-of-Life Scale (WHOQOL)	Environment
			Yes	Living situation: Have a bedroom/living room / children's room / hobby room	
SUPPORT SYSTEM	10	9,64			

<b>TO REST</b>	10	9,55	Alike	Oxford Sleep Questionnaire	Infancy focused sleep measures
			Alike	Sleep and Settle Questionnaire	Infancy focused sleep measures
			Alike	SNORI	Infancy focused sleep measures
			Yes	Child/Adolescent Sleep Habits Questionnaire (CSHQ)	
			Yes	Sleep quality/problems	
			Yes	Pittsburgh Sleep Quality Index	
			Yes	Family history interview	Report of sleep problems
<b>SELF-REGULATION</b>	10	9,55	Yes	Cognitive Emotion Regulation Questionnaire (CERQ)	
			Yes	Early Childhood Behaviour Questionnaire (ECBQ)	Inhibitory Control, impulsivity
			Yes	Children's Behaviour Questionnaire (CBQ)	Inhibitory Control, impulsivity
			Yes	Behaviour Rating Inventory of Executive Function (BRIEF-2)	
			Yes	Brief Self-Control Scale	
			Yes	Strength and Difficulties Questionnaire (SDQ)	
			Yes	Social responsiveness Scale (SRS-2)	
			Yes	Effortful control subscale of Emotionality, Activity, Sociability Temperament Assessment	
			Yes	Child Behaviour Checklist (CBCL)	
			Yes	Aberrant Behaviour Checklist-Community (ABC-C)	Hyperactivity/noncompliance
			Yes	Cambridge Neuropsychological Test Automated Battery (CANTAB)	Cognitive

			Yes	NEuroPSYchological Assessment – Second Edition (NEPSY-II)	Tasks of inhibition
<b>ACCESS TO HEALTHCARE</b>	10	9,55			
<b>ADAPTED ENVIRONMENT</b>	10	9,55	Yes	London Handicap Scale	Environmental factors
<b>TRUST (PEOPLE)</b>	10	9,4	Yes	Multidimensional Scale of Perceived Social Support (MSPSS)	Special person/friends subscales
			Yes	Life course interview	Partnership, friendship, social support
			Yes	WHO-QOL-BREF	
			Yes	Child Behaviour Checklist (CBCL)	
			Yes	Social communication questionnaire (SCQ-40)	
			Yes	Social responsiveness Scale (SRS-2)	
			Yes	Social behaviour polygenic scores	
<b>SELF-CONFIDENCE</b>	10	9,36	Alike	ASD-adapted version of the Stigma Scale	
			Alike	Stigma Scale	
			Alike	Parental Stress Index (PSI-Short Form)	
			-	Self-esteem Questionnaires	
			-	Harter scale	
<b>SELF-ACCEPTANCE</b>	10	9,36			
<b>EDUCATION</b>	10	9,27	Yes	Educational level	
			Yes	Type of school	
			Yes	Support needed	

			Yes	Education history and further education	
			Yes	GPA	Type of school they attended, highest education attainment, age of graduation
			Yes	Vineland-II	Ask level of education of parents, and individuals' education/highest grade completed
			Yes	Background History Questionnaire	
<b>SELF-ESTEEM</b>	10	9,27			
<b>TRUST (PHYSICAL ENVIRONMENT)</b>	10	9,27			
<b>EDUCATIONAL SUPPORT (INSTITUTIONAL)</b>	10	9,18	Yes	Questionnaire about school	Type and intensity of support
			Yes	ADHD Child Evaluation (ACE)	
			Yes	Special school	
			Yes	Additional support in/outside school provided	
			Yes	Treatment/therapy	
			Yes	Family history interview	
			Yes	Background history questionnaire	
<b>EDUCATIONAL SUPPORT (FAMILIAR)</b>	10	9	Yes	ADHD Child Evaluation (ACE)	
			Yes	Private lessons	
			Yes	Parenting	Critical, warmth, coping
			Yes	Family history interview	
			Yes	Background history questionnaire	
	10	8,91	Alike	Vineland	

<b>COMMUNICATION SKILLS</b>			Alike	Social Responsiveness Scale (SRS-2)	Communication subscale
			Alike	ADOS	
			Yes	Language level	
			Yes	Language age level	
			Yes	Cognitive age level	
			Yes	Language disorder	
			Yes	Diagnostic Evaluation of Articulation and Phonology	Phonology subtest
			Yes	Children's Communication Checklist (CCC)	
			Yes	Communication Checklist-Adults (CC-A)	
			Alike	SES (socio-economic status)	
			Yes	Employment	
			Yes	Income/Welfare	
			Yes	Housing Situation	
			Yes	WHO-QOL-BREF	
<b>SENSORY STRATEGIES</b>	10	8,73	Alike	ECBQ Perceptual Sensitivity	
			Alike	CBQ	Perceptual Sensitivity
			Alike	ICBQ Perceptual Sensitivity	
			Alike	Infant-Toddler/Short Sensory Profile	
			Alike	Repetitive/restricted behaviour (RRB)	
			Alike	Child Routines Inventory (CRI)	
			Alike	ADHD Child Evaluation (ACE)	
			Alike	ADI	
			Alike	Sensory profile	

			Alike	ADI-R	Section on Interests and Behaviours asks about unusual sensory interests and sensory sensitivities
			Alike	ADOS	
			Alike	Measures of sensory sensitivities in questionnaires	
<b>PHYSICAL EXERCISE</b>	10	8,55	Yes	WHOQoL	
			Yes	Life course interview	Physical activities
			Yes	Actometer assessment	
			Yes	Family Environment Scale	Active recreational orientation
			Yes	WHO-QOL-BREF	
<b>FAMILIAL RELATIONS</b>	9	9,09	Yes	Multidimensional Scale of Perceived Social Support (MSPSS)	Family subscale
			Yes	EPDS	
			Alike	Parental Stress Index	
			Yes	Dyadic Adjustment Scale	
			Yes	Parent-Child Relationship	
			Yes	Sibling relationships	
			Yes	Family constellation	
			Yes	Cognitively stimulating parenting	
<b>COGNITIVE DEVELOPMENT</b>	9	8,73	Alike	CANTAB	Battery of cognitive tasks
			Alike	NEPSY-II	Subtest of inhibition and theory of mind
			Alike	WASI-II	
			Alike	Mullens scale of early learning - MSEL	

			Alike	experimental IQ	
<b>ROUTINE</b>	9	8,64			
<b>PLANNING</b>	9	8,55			
<b>WORK</b>	9	8,09	Yes	WHOQoL	
			Yes	Child Behaviour Checklist (CBCL)	
			Yes	Employment	
			Yes	ADHD Child Evaluation (ACE)	Background
			Yes	Brief-A	Executive function
<b>COMMUNITY INVOLVEMENT</b>	8,5	7,9	Alike	Vineland	Play and Leisure subscale
			Yes	WHOQoL	
			Yes	Mental Health Continuum Short Form (MHC-SF)	Social-relational well-being subscale
			Yes	Child Behaviour Checklist (CBCL)	
			Yes	Parent interview	
			Yes	Life Course Interview	
			Yes	Vineland-II	Play and Leisure subscale
			Yes	WHO-QOL-BREF	
			Yes	Vineland	Play and Leisure subscale, Interpersonal relationship subscale
			Yes	Social behaviour polygenic scores	
<b>SOCIAL RELATIONS</b>	8	8,27	Yes	Social communication questionnaire (SCQ-40)	
			Yes	Social behaviour GWAS	For a spectrum of different social outcomes (peer problems and prosocial)

					behaviour, different developmental stages, parent (home), teacher (school) and self-assessments
			Yes	Social communication questionnaire (SCQ-40)	
			Yes	ADOS-II	
			Yes	ADI-R	
			Yes	Vineland-II	
<b>TASK INITIATION</b>	8	8,18			
<b>LEARN SKILLS</b>	8	8,18			
<b>PEERS SUPPORT</b>	8	8,18			

**NOT PRIORITISED DIMENSIONS (median and mean  $\leq 8$ ; n=8)**

NOT PRIORITISED DIMENSIONS (n=8)	Median	Mean	Available	Outcome name	Domain/Subscale
<b>MANAGE MOTIVATION</b>	8	7,73			
<b>CREATIVE ACTIVITIES</b>	8	7,73	Alike	ADOS	Imagination/Creativity item in module 3
			Yes	Family Environment Scale	Intellectual-cultural orientation
<b>TO PLAY</b>	8	7,64	Yes	WHOQoL	
			Yes	CBQ	High Intensity Pleasure subscale
			Yes	Vineland	Play and Leisure subscale
			Yes	VABS-II	Domain on "Play and leisure"

			Yes	Social responsiveness Scale (SRS-2)	
			Yes	Child Behaviour Checklist (CBCL)	
			Yes	Parent interview	Garden/playground, playmate
			Yes	Life course interview	Physical activities, social activities, hobbies, and chores
			Yes	ADOS	
			Yes	Vineland-II	Play and Leisure subscale
			Yes	Vineland	Play and Leisure subscale
<b>BALANCED DIET</b>	8	7,18			
<b>NATURE</b>	7	7,09	Yes	SAIL-SF (Spiritual Attitude and Involvement List – Short Form)	Connectedness with nature subscale
			Yes	SAIL	
			Yes	Mayer's scale on connectedness to nature	
			Yes	Parent interview	Living conditions-garden/green space in neighbourhood where child can play?
<b>TO READ</b>	6	6,82	Alike	Vineland	Written communication subdomain
<b>SERVICE DOG</b>	6	5,91	No		
<b>PETS</b>	5	5,18	No		

