

Supplementary online materials for ‘The development, feasibility and acceptability of Empower-Autism: A new psycho-educational and psycho-therapeutic programme for caregivers of children recently diagnosed with autism’

1. Summary of Empower-Autism programme content

The programme consists of 15 hours’ group-based contact time with manualised content, delivery methods and ethos.

Autism psycho-education content: The programme contains up-to-date and evidence-informed content aiming to provide understanding, insight, empathy and empowerment through autism knowledge and practical strategies for use in daily life. Content also focusses on the autism context, such as the education system and local, national and online sources of information and support to facilitate informed choices for ongoing care.

ACT content: The ACT components aim to enable caregivers to reflect upon their own wellbeing, including their emotional response to the diagnosis and parenting their child and provide an experiential and skills-based introduction to ACT tools and processes. The ACT framework includes six main concepts, adapted from the ACT hexaflex (Hayes et al., 2012) and is depicted within a flower schematic to increase accessibility for caregivers (see part 3 below): mindful awareness and pausing; mindful noticing of thoughts, and feelings; cognitive defusion (unhooking and distancing from unhelpful thoughts to reduce their impact); expansion (making space for difficult feelings and sensations); values clarification (reflecting on what is important to you); and committed action (small steps consistent with your values). An ACT-consistent stance is modelled by facilitators throughout and this includes: showing an understanding of group or individual perspectives; responding to emotions in an empathetic way; encouraging noticing of own experience; modelling psychological flexibility; reflecting on whether fixing the problem will work and, where appropriate, presenting or modelling “sitting with” a feeling or problem as an alternative.

Delivery methods: A range of delivery methods were employed including didactic presentation, and group and paired reflective discussion. First-hand autistic perspectives were included through videos, descriptions, quotes, and signposting to personal accounts. Optional activities and manualised

decision points allowed responsive tailoring of content to the needs of the group. Extended learning was offered through: (a) home practice suggestions, (b) paper resource packs with further information and signposting to sources of support, and (c) additional online resources.

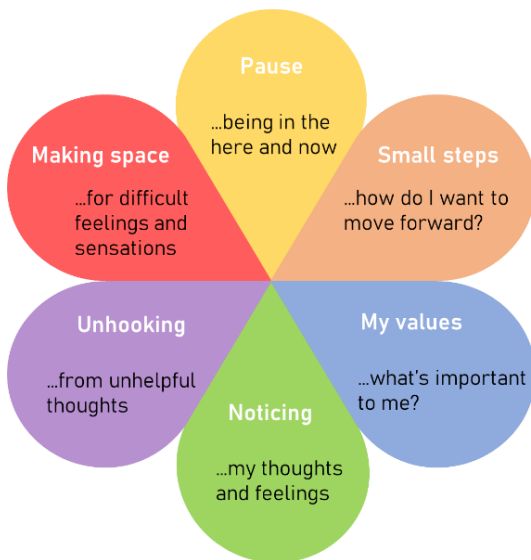
Ethos: The intended ethos of the programme was given considerable consideration. It included: (a) recognition and valuing of existing expertise brought by participants; (b) an open-minded approach with acceptance of the diverse range of experiences, thoughts, feelings and responses and an emphasis on compassion to self and others; (c) content shared as an ‘offering’ and participants actively encouraged to take what works for them and leave aside the rest; (d) autism/neurodiversity positivity, dispelling ‘doom and gloom’ narratives about autism and offering a more balanced and affirmative tone.

