

Journal of Family Therapy (2016) **00**: 00–00 doi: 10.1111/1467-6427.12106

# Non-violent resistance parent training for the parents of young adults with High Functioning Autism Spectrum Disorder

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A 'dependence trap' between parents and young adults with High Functioning Autism Spectrum Disorder (HF-ASD) develops when parents accommodate to the needs of their grown-up child in ways that may hinder development and cause distress. Non-Violent Resistance (NVR) parent training may help parents reduce their accommodation, manage arising conflicts through de-escalation techniques, and amass external support for themselves and their child. Parents of four young adults with HF-ASD received a tenweek modified NVR parent training. Cases were evaluated through semistructured interviews and self-report questionnaires. The parents reported improved independent functioning, reduced parental helplessness and accommodation, and enhanced support. Questionnaires showed improvements in reported parental hopefulness and reduced parental depression.

#### Practitioner points

- Families with a grown-up child with HF-ASD may be characterised by excessive parental accommodation that is detrimental to optimal functioning
- Accommodation increases dependence, which in turn requires continued accommodation, forming a 'dependence trap'
- NVR parent training may help parents to young adults with HF-ASD reduce parental accommodation, helplessness and depression, while improving hopefulness and adaptation

Keywords: Autism Spectrum Disorder; young adults; dependence; accommodation; parent training; non-violent resistance.

#### Introduction

This paper presents a structured intervention for parents of young adults with High Functioning Autism Spectrum Disorder (HF-ASD).

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HF-ASD is characterised by social communication difficulties and restricted and repetitive behavioural patterns, alongside normative cognitive and language abilities (American Psychiatric Association, 2000). Although individuals with HF-ASD have the potential to achieve overall successful functioning, in many cases these expectations are not realised (Howlin, 2004; Klin *et al.*, 2007). Instead, the parents of young adults with HF-ASD often find themselves highly involved in their grown-up child's life, with the young adult relying more and more on the parents' assistance, failing to develop the ability to cope on his/her own (Renty and Roeyers, 2006), and with parents becoming burdened and distressed. There is also evidence of negative family dynamics, involving recurrent conflicts and harsh feelings between parents and child or between the parents themselves (Orsmond, Seltzer, Greenberg and Krauss, 2006; Stoddart, 1999).

While there are various interventions aimed for young adults with HF-ASD (Gantman, Kapp, Orenski and Laugeson, 2012; Hume, Loftin and Lantz, 2009), there is little emphasis on the parents' roles. We aimed to formulate a parent-centered intervention, targeting the young adult's dependence, the parental distress and the family atmosphere.

The programme presented was an adaptation of the NVR model, originally devised to help parents of aggressive and self-destructive children to resist the child's negative behaviours in a non-violent and non-escalating manner. Although the parents are the only family members directly involved in treatment, NVR is a systemic approach that aims to modify interactive patterns that are hypothesised to aggravate symptoms and distress. NVR was inspired by coercion and accommodation models (Patterson, Dishion and Banks, 1984; Storch et al., 2007) according to which parents and child become trapped in recurrent patterns in which the child's dependent demands escalate, becoming more and more aversive, until the parents capitulate. Gradually, the parents learn to accommodate continuously to the child's expectations, so as to avoid those negative cycles. According to the model, both sides come to believe that the child cannot cope on his or her own and that there is no alternative to continuing parental accommodation, a process that perpetuates the child's dependence. This pattern was termed 'the dependence trap' (Lebowitz, Dolberger, Nortov and Omer, 2012). The dependence trap is a systemic concept in the sense that it describes an interactive pattern that is not fully explained by the individual characteristics of the different family members. This pattern maintains a situation in which the young adult's functioning remains at a sub-optimal level, and the parents' services at an overprotective level. However, it is not assumed that the dependence trap serves an ulterior function for the family, an assumption that might have a blaming connotation or minimise the biological basis of the child's condition (Roffman, 2005).

In several studies, NVR was shown to reduce parental helplessness, increase the parents' sense of support, diminish parental outbursts, reduce family escalation and reduce symptomatic behaviour of children with externalising disorders (Lavi-Levavi, 2010; Ollefs, Schlippe, Omer and Kriz, 2009; Weinblatt and Omer, 2008). In a modified form, NVR was found to be similarly effective in reducing parental accommodation and symptoms with anxious children (Lebowitz, Omer, Hermes and Scahill, 2013), and overly dependent young adults (Lebowitz *et al.*, 2012). In those cases the approach helped to diminish the young adult's withdrawal, to increase independent functioning, and to open the family to the involvement of support figures. Considering that these are all goals that may be relevant for families of young adults with HF-ASD, we assumed NVR could also be effective with this population.

NVR's effectiveness in the studies dealing with anxious and dependent behaviour was attributed to several means: (a) parents were helped to reduce the assistance they provided in areas where they had reason to believe their child could become more independent; (b) parents were trained to minimise escalation, learning to resist in a calm, decisive manner; and (c) parents were helped to overcome their isolation by recruiting a supportive network both for them and for the child.