## 5. ANNEXES

### 5.1. Annex I: WP1 Researchers' Questionnaire Responses

#### SECTION A

Dimensions identified by the co-creation groups: data collection template	
<b>1. Name of the dimension:</b> SELF-CONTROL	
<b>2. Description of the dimension:</b> To consciously regulate and manage one's emotions, thoughts, and actions in order to achieve goals, especially in social interactions.	
<b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS and RaDiaNT & SPARK)	
<b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Effortful control subscale of Emotionality, Activity, Sociability Temperament Assessment; Strength and Difficulties Questionnaire (SDQ); CBCL and YCBCL), RaDiaNT (BRIEF-2 measures cognitive, behavioural, and emotional regulation, BRIEF-A has nine scales: Inhibit, Self-Monitor, Plan/Organize, Shift, Initiate, Task Monitor, Emotional Control, Working Memory, and Organization of Materials, SDQ, ABC-C hyperactivity/noncompliance subscale, we also have cognitive CANTAB and NEPSY-II tasks of inhibition which may measure ability to withhold a motor response) , SPARK: (CBCL)	
<b>1. Name of the dimension:</b> PERSONAL DEVELOPMENT	
<b>2. Description of the dimension:</b> To be able to meet your needs and desires, accomplish your aspirations, and/or feel helpful to others.	
<b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS & RaDiaNT)	
<b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Life Course Interview: Education/Vocational training; Romantic Relationships and Sexuality; Reproduction), RaDiaNT (WHO-QOL-BREF: asks many questions about things that could help/hinder personal development - if satisfied with health, if they have pain that prevents them from doing what they want to do, how safe they feel, physical environment, if they have enough money etc.), SPARK (Background History Questionnaire)	
<b>1. Name of the dimension:</b> INDEPENDENCE	
<b>2. Description of the dimension:</b> To be able to cope with your problems having a feeling of control.	
<b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS & RaDiaNT & SPARK)	

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (Childhood-effortful control; Adulthood Economically active; Independent live), RaDiaNT (Vineland-II coping skills subscale, ACE Medical asks about living arrangement - e.g. independent or not), SPARK (Vineland: Coping skills subscale, Personal daily living skills, domestic daily living skills). Just a thought about the description: Independence could be taking care of your own basic needs and well-being, and coping could be the ability to cope with difficulties/problems which may be measured separately in some measures.

**1. Name of the dimension: SAFE ENVIRONMENT**

**2. Description of the dimension:** To have a place to be alone, calm, and self-regulated without unexpected changes (e.g. your own room).

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (HOME; Environment scale-WHOQOL; Living situation-Has a bedroom/living room/children's room/hobby room)

**1. Name of the dimension: ADAPTED ENVIRONMENT**

**2. Description of the dimension:** To live in an adapted environment to your needs (e.g. descriptive signs, self-checkout at shops, etc.).

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (London Handicap Scale-environmental factors)

**1. Name of the dimension: COMMUNITY INVOLVEMENT**

**2. Description of the dimension:** To hang around with friends or people that make you feel good, connected and not to feel lonely (meaning to have people surrounding you that have the ability to think in the same way or at the same pace).

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS & RaDiaNT & SPARK & EAGLE)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (Parent interview at childhood and Life Course Interview at adulthood (e.g., friendship, social support, other social activities), RaDiaNT (Vineland-II Play and Leisure subscale, WHO-QoL-BREF – asks about satisfaction of personal relationships, and the support they get from friends), SPARK (Vineland: Play and Leisure subscale, Interpersonal relationship subscale), EAGLE (social behaviour polygenic scores predicting peer problems and prosocial behaviour)

**1. Name of the dimension: FAMILIAR RELATIONS**

**2. Description of the dimension:** To have a caring, supportive and trustable family.

<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Dyadic Adjustment Scale; Parent-Child Relationship; Sibling relationships; Family constellation; Cognitively stimulating parenting)</p>
<p><b>1. Name of the dimension:</b> EDUCATION</p> <p><b>2. Description of the dimension:</b> To acquire knowledge, skills, and understanding through formal or informal learning processes.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Education history and further education; GPA, type of school they attended, highest education attainment, age of graduation), RaDiaNT (ask level of education of parents, and individuals' education/highest grade completed in Vineland_II), SPARK (Background History Questionnaire)</p>
<p><b>1. Name of the dimension:</b> ECONOMIC SITUATION</p> <p><b>2. Description of the dimension:</b> To be able to ensure financial security for present and future needs.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Employment, Income/Welfare, Housing Situation), RaDiaNT (WHO—QOL-BREF asks individual 'have you enough money to meet your needs', ACE Medical asks parents for their annual household income range.)SPARK (Area Deprivation Index)</p>
<p><b>1. Name of the dimension:</b> OCCUPATION</p> <p><b>2. Description of the dimension:</b> To find and choose a paid or unpaid job, maintaining and achieving advancement at work and being able to leave a job in an appropriate manner.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Employment-whether they were employed, professional position, and how often they work), RaDiaNT (do not directly ask occupation for our participant, but ask about parent/caregiver occupation in ACE background, Brief-A – executive function asks about trouble concentrating on tasks, e.g. school/work, trouble changing from one task to another, trouble starting/ finishing tasks etc. which would all be relevant to being able to maintain work).</p>
<p><b>1. Name of the dimension:</b> COGNITIVE ACTIVITY</p> <p><b>2. Description of the dimension:</b> To make mental connections (e.g. between memories, facts, knowledge you've gathered through the years...), letting your mind work at its highest level, being absorbed in your passions.</p>

<p><b>3. Feasibility of its assessment in the current cohort:</b> Not feasible in BLS, somewhat feasible in RaDiaNT - however more cognitive ability/ performance, somewhat feasible in SPARK</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> RaDiaNT (measures of cognitive ability CANTAB battery of cognitive tasks, NEPSY-II subtest of inhibition and theory of mind, WASI-II, Mullens Scales of Early Learning), SPARK (predictive – experimental IQ)</p>
<p><b>1. Name of the dimension:</b> TO PLAY</p> <p><b>2. Description of the dimension:</b> To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Parent interview-garden/playground, playmate; Life course interview-physical activities, social activities, hobbies, and chores), RaDiaNT (ADOS, Vineland-II Play and Leisure subscale), SPARK (ADOS, Vineland Play and Leisure subscale)</p>
<p><b>1. Name of the dimension:</b> PETS</p> <p><b>2. Description of the dimension:</b> To spend time with domestic animals kept for companionship or pleasure.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Not feasible in BLS or RaDiaNT or SPARK</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b></p>
<p><b>1. Name of the dimension:</b> NATURE</p> <p><b>2. Description of the dimension:</b> To connect with the environment in natural spaces (e.g. go to the forest, mountains, sea, walks with dogs...).</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Parent interview-living conditions-garden/green space in neighbourhood where child can play?)</p>
<p><b>1. Name of the dimension:</b> CREATIVE ACTIVITIES</p> <p><b>2. Description of the dimension:</b> To involve in imaginative activities as handicraft, painting, writing, listening or playing music, etc.</p>
<p><b>3. Feasibility of its assessment in the current cohort:</b> Feasible (BLS)</p> <p><b>4. List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Family Environment Scale, Intellectual-cultural orientation measures to which the family is concerned about political, social, intellectual and cultural activities)</p>

**1. Name of the dimension: PHYSICAL EXERCISE**

**2. Description of the dimension:** To engage in any bodily activity that enhances or maintains physical fitness and overall health.

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS, RaDiaNT)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (Life course interview-physical activities; Actometer assessment in childhood; Family Environment Scale, Active recreational orientation), RaDiaNT (WHO-QoL BREF asks how satisfied you are with your health)

**1. Name of the dimension: TO REST**

**2. Description of the dimension:** To be able to get enough rest along the days (e.g. breaks between classes) and to sleep well.

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS, RaDiaNT)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (parent-reported sleep quality/problems), RaDiaNT (Child/Adolescent Sleep Habits Questionnaire (CSHQ), Pittsburgh Sleep Quality Index, and Family history interview report of sleep problems)

**1. Name of the dimension: SERVICE DOG**

**2. Description of the dimension:** To have a service dog to carry out daily activities.

**3. Feasibility of its assessment in the current cohort:** Not feasible in BLS or RaDiaNT or SPARK

**4. List of existing outcomes for its assessment in the cohort (max 10):**

**1. Name of the dimension: SELF-CONFIDENCE**

**2. Description of the dimension:** To have the feeling that it is okay to be who you are.

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (Self-esteem Questionnaires, Harter scale in childhood)

**1. Name of the dimension: PREDICTABILITY AND CONTROL**

**2. Description of the dimension:** To have a predictable day, to know what is going to happen and to have control over situations, as it's a nice feeling to know that things have gone as expected.

<p>3. <b>Feasibility of its assessment in the current cohort:</b> Not feasible in BLS, indirect measure in RaDiaNT</p> <p>4. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> Not directly assessed in RaDiaNT, but ask about coping skills in Vineland-II</p>
<p>1. <b>Name of the dimension:</b> TRUSTED PEOPLE/PERSON</p> <p>2. <b>Description of the dimension:</b> To develop as a person in an environment in which you trust, knowing that you are trusted too.</p>
<p>3. <b>Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK, EAGLE)</p> <p>4. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Life course interview-partnership, friendship, social support), RaDiaNT (WHO-QOL BREF asks how safe you feel in your environment, is your physical environment healthy, if you are satisfied with your personal relationships, support you get from your friends), SPARK (CBCL, SCQ, SRS), EAGLE social behaviour polygenic scores predicting peer problems and prosocial behaviour</p>
<p>1. <b>Name of the dimension:</b> EDUCATIONAL SUPPORT (INSTITUTIONAL)</p> <p>2. <b>Description of the dimension:</b> To have additional support specialized for individuals with ADHD or autism at educational institutions (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).</p>
<p>3. <b>Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK)</p> <p>4. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (special school; additional support in/outside school provided; treatment/therapy-whether their child was ever treated for any of the problems raised in the interview for example sleeping or eating problems, depressive mood or social relationships, or other psychological, speech or learning problems), RaDiaNT (Family history interview asks if received special supports in school), SPARK (Background history questionnaire)</p>
<p>1. <b>Name of the dimension:</b> EDUCATIONAL SUPPORT (FAMILIAR)</p> <p>2. <b>Description of the dimension:</b> To have help with school homework or to mediate with school if you have problems (e.g. with teachers, with schoolmates).</p>
<p>3. <b>Feasibility of its assessment in the current cohort:</b> Feasible (BLS, RaDiaNT, SPARK)</p> <p>4. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Private lessons; parenting-critical, warmth, coping), RaDiaNT (Family history interview asks if received special supports in school), SPARK (Background history questionnaire)</p>
<p>1. <b>Name of the dimension:</b> TO READ</p> <p>2. <b>Description of the dimension:</b> To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.</p>

**3. Feasibility of its assessment in the current cohort:** Not feasible in BLS, somewhat feasible in RaDiaNT

**4. List of existing outcomes for its assessment in the cohort (max 10):** RaDiaNT (Vineland written communication subdomain)

**1. Name of the dimension: HEALTHY LIFE-STYLE**

**2. Description of the dimension:** To adopt and maintain habits and behaviours that promote overall well-being and optimal physical and mental health.