2. Table showing detailed content by session

Topic	Content
Session 1: Introduction to autism and ACT	<ul style="list-style-type: none"> • ‘Meet and greet’; ground rules • Introduction to autism (definitions, prevalence, terminology, diagnostic criteria, co-occurring conditions, causes, core characteristics) • The spectrum wheel, spiky profiles, and diversity of presentations • First-hand accounts: what it’s like to be autistic • Opportunity to reflect upon ‘autism journey’ to date • Talking with your child about autism • Brief introduction to ACT (self care, pausing and noticing)
Session 2: Thinking styles, the education system, and managing stress	<ul style="list-style-type: none"> • Thinking styles and autism (Central coherence, theory of mind and the double empathy problem) • Working with the education system (Legislation and statutory processes; additional support and reasonable adjustments; working together with schools; sources of information, advice and support) • Short- and long-term ways to manage stress (cognitive defusion, the ‘stress bucket’; short-and long-term self-care strategies)
Session 3: Communication and autism	<ul style="list-style-type: none"> • Language, non-verbal communication, understanding and social interaction • ACT activity: Pausing, Noticing and Making Space • Developing interaction with your child: Golden Moments • Supporting understanding and using visual supports • Learning the language of emotions • Links to communication-related support, websites, apps and resources

Session 4: Who and what matters to you	<ul style="list-style-type: none"> • Knowing your values and allowing them to guide you; small steps; potential barriers • Open discussion and relevant ACT exercises and strategies • Further reflection on ACT and what is most useful to you
Session 5: Your child; their world	<ul style="list-style-type: none"> • Sensory systems and sensory regulation; environmental adaptations and sensory strategies; signposting to resources and sources of advice and support • Emotions and energy regulation • Understanding behaviour • Closing reflections

3. Participant-facing ACT Framework



4. Proposed change mechanisms and corresponding programme content

Proposed change mechanism	How the programme sought to address this
<p>Improved understanding of autism and use of strategies to meet the child's needs</p> <p>Participants have an up-to-date and accurate understanding of autism and how autism affects their individual child. They know where to find further good quality information.</p>	<ul style="list-style-type: none"> • Up-to-date and evidence-informed information about autism to counteract misunderstandings and myths (session 1) • Extension activities and signposting to good quality information (extension resources) • Focus on diversity across autistic people and opportunity to consider the relevance of learning for their own child (throughout) • Manualised sharing of common good practice strategies to use in daily life to support communication, social

	<p>connection, sensory needs, emotions, and behaviour (throughout)</p> <ul style="list-style-type: none"> • Informal sharing of strategies within group discussions (throughout) • Reflection on which strategies have worked or could work for their own child (throughout)
<p>More informed and flexible response to new context</p> <p>Participants are able to respond in a more informed and flexible way to the new service provision context (e.g., when interacting with school, when looking for support)</p>	<ul style="list-style-type: none"> • Understanding of education system and child’s rights (session 2) • Reflection on working together with schools (session 2) • Sharing of experiences of support and adjustments provided by schools (session 2) • Knowledge of where to find information, advice and support on a range of topics, e.g., links to local and national statutory and voluntary organisations (throughout) • Signposting and referral to other supports and agencies, as appropriate (throughout) • Links to resources and apps (e.g. relating to communication, emotions etc) • Learning to pause and notice thoughts and feelings before acting • Learning to consider whether problem solving is the right approach or whether accepting or ‘sitting with’ is the right approach
<p>Greater insight & empathy with child</p> <p>Increased ability to understand the child’s lived experience and see things from their point of view; empathy with the child’s experiences</p>	<ul style="list-style-type: none"> • Sharing of first-hand autistic accounts and perspectives (session 1 and throughout) • Understanding how autism manifests in their child; considering their strengths and difficulties in different areas (e.g., communication, sensory processing; sessions 1, 3) • Emphasis on internal experiences (sensory, emotions, energy, cognitive processing, etc) (throughout) • Understanding situations from the child’s point of view (e.g., social interaction, behaviour) (session 3, 5) • Understanding the double empathy problem (session 2) • Understanding how functioning can change according to context (e.g., understanding, energy, sensory processing; session 2, 5) • Modelling of open-minded and compassionate ethos (throughout)