The aim of NVR is to reduce and modify parental assistance in ways that may create the conditions for incremental improvement. We did not expect that the young adult will immediately accept the reduction in services from the parents. At least at the early stages of treatment, continued or even aggravated demands were expected. In those stages, the effects of NVR were assumed to manifest themselves chiefly in the parents. However, as the parents succeed in reducing accommodation and preventing escalation, we expected progressive improvements in the young adult's functioning and a reduction in family conflicts.

In this paper, we present a preliminary evaluation of NVR's effectiveness in four families of dependent young adults with HF-ASD. Evaluation data included qualitative analysis of interviews and self-report questionnaires collected before and after the intervention.

## Hypotheses

We hypothesised that NVR would help parents perceive how they contribute to their grown-up child's dependence, reduce services they deem inappropriate, withstand demands and resistance without escalating, and reduce their sense of helplessness and hopelessness. In addition, we hypothesised that following NVR the young adults' independent functioning would improve.

#### Methods

## **Participants**

Seven parents from four families (three couples, and one widowed father) were recruited through an ASD specialist clinic. All parents had a young adult son<sup>1</sup> (aged 20 to 26), who was diagnosed with HF-ASD according to DSM-IV-TR criteria, and reported on deep worries and distress regarding their son's lack of independence. Participants gave their formal consent to take part in the study.

#### Intervention

NVR Parental training has been described elsewhere in detail (Omer, 2004). We will briefly describe the NVR elements used in the work conducted with parents of young adults with HF-ASD.

- 1. Focusing on resistance rather than control. According to NVR, parents cannot dictate to their son how to conduct his own life. Their role is to focus on changing their own acts and on resisting, instead of controlling, their son's dependent and aggressive behaviours. The parents were helped to formulate and deliver an announcement declaring their intent to resist unacceptable behaviours and to stop providing unjustified services. The son was not required to agree to the parental plan. Rather, the announcement reflected the parents' unilateral decision to change their own attitude and behaviour.
- 2. Creating a network of support. Parents were helped to recruit a network of supporters, including relatives, friends and professionals. The supporters were crucial to this intervention, as they gave encouragement and legitimisation to the parents, and in addition provided actual help in areas where the son still needed assistance.

- 3. Gradual reduction of services. The parents were helped to reduce their inappropriate assistance in areas in which they believed their son was able to function on his own. In areas in which they believed their son still needed assistance, parents were encouraged to involve supporters, aimed to diminish the child's exclusive dependence upon them.
- 4. Anti-escalation training. The parents learned to identify their own escalatory patterns and develop ways of countering them. Anti-escalation strategies included: delaying response, avoiding a dominance-oriented stance, avoiding arguments, and developing self-control. Parents were also encouraged to make unilateral conciliatory overtures which served to remind both the parents and the son that their relationship remained positive (see case 2 for an example).
- 5. Fostering mentalisation. This element of the intervention, not originally a part of the NVR programme, was developed specifically for the present protocol because of the difficulties individuals with ASD may have in understanding emotions and mental states (Baron-Cohen, 1995). In order to foster mentalisation, parents were helped to deliver verbal and written messages, highlighting the cognitions and emotions of both partners in the interaction. Those messages consisted of four elements: (i) a description of the son's problematic behaviour in a given situation; (ii) the parents' perception of the son's emotional and mental states that were connected to that behaviour; (iii) the parents' own emotional and mental states in relation to the event; and (iv) a description of how the parents intended to address similar events in the future (see case 2 for an example).

The adapted NVR protocol was administered in ten weekly sessions conducted by trained clinical psychologists. In addition, parents received up to two support phone conversations a week, conducted by a trained undergraduate student, who was also present in the therapy sessions. The phone conversations aimed to clarify practical aspects of the interventions and to deal with possible parental concerns regarding their implementation.

#### **Evaluation**

Parents were interviewed twice – once before and once after the intervention. They were first asked to freely report on their son's

condition. They were then specifically asked about: (a) their son's level of functioning; (b) the nature and extent of assistance they provided; (c) their reasons for providing the assistance; (d) their feelings regarding the son's dependence; (e) their relationship with the son; and (f) the family's available support figures. The interviews were audio recorded and transcribed, and a qualitative analysis was performed, after a modified form of Glaser's (1967) model, as follows. Three judges were instructed to devise categories that would best describe the excerpts. Excerpts could fit more than one category. Categorisation was ended when the judges agreed about all categories and placements of the excerpts.

In addition to the interview, parents filled out the following questionnaires before the intervention and two months after its completion.

Beck Depression Inventory (BDI; Beck, Steer and Carbin, 1988). The BDI is a self-report measure of the severity of depressive symptomatology. Its twenty-one items (item example: 'I feel guilty most of the time') are rated on a four-point scale ('not at all' to 'extremely'). The BDI has good internal consistency in non-psychiatric participants (Chronbach's  $\alpha = .81$ ) and mean correlations of 0.6–0.74 with clinical ratings (Beck *et al.*, 1988).