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (WHOQOL-BREF; sleep, physical environment, leisure activities)

**1. Name of the dimension: SENSORY STRATEGIES**

**2. Description of the dimension:** To find isolation, stimming (e.g. putting things in order, moving legs, rocking back and forth, using fidgeting toys to play with hands when stressed, headphones, etc.).

**3. Feasibility of its assessment in the current cohort:** Not feasible in BLS, somewhat feasible in RaDiaNT

**4. List of existing outcomes for its assessment in the cohort (max 10):** RaDiaNT (ADI-R interview section on Interests and Behaviours asks about unusual sensory interests and sensory sensitivities, ADOS may capture this – we also collect measures of sensory sensitivities in questionnaires)

**1. Name of the dimension: PSYCHOTHERAPY**

**2. Description of the dimension:** To have professional treatment to improve mental and emotional well-being.

**3. Feasibility of its assessment in the current cohort:** Feasible (BLS)

**4. List of existing outcomes for its assessment in the cohort (max 10):** BLS (Treatment/therapy using Mannheimer Parent Interview)

## SECTION B

### Dimensions and outcomes identified by researchers: data collection template

**1. Name of the dimension: SYMPTOMS IMPROVEMENTS (E.G. SOCIAL COMMUNICATION)**

**2. Description of the dimension:** Symptomatology associated with autism spectrum disorder

<p>3. <b>Why this dimension is relevant:</b> This is relevant as it measures a change in a trait associated with autism that may be important for understanding developmental trajectories and how dimensions may change over time. This could include current and historical behaviours, including social interaction, communication, and stereotypical behaviour</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> Feasible in BLS</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> Social communication questionnaire (SCQ-40)</p>
<p>1. <b>Name of the dimension:</b> BIOPHYSICAL HEALTH</p> <p>2. <b>Description of the dimension:</b> Presence of physical health conditions.</p>
<p>3. <b>Why this dimension is relevant:</b> Physical health conditions can have significant bi-directional impacts on mental well-being.</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> Feasible in BLS and RaDiaNT cohorts.</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Prenatal and neonatal health, Disability, Health Utilities Index (HUI); WHOQoL; SF-12), RaDiaNT (WHOQoL, ACE medical)</p>
<p>1. <b>Name of the dimension:</b> COGNITION</p> <p>2. <b>Description of the dimension:</b> The ability to process and understand information, think critically, solve problems, make decisions, and effectively use cognitive skills.</p>
<p>3. <b>Why this dimension is relevant:</b> Enhancing cognitive competence can improve overall mental flexibility, leading to better resilience.</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> Feasible in BLS and RaDiaNT.</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> BLS (Harter scales (subscale: cognitive competence), Wechsler Adult Intelligence Scales (WAIS), Executive functions, attention, memory), RaDiaNT (WASI-II, Mullens scale of early learning - MSEL, CANTAB – attention, working memory, social cognition, executive function, NEPSY-II – response inhibition, theory of mind)</p>
<p>1. <b>Name of the dimension:</b> SOCIAL BEHAVIOUR</p> <p>2. <b>Description of the dimension:</b> Questionnaire and genetic measures of social behaviour</p>
<p>3. <b>Why this dimension is relevant:</b> Social competence can provide resilience against adverse later-life outcomes and is linked to a better quality of life</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> It is feasible (SPARK and/or SSC) and RaDiaNT; (a) Genome-wide information is used to describe social phenotypes in autistic individuals and (if available) their siblings that can, otherwise, not be studied as phenotype information is missing, (b) Questionnaire measures</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> EAGLE (social behaviour GWAS for a spectrum of different social outcomes (peer problems and prosocial behaviour, different developmental stages, parent (home), teacher (school) and self-assessments), SCQ-40, RaDiaNT (SCQ, ADOS-II, ADI-R, Vineland-II)</p>

<p>1. <b>Name of the dimension:</b> DEVELOPMENTAL MILESTONES</p> <p>2. <b>Description of the dimension:</b> Age at which individuals master important developmental milestones such as sitting, crawling, standing.</p>
<p>3. <b>Why this dimension is relevant:</b> Mastering developmental milestones shapes future developmental trajectories.</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> It is feasible (SPARK and/or SSC and RaDiaNT)</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> Age of walking, age of sitting, age of crawling, age of smiling, age of self-feeding, RaDiaNT (ACE medical and ADI-R record age of walking, and first words)</p>
<p>1. <b>Name of the dimension:</b> LANGUAGE PERFORMANCE AND COMMUNICATION</p> <p>2. <b>Description of the dimension:</b> Measures to describe the production and perception of language and the ability to communicate efficiently</p>
<p>3. <b>Why this dimension is relevant:</b> Better language and communication abilities are related to better daily functioning and better educational outcomes</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> It is feasible (SPARK and/or SSC and RaDiaNT)</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> Language level, language age level, cognitive age level, language disorder is recorded. In RaDiaNT we collect the Diagnostic Evaluation of Articulation and Phonology – Phonology subtest and the Children's Communication Checklist (CCC) and Communication Checklist-Adults (CC-A).</p>
<p>1. <b>Name of the dimension:</b> MOTOR PERFORMANCE</p> <p>2. <b>Description of the dimension:</b> Measures to describe the motor skills</p>
<p>3. <b>Why this dimension is relevant:</b> Better motor abilities are related to better daily functioning and healthy life style</p> <p>4. <b>Feasibility of its assessment in the current cohort:</b> It is feasible (SPARK and/or SSC and RaDiaNT)</p> <p>5. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> DCDQ, RaDiaNT also includes Vineland motor skills subscale, Mullens measure of motor skills.</p>

## 5.2. Annex II: WP2 Researchers' Questionnaire Responses

### SECTION A

#### Dimensions identified by the co-creation groups: data collection template

<p>1. <b>Name of the dimension:</b> SELF-CONTROL</p> <p>2. <b>Description of the dimension:</b> To consciously regulate and manage one's emotions, thoughts, and actions in order to achieve goals, especially in social interactions.</p> <p>3. <b>Feasibility of its assessment in the current cohort:</b> We think this is feasible and from work we have already done, we agree that emotion awareness and regulation are very important facets in MH research</p> <p>4. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> In the EU-AIMS LEAP sample, we are using the following measures: Cognitive Emotion Regulation Questionnaire (CERQ) - this was selected and developed with the A-Reps and Affective Reactivity Index (more about irritability). In BASIS/STAARS, we have some executive functioning measures (ECBQ/CBQ Inhibitory Control, Impulsivity subscales; BRIEF-2 in SuperSTAARS), but worth noting that the description for this dimension (i.e., conscious/intentional, goal-oriented exercise of self-control) isn't necessarily captured perfectly by core EF measures in childhood. Separately, specifying 'especially in social situations' runs the risk of focusing on masking/ compensation behaviour, which is important to have, but there's a bit of a grey area in terms of whether it is healthy or actually improves wellbeing (e.g., or if doing more of it leads to more frustration if it doesn't work or comes at a great cost in terms of burnout, or feelings of isolation/stigmatising of one's true self, etc.).</p>
<p>5. <b>Name of the dimension:</b> PERSONAL DEVELOPMENT</p> <p>6. <b>Description of the dimension:</b> To be able to meet your needs and desires, accomplish your aspirations, and/or feel helpful to others.</p>
<p>7. <b>Feasibility of its assessment in the current cohort:</b> To us, this construct feels a bit more abstract and might be a bit tough to measure as it's talking about a few different constructs. Also mostly not applicable to childhood cohorts.</p> <p>8. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> possibly incorporated into some QoL questionnaires that focus on satisfaction (rather than objective indices) because peoples' needs, desires, aspirations etc. are going to be very individually different. However we can't think of any specific measures here, other than the QoL scales already noted in the example above.</p>
<p>5. <b>Name of the dimension:</b> INDEPENDENCE</p> <p>6. <b>Description of the dimension:</b> To be able to cope with your problems having a feeling of control.</p>
<p>7. <b>Feasibility of its assessment in the current cohort:</b> Feasible, however worth noting that the description talks about being able to cope and feeling in control, which are not necessarily the same thing as having independence. A related construct, that might be especially relevant to children and adults might be self-efficacy here.</p>

<p><b>8. List of existing outcomes for its assessment in the cohort (max 10):</b> included in existing QoL measures (e.g., the WHOQoL, where Independence is a specific facet). For coping ability, the closest we have in BASIS/STAARS is the Vineland Coping Skills subscale (though again, a childhood measure and not related to independence)</p>
<p><b>5. Name of the dimension: SAFE ENVIRONMENT</b></p> <p><b>6. Description of the dimension:</b> To have a place to be alone, calm, and self-regulated without unexpected changes (e.g. your own room).</p>
<p><b>7. Feasibility of its assessment in the current cohort:</b></p> <p><b>8. List of existing outcomes for its assessment in the cohort (max 10):</b> we are not sure if there are any measures of this but perhaps measures that are neurodiversity affirmative (if these are available) i.e., the opposite of things like Stigma Scale - so, they are focused on exposure to neurodiversity affirmative environments, rather than exposure to stigma/expectations of NT environments?</p>
<p><b>5. Name of the dimension: ADAPTED ENVIRONMENT</b></p> <p><b>6. Description of the dimension:</b> To live in an adapted environment to your needs (e.g. descriptive signs, self-checkout at shops, etc.).</p>
<p><b>7. Feasibility of its assessment in the current cohort:</b></p> <p><b>8. List of existing outcomes for its assessment in the cohort (max 10):</b></p>
<p><b>5. Name of the dimension: COMMUNITY INVOLVEMENT</b></p> <p><b>6. Description of the dimension:</b> To hang around with friends or people that make you feel good, connected and not to feel lonely (meaning to have people surrounding you that have the ability to think in the same way or at the same pace).</p>
<p><b>7. Feasibility of its assessment in the current cohort:</b> Based on the description this is less about wider community involvement and more about spending time with others in social/peer interactions. A bit unclear whether the focus is on interacting in groups and being able to not feel excluded, or on forming meaningful long-term friendships. The construct would not be defined clearer to determine the most suitable measure. "Social networks beyond immediate family and school" would be a constructed that was also suggested in previous studies like Mukherjee &amp; Beresford (2023)</p> <p><b>8. List of existing outcomes for its assessment in the cohort (max 10):</b> For the former, in BASIS/STAARS we have the Vineland Play and Leisure subscale in childhood which matches somewhat (but not perfectly). For the latter, Tony added a Friendships and Peer Relationships dimension in Section B - see other measures there. There are also community involvement scales included in existing QoL measures e.g., as a facet of WHOQOL. There are autism and disability add on to the WHOQOL that may also capture specific experiences of autistic people, or those with physical disabilities, for example.</p>
<p><b>5. Name of the dimension: FAMILIAL RELATIONS</b></p> <p><b>6. Description of the dimension:</b> To have a caring, supportive and trustable family.</p>

**7. Feasibility of its assessment in the current cohort:** Maybe a suitable operationalization here could be "parent's capacity and skills in managing mental health and behavioural problems" - however we are not aware of any existing measures of this construct in our cohorts

**8. List of existing outcomes for its assessment in the cohort (max 10):** Multidimensional Scale of Perceived Social Support (MSPSS) – family subscale (PIP/CANDY)

**5. Name of the dimension: EDUCATION**

**6. Description of the dimension:** To acquire knowledge, skills, and understanding through formal or informal learning processes.