<p>More informed and flexible responding to the child; stronger relationship</p> <p>Increased ability to tune into their child's mood, thoughts and feelings, enabling them to be more attuned in their responses, leading to a stronger, more trusting relationship</p>	<ul style="list-style-type: none"> • Knowledge of how to support their child to understand their autism in a constructive way (session 1) • Golden moments: reflecting on moments of positive interaction with/for their child and encouragement to enable those moments • Pausing in the moment to consider the child's communication, social, sensory, emotional and energy needs (session 3, 5) • Taking time to understand their child's experience and perspective before addressing a 'problematic' behaviour (session 5) • Reflecting upon what the parent is bringing (thoughts, feelings, behaviours) to moments of parent-child disagreement or child behavioural responses
<p>Social connection & validation</p> <p>Feeling less isolated and more socially connected. Validation of experiences, expertise and feelings. Protection against minority stress and stigma</p>	<ul style="list-style-type: none"> • Meeting other people with an autistic child (throughout) • Sharing emotional responses to the diagnosis / their journey to date (session 1) • Sharing (offering and receiving) parenting experiences and expertise within structured and unstructured discussions (throughout) • Understanding that other children have similar (and dissimilar) needs (throughout) • Understanding that other caregivers have similar (and dissimilar) parenting joys and challenges (throughout)
<p>Increased acceptance & hope</p> <p>Being more 'at ease' with child's autism; accepting (or embracing) their child for who they are; not fighting against autistic traits; having hope for the future; feeling less anxious about the present and the future</p>	<ul style="list-style-type: none"> • Autism and neurodiversity positive ethos (throughout) • Hearing alternative perspectives and narratives from other caregivers and facilitators (throughout) • Focus on strengths and difference as well as difficulty (throughout) • Sharing of first-hand autistic accounts and perspectives (session 1 and throughout)
<p>Improved understanding of and attention to own emotional needs & use of strategies to meet these</p>	<ul style="list-style-type: none"> • Understanding the importance of self-care, generally and in the context of parenting (session 4 and throughout) • Encouragement to pause and notice thoughts and feelings • Time and space to process thoughts and feelings and to 'sit with' difficult thoughts and feelings

	<ul style="list-style-type: none"> • Opportunity to try out a range of simple exercises to promote wellbeing and to select the ones that work for you (session 4, throughout) • Time to reflect on and re-connect with what's important in life for you as an individual / as a parent (session 4) • Make a plan to take small steps to keep connected with your values and consider what barriers there might be along the way (session 4) • Reflection on healthy / unhealthy strategies for dealing with short- and long-term stress and practice using healthier strategies (session 2) • Reflection on the link between you and your child's thoughts, feelings and behaviour and how to manage your feelings in challenging moments (session 5) • Compassionate ethos (throughout)
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5. Post-session participant feedback form

Are you (please circle): A trial parent (who signed the consent form) / Accompanying adult

Day (please circle): Monday / Tuesday

Session (please circle): 1 2 3 4 5

How satisfied were you with today's session? (please circle one)

Very satisfied
 Satisfied
 Unsatisfied
 Very unsatisfied

Which parts of today's session were most helpful to you?

Which parts were least helpful?

Were there any parts that you really disliked or made you feel too uncomfortable?

How do you feel as you leave the session today?

Any other feedback?

6. Post-session facilitator feedback form

Name of practitioner:

Day (please highlight): Monday / Tuesday

Session (please highlight): 1 2 3 4 5

How satisfied were you with today's session? (please highlight)

😊 Very satisfied 😊 Satisfied 😐 Unsatisfied 😞 Very unsatisfied

What went well in this session? What made it go well?

What went less well? What (if anything) would you want to change if you did this again?

How were the timings of the session?

What were the group dynamics like? Did the dynamics impact upon your delivery? What (if anything) could be done to overcome these issues?

Were there any particular issues/questions/responses that were difficult to address? How could things be done differently if this happened again?

What further support/training/supervision would be helpful around this session?

How was working with the co-deliverer?

Did you have everything you needed practically speaking?

Is there anything else you would like to mention or feedback about this session?