**7. Feasibility of its assessment in the current cohort:** It would be important to understand here whether the preference is for accessibility of education (supportive school environment), or for actual educational attainments etc.; there is a rather large difference between educational performance under mandatory schooling in children/adolescents, and one's eventual educational attainment or informal learning as an adult, which more heavily reflects choices, priorities, and access to education/technology (they will be interlinked but education is a broad concept, especially when we think more on learning, skills etc. that again will have different priorities across individuals). - see also parents comments in Mukherjee & Beresford (2023) on mainstream vs special school settings.

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: ECONOMIC SITUATION**

**6. Description of the dimension:** To be able to ensure financial security for present and future needs.

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):** Closest measure we have in our existing childhood cohorts would be family SES, but this doesn't really cover what the description aims for

**5. Name of the dimension: OCCUPATION**

**6. Description of the dimension:** To find and choose a paid or unpaid job, maintaining and achieving advancement at work and being able to leave a job in an appropriate manner; in adults closest would again be existing QoL measures, e.g. facets of the WHOQOL

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):** incorporated into existing QoL measures e.g., as specific facets of WHOQOL.

**5. Name of the dimension: COGNITIVE ACTIVITY**

**6. Description of the dimension:** To make mental connections (e.g. between memories, facts, knowledge you've gathered through the years...), letting your mind work at its highest level, being absorbed in your passions.

**7. Feasibility of its assessment in the current cohort:** This is a tough one because it's talking about a lot of different things. It doesn't seem to be describing cognitive ability relative to others (i.e., IQ), but is it instead about associative thinking ability, or deciding/being able to engage in cognitively stimulating tasks, or simply maintaining intense interests? In any way a complex construct which would need defining more clearly in order to determine a suitable measure

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: TO PLAY**

**6. Description of the dimension:** To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.

**7. Feasibility of its assessment in the current cohort:** Again a relatively broad construct that might need defining more specifically

**8. List of existing outcomes for its assessment in the cohort (max 10):** incorporated into existing QoL measures e.g., as specific facets of WHOQOL. In terms of measures we are not aware of any specific measures, however there are a few approximations that might be suitable, e.g. leisure as a facet of the WHOQOL (which might also include some of the more creative constructs below), In BASIS/STAARS we have the CBQ High Intensity Pleasure subscale, which captures enjoyment of/engagement in fun play activities with no social caveats. Vineland Play and Leisure subscale also captures a variety of play behaviours, alone, with parents, in groups (but is biased towards neurotypical social ability as it also includes items about sharing toys, engaging socially, etc.)

**5. Name of the dimension: PETS**

**6. Description of the dimension:** To spend time with domestic animals kept for companionship or pleasure.

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: NATURE**

**6. Description of the dimension:** To connect with the environment in natural spaces (e.g. go to the forest, mountains, sea, walks with dogs...).

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: CREATIVE ACTIVITIES**

**6. Description of the dimension:** To involve in imaginative activities as handicraft, painting, writing, listening or playing music, etc.

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: PHYSICAL EXERCISE**

**6. Description of the dimension:** To engage in any bodily activity that enhances or maintains physical fitness and overall health.

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):** Also a facet of WHOQOL

**5. Name of the dimension: TO REST**

**6. Description of the dimension:** To be able to get enough rest along the days (e.g. breaks between classes) and to sleep well.

**7. Feasibility of its assessment in the current cohort:** This is really interesting - there are sleep measures, but possibly also this interconnects with preventative strategies re: burnout? There are measures of burnout that now exist but all so far are more negatively phrase (i.e., risk factors) rather than thinking in this way around what things might be protective. We are doing some qualitative work in AIMS on this that could inform measurement, but this won't be ready for a while and not aware of any existing measures that are more 'resilience' focused in this regard other than sleep questionnaires and looking at sleep quantity and quality. This also seems focused on the wider ability to rest/manage and respond to tiredness and be able to take the time to recuperate properly, which might be a bit difficult to measure in younger children, who won't yet contend with burnout/work-life balance issues.

**8. List of existing outcomes for its assessment in the cohort (max 10):** sleep questionnaires like Child/Adolescent Sleep Habits Questionnaire (CSHQ), and some more basic or infancy focused sleep measures (Oxford Sleep Questionnaire, Sleep and Settle Questionnaire, SNORI) but not sure if these are what is meant here.

**5. Name of the dimension: SERVICE DOG**

**6. Description of the dimension:** To have a service dog to carry out daily activities.

**7. Feasibility of its assessment in the current cohort:** we are not aware of any measures, however maybe this could be considered within a 'support person' type context, or therapeutic context, even though referring to service dog (because the role is emotional/practical support)

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: SELF-CONFIDENCE**

**6. Description of the dimension:** To have the feeling that it is okay to be who you are.

**7. Feasibility of its assessment in the current cohort:** We find this measure feasible and very important and it does link with the point earlier about whether there are any more neurodiversity affirmatively phrased questionnaires that are the opposite to Stigma Scales (i.e., around identity, awareness, acceptance). We also feel like this might relate partly to masking and the feeling of not needing to always mask/compensate. Potentially difficult to measure in childhood

cohorts though (before identity development and stable sense of self vs. others really starts to form). Again, self-efficacy might be an important and related construct here

8. **List of existing outcomes for its assessment in the cohort (max 10):** We unfortunately don't have specific measures for it, but hopefully others will? Yes – LEAP uses an ASD-adapted version of the Stigma Scale, originally designed to assess experiences of stigma/discrimination (and self-acceptance) related to mental health conditions. The ASD-adapted version adjusts this to focus on autism and/or related conditions, and includes relevant items concerning self-stigma vs. self-acceptance, e.g., "I do not feel bad about being autistic"; "I would say I am autistic if I was applying for a job"; "I feel the need to hide my autism from my friends", "People have become more accepting of me after I disclosed to them that I am autistic", etc. NB since R2D2-MH does not exclusively focus on autism, it may be prudent to create an updated questionnaire focusing on "neurodevelopmental and/or other conditions" for example, rather than specifying autism in each item. If so, it may be useful to refer to the original Stigma Scale which is more general.

5. **Name of the dimension: PREDICTABILITY AND CONTROL**

6. **Description of the dimension:** To have a predictable day, to know what is going to happen and to have control over situations, as it's a nice feeling to know that things have gone as expected.

7. **Feasibility of its assessment in the current cohort:** we want to include the opinion of one of our group members here "I have a perhaps controversial opinion on this - this dimension is geared towards a desire for certainty (indicating a relative intolerance of uncertainty). I am autistic and I understand the desire for predictability/control, but I do not think the world is very predictable/certain, and hoping/expecting it to be this way can increase frustration and disappointment. Of course a stable home environment and social life are very important, but I would argue that the ability to tolerate and cope with some degree of uncertainty provides more stable resilience in the longer term, i.e., adapting to the unpredictable world rather than hoping for predictability (which keeps a person more vulnerable/frustrated by any unexpected events, which will never not exist unless one just isolates from the world). This is only my view of course - I would argue for a "Managing/coping with uncertainty" dimension, as much as I understand this is not necessarily an easy thing to cultivate!"

8. **List of existing outcomes for its assessment in the cohort (max 10):** again we are only aware of inverse measures like the Intolerance of Uncertainty Scale.

5. **Name of the dimension: TRUSTED PEOPLE/PERSON**

6. **Description of the dimension:** To develop as a person in an environment in which you trust, knowing that you are trusted too.

7. **Feasibility of its assessment in the current cohort:** A hugely important factor, though trust specifically can be difficult to measure (and can fluctuate). However, close friendships typically include a high level of trust, and we have measures of whether children have close friends they can confide in even in childhood (see the Friendships and Peer Relationships dimension in Section B)

8. **List of existing outcomes for its assessment in the cohort (max 10):** Multidimensional Scale of Perceived Social Support (MSPSS) – special person/friends subscales (PIP/CANDY)

**5. Name of the dimension: EDUCATIONAL SUPPORT (INSTITUTIONAL)**

**6. Description of the dimension:** To have additional support specialized for individuals with ADHD or autism at educational institutions (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: EDUCATIONAL SUPPORT (FAMILIAL)**

**6. Description of the dimension:** To have help with school homework or to mediate with school if you have problems (e.g. with teachers, with schoolmates).

**7. Feasibility of its assessment in the current cohort:**

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: TO READ**

**6. Description of the dimension:** To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.

**7. Feasibility of its assessment in the current cohort:** These all seem somewhat related to some of the other aspects above that are incorporated into e.g., QoL scales, such as leisure activities, education/employment. I guess the preference would then be to use measures that are focused more on satisfaction, rather than specific strategies (i.e., someone's leisure activities could differ from another person, but they both feel certain levels of satisfaction from those differing activities that could be comparable in a scale, and then would need to think about whether we want to better understand what some of those are). It could be worth expanding this, because not everyone enjoys/can manage to do a lot of reading, but they could instead enjoy films/shows, podcasts, audiobooks, video games, music, sports, puzzles, train sets, collecting, etc. These are all forms of enjoying/finding satisfaction in various media - why limit it to reading?

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: HEALTHY LIFE-STYLE**

**6. Description of the dimension:** To adopt and maintain habits and behaviours that promote overall well-being and optimal physical and mental health.

**7. Feasibility of its assessment in the current cohort:** It would be interesting to better understand whether this is meant in a more 'traditional' context (e.g., diet, physical activity etc.) that are covered in existing QoL measures, or other aspects that may be far more highly individualised between people - and therefore possibly harder to measure well (though there are general habits/behaviours that are possibly more widely optimal e.g., sleep hygiene). Also it may be worth noting that in childhood this will depend strongly on whether parents/family provide an environment that encourages or even enforces a healthy lifestyle (which

will typically coincide with things like family economic stability, educational support, etc.). Later on it may depend a lot more on personal choice, preference, motivation, etc.

**8. List of existing outcomes for its assessment in the cohort (max 10):**

**5. Name of the dimension: SENSORY STRATEGIES**

**6. Description of the dimension:** To find isolation, stimming (e.g. putting things in order, moving legs, rocking back and forth, using fidgeting toys to play with hands when stressed, headphones, etc.).

**7. Feasibility of its assessment in the current cohort:** There are quite a few measures of RRB and sensory, and it might be interesting to reconsider some of the items in a more 'resilience' perspective (e.g., if someone says 'yes' to using headphones with loud noises, to factor this in as a potential resilience strategy, rather than an indicator of sensory distress per se). The only issue with this could be that these measures are often parent reported, and parents may have differing perspectives (not always) on whether these strategies represent something beneficial or not. Also important to note, not all neurodivergent people experience significant/frequent sensory overload, so might be important to have an option for people who simply do not need sensory strategies (rather than e.g., low scores indicating lower wellbeing/resilience, just because a person doesn't engage in these strategies).

**8. List of existing outcomes for its assessment in the cohort (max 10):** Yes, we have sensory measures (e.g., ICBQ/ECBQ/CBQ Perceptual Sensitivity, Infant-Toddler/Short Sensory Profile) but these are more about sensitivity than actually engaging in strategies. We also have repetitive/restricted behaviour (RRB) measures but again these are arguably impairment-focused and stigmatising rather than measuring the intentional use of things like stimming, fidgeting, headphones for emotional/motor/sensory regulation. The Child Routines Inventory (CRI) also includes some items that may be of interest in terms of sensory features.

**5. Name of the dimension: PSYCHOTHERAPY**

**6. Description of the dimension:** To have professional treatment to improve mental and emotional well-being.

**7. Feasibility of its assessment in the current cohort:** For this kind of facet, it may be a case of having a more demographic survey that asks people things like whether they are receiving therapies, what for, for how long etc. Also worth noting that in earlier childhood, psychotherapy will only be seen quite rarely (i.e., in more severe cases of adversity/trauma and associated mental health difficulties). Tony confirms it does happen but is very limited, so won't apply to most children. This is certainly one of the more adolescent/adult-oriented measures

**8. List of existing outcomes for its assessment in the cohort (max 10):**

## SECTION B

### Dimensions and outcomes identified by researchers: data collection template

WP2: We discussed whether this isn't what we are interested in as an outcome measure rather than as a resilience factor. Ultimately the psychiatric resilience literature, and concepts like mental wellbeing, QoL, all refer to aspects of mental health as an outcome. However, quite a few of the dimensions/factors on this list can be seen as outcomes too (all of which make up various parts of mental health). Worth thinking about whether we are looking for factors that are simply indicators of wellbeing, or predictors or paths to better outcomes? Of course virtually all cohort studies will have plenty of measures of mental health problems (or a lack of them), but these are more conventional psychiatric measures, and not sure how it would contribute to work towards understanding what ultimately predicts resilience, QoL, wellbeing, functioning, etc.

**6. Name of the dimension: INTIMATE RELATIONSHIPS**

**7. Description of the dimension:** The ability to maintain healthy intimate relationships, with clear boundaries and in which both people's needs and preferences are prioritised. Equally, the ability to exercise necessary distance and/or end relationships if they are not going well.

**3. Why this dimension is relevant:** Healthy intimate relationships are a core aspect of social and emotional life, and have been shown to predict various measures of mental and physical wellbeing. Despite traditional notions of autistic individuals preferring isolation, many neurodivergent people do desire and benefit from intimate relationships, though they may struggle with starting and maintaining them, and may be at higher risk of relationship difficulties and staying in unhealthy relationships for longer than necessary. This is why the proposed dimension emphasises the needs of both people being prioritised, as well as exercising proper boundaries and the ability to end unhealthy relationships where appropriate.

**4. Feasibility of its assessment in the current cohort:** This is an adolescent/adult-specific dimension, so is not possible to assess in childhood cohorts.

**5. List of existing outcomes for its assessment in the cohort (max 10):**

**6. Name of the dimension: FRIENDSHIPS and PEER RELATIONSHIPS**

**7. Description of the dimension:** The ability to interact with peers and form peer relationships....

**8. Why this dimension is relevant:**

**9. Feasibility of its assessment in the current cohort:**

**10. List of existing outcomes for its assessment in the cohort (max 10):** SDQ Prosocial, Peer Problems (reverse scored?) (BASIS/STAARS & LEAP), Vineland Interpersonal Relationships (BASIS/STAARS)

**6. Name of the dimension: COMMUNICATION STRATEGIES**

**7. Description of the dimension:** The access to and support through verbal or non-verbal communication strategies in order to be able to express ones needs, desires and oneself to others.

**8. Why this dimension is relevant:**

**9. Feasibility of its assessment in the current cohort:**

**10. List of existing outcomes for its assessment in the cohort (max 10):** there are several measures of communication in the current cohort, including the Vineland Adaptive Behaviour Scale, SRS communication subscale and the ADOS ratings in EU-AIMS LEAP and BASIS/STAARS, however we are not aware of any measures including actual access to (non-verbal) communication support strategies. The existing communication scales again tend to be deficit-oriented, rather than including accessibility to support.

**1. Name of the dimension: IDENTITY DEVELOPMENT**

**2. Description of the dimension:** The freedom and support to explore and develop one's own interests, preferences, values, world views and attitudes towards oneself

**3. Why this dimension is relevant:** the development of one's identity is a major developmental challenge during adolescence (e.g. Erikson's stages of development). Our sense of personal identity shapes our experiences and interactions with others, guiding our actions, beliefs and behaviours and a cohesive sense of self is an important contributor to mental well-being. Here it could also be an important aspect whether there is an awareness or understanding of being autistic and whether or how this is integrated into one's identity

**4. Feasibility of its assessment in the current cohort:**

**5. List of existing outcomes for its assessment in the cohort (max 10):** We are not aware of any existing measures of this domain in our cohorts, however we wanted to include it, to highlight its importance and in case other groups suggested suitable measures

**1. Name of the dimension: EMOTIONAL AWARENESS**

**2. Description of the dimension:** To identify and be able to describe one's emotions/feelings, and generally be aware of their possible causes or triggers

**3. Why this dimension is relevant:** Being aware of one's emotions helps to identify problems or stressors that might benefit from healthy coping strategies, and can help to effectively communicate one's feelings to family, friends, and partners. Difficulty in identifying and describing one's emotions is known as alexithymia, a trait which varies across the population but tends to be higher in people with autism. Recent longitudinal research has shown that difficulty describing emotions predicted higher social-communication difficulties, and difficulty identifying emotions prospectively predicted more anxiety, at 1-2 year follow-up. This suggests that emotional awareness may play a role in both individual mental health and in social outcomes relevant to wellbeing and resilience.

**4. Feasibility of its assessment in the current cohort:**

**5. List of existing outcomes for its assessment in the cohort (max 10):** Toronto Alexithymia Scale (TAS-20) (reversed) (LEAP)

**1. Name of the dimension: CHILDHOOD FACTOR: NURTURING/ENRICHING HOME ENVIRONMENT**

**2. Description of the dimension:** The extent to which parents provide stimulating, educational, or otherwise developmentally favourable home environments, activities, and experiences which encourage learning and the development of skills, interests, and hobbies

**3. Why this dimension is relevant:** Having a nurturing and stimulating sensory environment is vital for cognitive, sensory, and functional development in childhood. This factor accounts for the fact that, unlike adults, children depend on their family (mainly parental provision of various activities, toys, books, etc.) to provide the resources and conditions that allow for the development of a range of longer-term interests, hobbies, and skills.

**4. Feasibility of its assessment in the current cohort:**

**5. List of existing outcomes for its assessment in the cohort (max 10):** Cognitively Stimulating Parenting Scale (CSPS) (dHCP)

**1. Name of the dimension: CHILDHOOD FACTOR: POSITIVE PARENTING**

**2. Description of the dimension:** The extent to which parents behave in a warm, involved, and consistent way towards children, and avoid negative parenting behaviours such as overreactivity/anger, hostility and criticism, and negative discipline practices such as corporal punishment

**3. Why this dimension is relevant:** Parents who engage in more warm, involved, consistent and otherwise positive behaviour towards children provide a safe and reliable environment during childhood, allowing children to develop without additional strain or danger in the home, and buffering against challenges children face outside the home. Conversely, negative parenting behaviours such as overreactivity, inconsistent and negative discipline practices such as corporal punishment can create an unsafe and/or unpredictable home environment for children, and a more adverse and less supportive parent-child relationship. A safe environment with warm and dependable parents stands as an important primary factor for wellbeing in early childhood, and serves as a resilience factor that may buffer against the effects of other challenges children may experience.

**4. Feasibility of its assessment in the current cohort:** Can be assessed in childhood with openly available questionnaires. We suggest the APQ (parent-report) below as it is one of the most comprehensive and widely used, assessing five dimensions: positive involvement with children, supervision and monitoring, use of positive discipline techniques, consistency in the use of such discipline, and use of corporal punishment.

**5. List of existing outcomes for its assessment in the cohort (max 10):** Alabama Parenting Questionnaire (APQ) (Not used in main cohorts as far as we know but a well-known measure and available at KCL)

**1. Name of the dimension: AFFECTIVE EMPATHY**

**2. Description of the dimension:** Caring about and/or being emotionally affected by the feelings and needs of others

**3. Why this dimension is relevant:** Despite traditional notions of autistic people lacking empathy, it is increasingly clear that while some may score lower on theory of mind and/or perspective-taking (elements of 'cognitive empathy'), many neurodivergent people have particularly high levels of 'affective empathy' – the tendency to be emotionally affected when witnessing the emotions of others. This typically confers a tendency toward caring and considerate behaviour towards others. While empathy for others is not necessarily immediately beneficial to individual resilience or wellbeing, arguably being more empathetic and attentive to others' emotions and needs should increase the long-term quality and quantity of close friendships and intimate relationships, increasing social support. Higher empathy may also serve as a social motivator that could counteract the effects of social challenges that may discourage seeking out meaningful social interaction.