7. Ratings on detailed satisfaction items (n=130)

Item	In-person groups					Online groups					
	Missing datapoint	Definitely agree	Slightly agree	Not sure	Not sure / Slightly / definitely disagree	Missing datapoint	Definitely agree	Slightly agree	Not sure	Slightly disagree	Definitely disagree
I understood the aims of today's session	0	60 (88.2%)	8 (11.8%)	0	0	0	57 (91.9%)	5 (8.1%)	0	0	0
The information was pitched at the right level	1 (1.5%)	58 (85.3%)	9 (13.2%)	0	0	0	49 (79.0%)	12 (19.4%)	1 (1.6%)	0	0
There was the right amount of information	3 (4.4%)	53 (77.9%)	6 (8.8%)	5 (7.4%)	1 (1.5%)	0	47 (75.8%)	13 (21.0%)	2 (3.2%)	0	0
The facilitators were knowledgeable	0	66 (97.1%)	2 (2.9%)	0	0	0	61 (98.4%)	1 (1.6%)	0	0	0
The facilitators were supportive	1 (1.5%)	63 (92.6%)	4 (5.9%)	0	0	0	61 (98.4%)	1 (1.6%)	0	0	0
I felt comfortable within today's session	2 (2.9%)	56 (82.4%)	7 (10.3%)	1 (1.5%)	3 (4.4%)	0	57 (91.9%)	5 (8.1%)	0	0	0
I learnt things that will be helpful to me as a parent to my child with autism	1 (1.5%)	61 (89.7%)	4 (5.9%)	2 (2.9%)	0	0	57 (91.9%)	4 (6.5%)	1 (1.6%)	0	0

I learnt things that will be helpful to me as a person	1 (1.5%)	60 (88.2%)	5 (7.4%)	2 (2.9%)	0	0	56 (90.3%)	5 (8.1%)	1 (1.6%)	0	0
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8. Sample characteristics for qualitative analysis, N=17 (in-person n=11; online n=6)

Nominated parent or carer demographics		Total (n)	In- person (n)	Online (n)
Relationship to child	Mother (Biological)	10	6	4
	Mother (Adoptive)	0	0	0
	Father (Biological)	4	3	1
	Grandmother (Biological)	1	1	0
	Aunt (Biological)	2	1	1
Gender	Female	13	8	5
	Male	4	3	1
Age in years	Range	32-59	32-59	35-45
	Mean (SD)	42.94 (7.00)	43.73 (8.20)	41.50 (4.32)
Marital Status	Single	6	4	2
	Co-habiting	3	3	0
	Married	8	4	4
Ethnicity (self-defined)	White British	8	7	1
	White European	2	0	2
	Asian / British Asian	5	2	3
	Black / Black British	1	1	0
	Mixed Ethnicity British	1	1	0
Native language	English	15	11	4
	Other (Punjabi, Dutch)	2	0	2
Highest education level	No qualifications	1	1	0
	GCSEs	5	3	2
	A Level/NVQ	4	4	0
	University diploma or degree	5	3	2
	Master's degree or higher	2	0	2
Employment	Full-time	3	2	1
	Part-time	9	5	4
	No employment	5	4	1
Household income	No income from employment	4	3	1
	Below £19,999	4	2	2
	£20,000 - £39,999	3	3	0
	£40,000 - £59,999	6	3	3

	£60,000 +	0	0	0
Other relevant diagnoses	Autism	0	0	0
	Generalised Anxiety Disorder	9	8	1
	Depression	7	7	0
	Borderline Personality Disorder	1	1	0
Child demographics				
Gender	Female	6	3	3
	Male	11	8	3
Age in years	Range	4-15	4-15	5-10
	Mean (SD)	8.88 (3.23)	9.45 (3.72)	7.83 (1.94)
Other diagnoses	ADHD	3	3	0
	Attachment disorder	1	1	0
	Sensory processing disorder	1	0	1
	Obsessive compulsive disorder	1	1	0
	Genetic micro-duplication	0	0	0