**4. Feasibility of its assessment in the current cohort:**

**5. List of existing outcomes for its assessment in the cohort (max 10):** Childhood: Child Empathising Quotient and Systemising Quotient (CEQSQ) (LEAP); Adulthood: Empathy Quotient (EQ) (LEAP). NB both of these scales contain items that measure other constructs than affective empathy, and if used, it may be advisable to select a subset of relevant items, excluding those that measure systemising, social understanding, or conduct problems.

### 5.3. Annex III: WP4 Researchers' Questionnaire Responses

#### SECTION A

##### Dimensions identified by the co-creation groups: data collection template

5. Name of the dimension: <b>SELF-CONTROL</b>
6. Description of the dimension: To consciously regulate and manage one's emotions, thoughts, and actions in order to achieve goals, especially in social interactions.
7. Feasibility of its assessment in the current cohort: Feasible for adults about themselves (self-report). For children, feasible but from the parent's opinion about the child self-control
8. List of existing outcomes for its assessment in the cohort (max 10): Brief Self-Control Scale (Twente). For children, at UNIGE we collect the SDQ and SRS-2 which have some relevant items: Strengths Weaknesses Questionnaires (SDQ) "Often fights with other children or enjoys hurting them"; "uncomfortable or clings to adults in new situations or loses his or her temper easily"; "gets angry easily and often". Social responsiveness Scale (SRS-2) : "When under stress, child seems to go on autopilot"; "Is able to communicate his feelings to others in words or gestures" ; "Gets frustrating trying to get ideas across in conversations" ; "has trouble keeping up with the flow of normal interactions with other children"
9. Name of the dimension: <b>PERSONAL DEVELOPMENT</b>
10. Description of the dimension: To be able to meet your needs and desires, accomplish your aspirations, and/or feel helpful to others.
11. Feasibility of its assessment in the current cohort: Feasible for adults about themselves (self-report). For children, it seems difficult to assess the ability to meet their needs and desires, and the possibility to accomplish your aspirations, but easier to assess feeling helpful to others.
12. List of existing outcomes for its assessment in the cohort (max 10): Psychological well-being subscale of the MHC-SF (Twente). For children, at UNIGE we collect the Strengths Weaknesses Questionnaires (SDQ) which has the following items: "I'm happy to help when someone has been hurt or isn't feeling well" ; "always ready to help others (parents, teachers, young people my age)"
9. Name of the dimension: <b>INDEPENDENCE</b>
10. Description of the dimension: To be able to cope with your problems having a feeling of control.
11. Feasibility of its assessment in the current cohort: Feasible for adults about themselves (self-report). For children, seems feasible either in a very "factual" manner with the developmental milestones, or from the parent perspective but on their own ability to cope.
12. List of existing outcomes for its assessment in the cohort (max 10): Autonomy subscale of Psychological Wellbeing Scales by Carol Ryff, 6 and 9 item versions are available (Twente). Twente's group new GSAAS: generic sense of ability to adapt. 10 simple items (Twente). Developmental milestones (CareConnect). For children, at UNIGE we collect the Parenting Self Efficacy questionnaire and the Parental Stress Index which both have relevant items. E.g. in the Parenting Self Efficacy questionnaire: "How confident are you in building your child's communication and social skills?" "Do you think that the

way you try to build your child's communication and social skills has a positive effect?" "How confident are you in how you are managing your child's challenging behaviours?" "Do you think that the way you try to manage your child's challenging behaviours has a positive effect?". In the Parental Stress Index (PSI-Short Form): "I often have the feeling that I cannot handle things very well" "I find myself giving up more of my life to meet my children needs than I ever expected" "I feel trapped by my responsibilities as a parent" "Since having this child I have been unable to do new and different things" "Since having a child I feel that I am almost never able to do things that I like to do".

**9. Name of the dimension: SAFE ENVIRONMENT**

**10. Description of the dimension:** To have a place to be alone, calm, and self-regulated without unexpected changes (e.g. your own room).

**11. Feasibility of its assessment in the current cohort:** We find the assessment of this dimension feasible, but we do not have any specific questionnaire in mind

**12. List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: ADAPTED ENVIRONMENT**

**10. Description of the dimension:** To live in an adapted environment to your needs (e.g. descriptive signs, self-checkout at shops, etc.).

**11. Feasibility of its assessment in the current cohort:** This measure would need to be adapted if we think about children.

**12. List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: COMMUNITY INVOLVEMENT**

**10. Description of the dimension:** To hang around with friends or people that make you feel good, connected and not to feel lonely (meaning to have people surrounding you that have the ability to think in the same way or at the same pace).

**11. Feasibility of its assessment in the current cohort:** feasible, either from self-report in adults or from parent-report in children

**12. List of existing outcomes for its assessment in the cohort (max 10):** Social-relational well-being subscale of the Mental Health Continuum Short Form (MHC-SF) (Twente). For children, at UNIGE we collect the Child Behaviour Checklist (CBCL) for ages 4-18 which has the following item: "List any organisations, clubs, teams or groups your child belongs to" and "compared to others of the same age how active is he in each?"

**9. Name of the dimension: FAMILIAR RELATIONS**

**10. Description of the dimension:** To have a caring, supportive and trustable family.

**11. Feasibility of its assessment in the current cohort:**

12. **List of existing outcomes for its assessment in the cohort (max 10):** PPD (Post-Partum Depression) measured by EPDS (CareConnect). As a quite indirect assessment, in the Parental Stress Index that we collect at UNIGE, there are the following items: "Having a child cause more problems than I expected in my relationship with my spouse/parenting partner. » ; "I feel alone and without friends.

**9. Name of the dimension: EDUCATION**

10. **Description of the dimension:** To acquire knowledge, skills, and understanding through formal or informal learning processes.

11. **Feasibility of its assessment in the current cohort:** Feasible in a very factual manner (level of education achieved)

12. **List of existing outcomes for its assessment in the cohort (max 10):** For children, at UNIGE we collect educational level and type of school (private, public, mainstream, special education program...) and support needed. We however do not collect any information about the subjective opinion of the children / adolescents about their educational program).

**9. Name of the dimension: ECONOMIC SITUATION**

10. **Description of the dimension:** To be able to ensure financial security for present and future needs.

11. **Feasibility of its assessment in the current cohort:** For children, we collect factual information about annual income of the family, but not information about whether or not the family feel safe enough to achieve their needs with this financial situation

12. **List of existing outcomes for its assessment in the cohort (max 10):** SES (socio-economic status) (CareConnect, UNIGE).

**9. Name of the dimension: OCCUPATION**

10. **Description of the dimension:** To find and choose a paid or unpaid job, maintaining and achieving advancement at work and being able to leave a job in an appropriate manner.

11. **Feasibility of its assessment in the current cohort:** Feasible with simple questions

12. **List of existing outcomes for its assessment in the cohort (max 10):** Not really adapted to children, but at UNIGE we collect the Child Behaviour Checklist (CBCL) for ages 4-18 which has the following item: "List any jobs or chores your child has" and "compared to others of the same age how well does he carry them out?"

**9. Name of the dimension: COGNITIVE ACTIVITY**

10. **Description of the dimension:** To make mental connections (e.g. between memories, facts, knowledge you've gathered through the years...), letting your mind work at its highest level, being absorbed in your passions.

11. **Feasibility of its assessment in the current cohort:** seems difficult to measure in children. Even for adults, the concept is quite broad.  
 12. **List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: TO PLAY**

10. **Description of the dimension:** To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.

11. **Feasibility of its assessment in the current cohort:** Feasible

12. **List of existing outcomes for its assessment in the cohort (max 10):** For children, at UNIGE we already collect the following measures: VABS-II, which has a full domain on "Play and leisure", the Social responsiveness Scale (SRS-2) that has the following item : "plays appropriately with children his age ?" , and the Child Behaviour Checklist (CBCL) for ages 4-18 which has the following questions: "List the sports your child most likes to take part in" "List your child favourite hobbies, activities and games other than sports" and "compared to others of the same age about how much time does he spends in each?" "how well does he do each one?

**9. Name of the dimension: PETS**

10. **Description of the dimension:** To spend time with domestic animals kept for companionship or pleasure.

11. **Feasibility of its assessment in the current cohort:** Feasible, but info not collected yet

12. **List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: NATURE**

10. **Description of the dimension:** To connect with the environment in natural spaces (e.g. go to the forest, mountains, sea, walks with dogs...).

11. **Feasibility of its assessment in the current cohort:**

12. **List of existing outcomes for its assessment in the cohort (max 10):** Connectedness with nature subscale of the SAIL-SF (Spiritual Attitude and Involvement List – Short Form) or SAIL (Twente). Mayer's scale on connectedness to nature (mentioned by Twente, not collected in their cohort). For UNIGE, seems feasible, but info not collected yet

**9. Name of the dimension: CREATIVE ACTIVITIES**

10. **Description of the dimension:** To involve in imaginative activities as handicraft, painting, writing, listening or playing music, etc.

11. **Feasibility of its assessment in the current cohort:**

12. **List of existing outcomes for its assessment in the cohort (max 10):** For UNIGE, not collected in everyday activities other than play / leisure listed above, but imagination is part of the ADOS assessment with the item "Imagination/Creativity" in module 3

**9. Name of the dimension: PHYSICAL EXERCISE**

10. **Description of the dimension:** To engage in any bodily activity that enhances or maintains physical fitness and overall health.

11. **Feasibility of its assessment in the current cohort:** Feasible but not collected yet

12. **List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: TO REST**

10. **Description of the dimension:** To be able to get enough rest along the days (e.g. breaks between classes) and to sleep well.

11. **Feasibility of its assessment in the current cohort:** Feasible

12. **List of existing outcomes for its assessment in the cohort (max 10):** For children, at UNIGE we collect the Children's Sleep Habits Questionnaire.

**9. Name of the dimension: SERVICE DOG**

10. **Description of the dimension:** To have a service dog to carry out daily activities.

11. **Feasibility of its assessment in the current cohort:** feasible but not collected yet

12. **List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: SELF-CONFIDENCE**

10. **Description of the dimension:** To have the feeling that it is okay to be who you are.

11. **Feasibility of its assessment in the current cohort:** Feasible in older children, adolescents and adults, but currently not collected in our cohorts

12. **List of existing outcomes for its assessment in the cohort (max 10):** At UNIGE, we collect some data about the self-confidence of parents in the Parental Stress Index (PSI-Short Form): "I often have the feeling that I cannot handle things very well" "I find myself giving up more of my life to meet my children needs than I ever expected" "I feel trapped by my responsibilities as a parent" "Since having this child I have been unable to do new and different things" "Since having a child I feel that I am almost never able to do things that I like to do"

**9. Name of the dimension: PREDICTABILITY AND CONTROL**

**10. Description of the dimension:** To have a predictable day, to know what is going to happen and to have control over situations, as it's a nice feeling to know that things have gone as expected.

**11. Feasibility of its assessment in the current cohort:** Feasible

**12. List of existing outcomes for its assessment in the cohort (max 10):** VABS-II, "Coping" domain

**9. Name of the dimension: TRUSTED PEOPLE/PERSON**

**10. Description of the dimension:** To develop as a person in an environment in which you trust, knowing that you are trusted too.

**11. Feasibility of its assessment in the current cohort:** Feasible but not collected yet and do not have in mind any specific / existing questionnaire

**12. List of existing outcomes for its assessment in the cohort (max 10):**

**9. Name of the dimension: EDUCATIONAL SUPPORT (INSTITUTIONAL)**

**10. Description of the dimension:** To have additional support specialized for individuals with ADHD or autism at educational institutions (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).

**11. Feasibility of its assessment in the current cohort: Feasible**

**12. List of existing outcomes for its assessment in the cohort (max 10):** At UNIGE, we collect data on type and intensity of support with a questionnaire about school. Also, in the ADHD Child Evaluation (ACE) interview that we collect for all children older than 6 years old there are the following items : "Does the child have special educational needs?" and "does the child receive extra support or help at school ?"

**9. Name of the dimension: EDUCATIONAL SUPPORT (FAMILIAR)**

**10. Description of the dimension:** To have help with school homework or to mediate with school if you have problems (e.g. with teachers, with schoolmates).

**11. Feasibility of its assessment in the current cohort: Feasible**

**12. List of existing outcomes for its assessment in the cohort (max 10):** In the ADHD Child Evaluation (ACE) interview for children after 6 years old : "does the child receive extra support or help at home ?"

**9. Name of the dimension: TO READ**

10. <b>Description of the dimension:</b> To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.
11. <b>Feasibility of its assessment in the current cohort:</b> Feasible but not really measured yet in our cohorts
12. <b>List of existing outcomes for its assessment in the cohort (max 10):</b>
9. <b>Name of the dimension: HEALTHY LIFE-STYLE</b>
10. <b>Description of the dimension:</b> To adopt and maintain habits and behaviours that promote overall well-being and optimal physical and mental health.
11. <b>Feasibility of its assessment in the current cohort:</b>
12. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> Growth percentile measures (height, weight, head measure) (CareConnect).
9. <b>Name of the dimension: SENSORY STRATEGIES</b>
10. <b>Description of the dimension:</b> To find isolation, stimming (e.g. putting things in order, moving legs, rocking back and forth, using fidgeting toys to play with hands when stressed, headphones, etc.).
11. <b>Feasibility of its assessment in the current cohort:</b> Feasible, but most questionnaires measure the level of sensory needs or sensory behaviours, rather than measuring sensory behaviours as a strategy
12. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> At UNIGE, we collect data on sensory behaviours shown by children (ADOS, ADI, Sensory profile) but that might not be in the sense intended by this item.
9. <b>Name of the dimension: PSYCHOTHERAPY</b>
10. <b>Description of the dimension:</b> To have professional treatment to improve mental and emotional well-being.
11. <b>Feasibility of its assessment in the current cohort:</b> Feasible
12. <b>List of existing outcomes for its assessment in the cohort (max 10):</b> At UNIGE, we collect info on type of treatment, as well intensity / frequency.

## SECTION B

### Dimensions and outcomes identified by researchers: data collection template

In our opinion the dimension above are sufficient, however efforts should be made in order to make for some dimension relevant outcomes to be measured for:

1. Preschool
2. School
3. Adolescence
4. Adults

This is extremely important since we should make efforts to make sure we are measuring relevant outcomes along the circle of life and not measuring it only on adults, thus missing the opportunity to evaluate early interventions.

Examples for dimensions and outcomes to be measured in preschool/school:

- Developmental milestones
- Elements from ABAS/ Vineland/ well being
- Parental dimensions – for example: parental stress, couple's satisfaction, parental sense of competence.
- Child dimensions – for example: Elements of anxiety and depression, child temperament, behavioural characteristics.

## 5.4. Annex IV: Questionnaire for the grouping, refinement, prioritization, and agreement on the dimensions identified

### Consensus on the descriptions for the categories and dimensions of the consensus process

Dear co-creation group member,

First of all, we sincerely appreciate your patience, time, and effort in participating in R2D2-MH's consensus process on outcome measures for interventions.

As you may recall, the intermediate session we held in Paris some time ago was highly valuable, allowing us to group the dimensions from the group discussions we had in the first phase into a series of categories proposed by APLICA and the members of the co-creation groups. To continue making progress we have prepared a questionnaire that presents the results achieved so far in this task and with the following objectives:

- 1- **To validate or suggest modifications on the descriptions for the categories and dimensions.** These descriptions were built from what was said by the members of the co-creation groups in the group discussions of the first phase and in the session held in Paris. In this questionnaire, you will have the opportunity to validate the descriptions, if you think that are already correct, or suggest modifications if deemed strictly necessary. The modifications suggested will only be applied in the event that more than one person points them out, since the aim of the questionnaire is to reach a consensus and not necessarily to adopt all the individual visions.
- 2- **To assess the relevance of the identified dimensions for the health and resilience of people with ADHD and autism.**

The questionnaire is divided into two sections:

**Section A**, in which categories relevant to the health and resilience of people with autism and ADHD will be presented.

**Section B**, in which dimensions relevant to the health and resilience of people with autism and ADHD will be presented.

In each of them, you will find instructions on how to fill out the questionnaire.

Thank you very much for your time and effort, APLICA team

## Which co-creation group do you belong to?

Young CCG  
Adults CCG

## What's your name?

## SECTION A: CATEGORIES

In this section of the questionnaire, we would like to present you the categories relevant to the health and resilience of people with autism and ADHD, obtained from the session that we held in Paris. The categories have been thought of as labels with descriptive function, which serve to group the dimensions homogenizing the results of the group discussions of the first phase of the consensus process. Because of their purely descriptive function, they will not be prioritized.

For each of them, its name and the description proposed will be presented. Please, answer the question that we will ask you by following the instructions below:

In the question, we will ask you opinion on the description by asking "Would you make any modifications to the description?"

- a. If you agree with the description, please reply "No, I agree with this description".
- b. If you consider the description needs to be modified in any way (adding, deleting or modifying any elements you find relevant), please reply "Yes" to this question. A text box will then appear where you can specify the modifications you suggest.

Thank you very much for your time and effort,

APLICA's team

## PERSONAL DEVELOPMENT

**Description:** To be able to meet your needs and desires, accomplish your aspirations and/or feel helpful to others. (Note: It could encompass all the categories that will be presented below, since the correct performance of individuals in these categories has as its ultimate goal, personal development).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## AUTONOMY

**Description:** The fundamental capacity of an individual to make self-directed decisions, exercise independence, and assert control over their own life choices and actions. (Note: Autonomy potentially requires tailored support systems or accommodations that empowers people's self-determination).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## EMOTIONAL WELLBEING

**Description:** State of mental health and stability characterized by a sense of self-confidence, emotional resilience, and positive self-esteem. (Note: Achieving emotional wellbeing involves fostering a supportive environment that acknowledges and accommodates your emotional experiences).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## SELF-REGULATION

**Description:** The ability to manage and modulate one's thoughts, emotions and actions, especially in social interactions. (Note: The capacity to perform this ability, empowers individuals to adapt to varying environments and demands while effectively managing stressors and challenges).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## COPING STRATEGIES

**Description:** Diverse set of adaptive techniques and approaches used to navigate and manage stress, challenges, and overwhelming situations. (Note: Such strategies aid in

---

developing resilience, enhancing problem-solving skills, and mitigating the impact of stressors on mental health and daily functioning).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Please tell us what changes you would like to make:**

## COGNITIVE PERFORMANCE

**Description:** The intellectual abilities, learning processes, and mental development of neurodivergent individuals. (Note: It involves early personal development and the acquisition of cognitive skills necessary for optimal functioning, problem-solving, decision-making, and adapting to changing circumstances).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Please tell us what changes you would like to make:**

## COMUNICATION

**Description:** The exchange of information, thoughts, feelings, and needs through various means and channels. This exchange may involve utilizing different modes such as verbal, non- verbal, or alternative communication methods. (Note: Establishing and maintaining a reliable and accessible communication system is crucial in ensuring understanding, facilitating social interactions, and advocating for personal needs and preferences).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Please tell us what changes you would like to make:**

## LIFESTYLE: HEALTHY HABITS AND LEISURE

**Description:** Lifestyle and leisure encompass a spectrum of activities, habits, and engagements that contribute to a balanced, fulfilling, and enjoyable life for individuals. (Note: These activities aim to promote mental well-being, reduce stress, and provide opportunities for relaxation, self-expression, and personal enjoyment).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## ENVIRONMENT

**Description:** Physical, social, professional and emotional surroundings that impact the well-being and experiences of individuals. (Note: It involves creating safe, accessible, and inclusive environments that accommodate sensory needs, provide appropriate support, and foster trust). Would you make any modifications to the description?

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## SOCIAL LIFE

**Description:** Relationships, connections, and interactions with individuals, families, peers, and the broader community. (Note: Facilitating social inclusion, fostering positive relationships, and providing opportunities for social participation and support contribute significantly to the emotional well-being and resilience).

### Would you make any modifications to the description?

Yes

No, I agree with this description

### Please tell us what changes you would like to make:

## EDUCATION

**Description:** To acquire knowledge, skills, and understanding through formal or informal learning processes. (Note: Education involves formal and informal systems of learning and skill development tailored to meet the diverse needs of individuals).

### Would you make any modifications to the description?

Yes

No, I agree with this description

**Please tell us what changes you would like to make:**

## SOCIO-ECONOMIC FACTORS

**Description:** Elements derived from the organization of societies, like economic status and work conditions, impacting the well-being, access to resources, and opportunities for individuals. (Note: The capacity of individuals for the correct development and stability of these elements is unequal, being easier to access for subjects who occupy positions better valued by society).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Please tell us what changes you would like to make:**

## SECTION B: DIMENSIONS

In this section of the questionnaire, we would like to present you the dimensions relevant to the health and resilience of people with autism and ADHD, obtained from the intermediate session we held in Paris.

For each of them, its name and the description proposed will be presented. Please, answer the two questions that we will ask you by following the instructions below:

In the first question, we will ask you opinion on the description by asking “Would you make any modifications to the description?”

If you agree with it, please reply “No, I agree with this description” to this question.

If you consider the description needs to be modified in any way (adding, deleting or modifying any elements you find relevant), please reply “Yes” to this question. A text box will then appear where you can specify the modifications you suggest

In the second question, we will ask you to assess how relevant do you think this dimension is for the health and resilience of people with autism and ADHD. We will ask you to score each dimension from 1 to 10, being 1 not relevant at all for the health and resilience of people with autism and ADHD and 10 very relevant.

Thank you very much for your time and effort, APLICA's team

## EDUCATION

**Category under which it is grouped:** Autonomy.

**Description:** To be able to acquire knowledge, skills, and understanding through formal or informal learning processes.

### Would you make any modifications to the description?

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

### SERVICE DOG

**Category under which it is grouped:** Autonomy + Coping strategies

**Description:** To have a trained animal assisting individuals with specific needs in their daily activities.

### Would you make any modifications to the description?

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

### SELF-ESTEEM

**Category under which it is grouped:** Emotional wellbeing

**Description:** Confidence and satisfaction in one's self-worth.

### Would you make any modifications to the description?

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**



1

10

**Please tell us what changes you would like to make:**

## SELF-CONFIDENCE

**Category under which it is grouped:** Emotional wellbeing + Social life

**Description:** Belief in one's abilities and judgments. To have the feeling that it is okay to be who you are.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## SELF-ACCEPTANCE

**Category under which it is grouped:** Emotional wellbeing

**Description:** State or process of recognizing, embracing, and fully acknowledging oneself, including understanding neurodiversity and one's strengths and weaknesses without judgment or the need for external validation.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## SOCIAL RELATIONS



**Category under which it is grouped:** Emotional wellbeing.

**Description:** Spending time with other individuals who uplift and connect with you, fostering a sense of belonging and preventing feelings of isolation. This involves being in the company of people who share similar thought processes, contributing to a sense of understanding and mutual connection.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## MANAGE MOTIVATION

**Category under which it is grouped:** Self-Regulation

**Description:** The personal ability to regulate and sustain internal drive or enthusiasm to start doing a certain task.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## TASK INITIATION

**Category under which it is grouped:** Self-Regulation

**Description:** The personal ability to initiate a task by translating thoughts into actions without excessive procrastination or avoidance.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

**TO REST**

**Category under which it is grouped:** Self-Regulation

**Description:** Engaging in relaxation, downtime, sleep or periods of respite, vital to recharge, manage sensory overload, and maintain mental and physical well-being amidst daily demands and stressors.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

**SELF-REGULATION**

**Category under which it is grouped:** Coping strategies.

**Description:** The ability to manage and modulate (increasing or decreasing) one's thoughts, emotions and actions, especially in social interactions.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## SENSORY STRATEGIES

**Category under which it is grouped:** Coping strategies.

**Description:** Techniques or approaches employed by people with autism or ADHD to manage sensory sensitivities, reduce sensory overload, and navigate environments comfortably (e.g. to find isolation, stimming...).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## PLANNING

**Category under which it is grouped:** Coping strategies.

**Description:** Process of organizing, strategizing, and structuring tasks or activities that helps to have a predictable day and have a feeling of control over situations.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

---

## ROUTINE

**Category under which it is grouped:** Coping strategies + Lifestyle and leisure

**Description:** Establishing predictable and structured patterns of behaviour or activities, offering stability, comfort, and predictability, aiding in managing anxiety and improving self- regulation.

**Would you make any modifications to the description?**

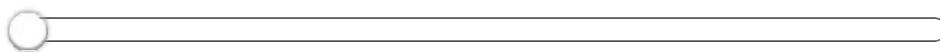
Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10



**Please tell us what changes you would like to make:**

## SUPPORT SYSTEM

**Category under which it is grouped:** Coping strategies + Emotional wellbeing.

**Description:** Network of individuals, professionals, or resources providing emotional or practical assistance to people with autism or ADHD, aiding in coping with challenges and fostering resilience.

**Would you make any modifications to the description?**

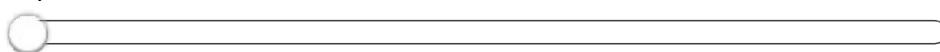
Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10



**Please tell us what changes you would like to make:**

## ACCESS TO HEALTHCARE

**Category under which it is grouped:** Coping strategies

**Description:** Having the ability to receive adequate physical and mental health services, treatments, or therapies.



**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10



**Please tell us what changes you would like to make:**

## COGNITIVE DEVELOPMENT

**Category under which it is grouped:** Cognitive performance

**Description:** Period of cognitive, emotional, and social growth during the formative stages of life.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10



**Please tell us what changes you would like to make:**

## COMUNICATION SKILLS

**Category under which it is grouped:** Communication

**Description:** Possessing a reliable way to express thoughts, emotions, and needs effectively.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10



**Please tell us what changes you would like to make:**

## PHYSICAL EXERCISE

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To engage in any bodily activity that enhances or maintains physical fitness and overall health.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## BALANCED DIET

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To eat in a way that incorporates a variety of foods in appropriate proportions, providing essential nutrients required for optimal health and well-being.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## PETS

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To spend time with domestic animals kept for companionship or pleasure.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## NATURE

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To connect with the environment in natural spaces (e.g. go to the forest, mountains, sea, walks with dogs...).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## TO PLAY

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To engage in recreational or enjoyable activities (individual or group) for amusement, pleasure, or entertainment.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very**

important)

1

10

Please tell us what changes you would like to make:

## TO READ

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** To engage with written material, such as books, magazines, or online content, for enjoyment, relaxation, or personal interest.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

Please tell us what changes you would like to make:

## CREATIVE ACTIVITIES

**Category under which it is grouped:** Lifestyle: healthy habits and leisure.

**Description:** Engaging in creative pursuits involving imagination and artistic expression (e.g. handicraft, painting, writing, listening or playing music, etc.)

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

Please tell us what changes you would like to make:

## APPROPRIATE SUPPORT



**Category under which it is grouped:** Environment.

**Description:** Having assistance and accommodations aligned with individual needs (adequate support systems, interventions, and resources).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## ADAPTED ENVIRONMENT

**Category under which it is grouped:** Environment

**Description:** To live in an environment with settings modified to accommodate specific requirements of individuals.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## SAFE ENVIRONMENT

**Category under which it is grouped:** Environment

**Description:** To have a place that feels safe and secure, to be in it alone, calm and self- regulated without unexpected changes (e.g. your own room).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## TRUST (PHYSICAL ENVIRONMENT)

Category under which it is grouped: Environment

Description: Confidence in the safety, reliability, and predictability of the physical surroundings, to have the opportunity to develop as a person in a context in which you trust.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## COMMUNITY INVOLVEMENT

Category under which it is grouped: Social Life

Description: Engaging and participating in societal activities, groups, or events (physically or virtually), socializing and feeling the group's support.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

## FAMILIAL RELATIONS

**Category under which it is grouped:** Social Life

**Description:** Positive interactions, connections, and support within the family unit.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

## TRUST (PEOPLE)

**Category under which it is grouped:** Social Life

**Description:** Have confidence in the honesty and security of the social environment and relationships with other people (friends, family, etc.), having the feeling that you are trusted too.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## LEARN SKILLS

**Category under which it is grouped:** Education



**Description:** Acquisition of various skills relevant to different age groups (life skills, adaptive strategies, coping mechanisms...).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

## PEERS SUPPORT

**Category under which it is grouped:** Education

**Description:** Assistance, camaraderie, and connection provided by individuals in the same age group within educational environment.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

## EDUCATIONAL SUPPORT (INSTITUTIONAL)

**Category under which it is grouped:** Education

**Description:** To have assistance provided within formal educational settings specialized for individuals with ADHD or autism (e.g. trained teachers, being allowed to have a pet in school, use technological tools like a laptop, to have a separate desk from classroom to avoid noise, to have breaks between classes, etc.).

**Would you make any modifications to the description?**

Yes

No, I agree with this description



**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

## EDUCATIONAL SUPPORT (FAMILIAL)

**Category under which it is grouped:** Education

**Description:** Support and guidance offered by family members for the performance of tasks related to education (homework, studying, etc.) or to mediate with education institutions or the people involved in them (teachers, schoolmates, etc.).

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## ECONOMIC SITUATION

**Category under which it is grouped:** Socio-economic factors

**Description:** To be able to ensure financial security for present and future needs.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

10

**Please tell us what changes you would like to make:**

## WORK

**Category under which it is grouped:** Socio-economic factors

**Description:** To find and choose a paid or unpaid employment or occupation. Maintaining and achieving advancement at work and being able to leave a job in an appropriate manner.

**Would you make any modifications to the description?**

Yes

No, I agree with this description

**Could you rate from 1 to 10 the importance of this dimension for the resilience of people with autism and ADHD? (1 being not important at all and 10 being very important)**

1

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**Please tell us what changes you would like to make:**

Thank you very much for the time and effort you have dedicated to completing this questionnaire.

Please click 'Done' to confirm that you have completed the questionnaire and submit your answers

Please note that once you click 'Done', your response will be submitted and you will no longer have access to the questionnaire

If you have any questions or would like to share any comments, please feel free to contact Josemi — APLICa at: [jmcarraco@aplicacoop.com](mailto:jmcarraco@aplicacoop.com)