A Hopefulness Scale. This fourteen-item self-report was designed specifically for this study. Parents were asked for their worries or positive expectations regarding their son's functioning in the coming year. Seven items referred to the son's functioning (e.g. 'My son will be more independent') and seven referred to the parents' own positions regarding their son's functioning (e.g. 'I won't be as worried for my son'). Each item was rated on a five-point Likert scale ('very unlikely' to 'very likely'). Internal consistency, based on parents' preintervention reports was high (Cronbach's  $\alpha = .85$ ).

Vineland Adaptive Behavior Scales – Second Edition (VABS-II; Sparrow et al., 2005). The VABS-II is a parent report measure of their child's adaptive behaviour, with norms ranging from infancy to adulthood. Out of the three domains covered by VABS-II (communication, daily living skills, socialisation), only the daily living skills scale was used, since this was the focus of the NVR intervention (example item: 'washes clothing as needed'). Parent rated the degree to which their son performed each behaviour on a three-point scale ('never', 'sometimes/partially', 'usually'). The scale has standard scores (M=100, S.D.=15). Higher scores represent better adaptive functioning. Reported reliability was over .90 for all scales (Sparrow et al., 2005).

#### Results

The results section describes the four cases, the categories that arose from the pre-and post-intervention interviews, and an analysis of the quantitative data. Names and background information were changed for confidentiality reasons.

#### Case 1

Adam and Ruth reportedly sought counselling due to what they viewed as the emotional dependency of their son, Ron, on his mother. Ron, in his mid-20s, received an HF-ASD diagnosis a few months prior to the parents' referral to the centre. The parents described Ron as being closed off and grumpy towards his father and siblings. They said he engaged in daily, lengthy, and one-sided, conversations with Ruth, including repetitive complaints about his father's and siblings' rudeness and untrustworthiness. When the mother was not immediately available, he used to leave her long, blaming letters. Ruth described her bedroom as a refuge ('sometimes I just hide there'). Ron, however, did not respect her privacy, often bursting into the room for further complaining, making her feel, she said, like a hostage in her own home.

Ruth said she feels unable to protect herself ('from the moment I get home, he doesn't leave me alone'), but thought she had to serve as a buffer between Ron and the rest of the family. This strategy only deepened her distress, as she felt alone with the burden. She felt she was the only channel of communication between Ron and the others, continually passing messages between them.

Ron's overall level of functioning was reported as relatively high. He attended university without special help, and was able to manage daily outdoor activities, such as grocery shopping and use of public transportation. However, he reportedly did not exhibit the same level of functioning at home, refusing to participate in household chores. Furthermore, although Ron received a monthly disability allowance, he fully relied on his parents for all his financial needs. His parents expressed their concern as to their limited ability to continue supporting him for many years to come.

In the first treatment sessions, it was decided that the first goals would be to help the mother protect herself and to re-involve the father in Ron's life. Adam and Ruth delivered to Ron a semi-formal announcement, both by word of mouth and in writing, declaring that

they would no longer tolerate his verbal outbursts toward his father and siblings, nor his lack of respect for his mother's privacy. They added that from that point on, Ruth would not mediate between Ron and his father, and invited him to address his father directly. When Ron protested in anger, saying he did not agree, they told Ron that the announcement reflected their joint decision as parents and that they would maintain those decisions because they believed it was their duty as parents to do so. Thereupon they stopped the discussion.

Ruth reported that the very delivery of the announcement brought her some relief. She said she felt less isolated and experienced her husband's willingness to become involved as a big help ('he is there for me now, for Ron, and for all of us, as a family'). Adam and Ruth were also relieved by Ron's unexpected response in the days and weeks after the announcement. They reported that he became less aggressive, his complaining bouts lessened, and he began speaking freely and directly with his father. Although he still had sporadic outbursts, mainly towards his siblings, Adam and Ruth said they could withstand Ron's anger without giving in to his demands (Adam: 'I am more confident in dealing with him'; Ruth: 'I do not panic or escalate'). Ruth associated Ron's improvement with the growing *positive* involvement of *both* parents in his life ('he felt that we are there for him, with him').

The therapist and the parents then decided to add two more goals to the intervention: promoting Ron's financial independence and involving him in household chores. Adam and Ruth came to an agreement with Ron that they would pay for his university tuition, but that he would be responsible for his daily expenses. Ron reportedly reacted well to the parents' assertive requests, beginning to take part in household chores.

At the concluding interview, Adam and Ruth expressed their improved perception of Ron, as a young man with much potential ('I recognise his maturity. I trust him'). They also expressed their feelings that they had better tools for dealing with him. They added that the change in the family allowed them to start investing in their marital relationship, which they said had long been neglected.

#### Case 2

David was a widower who was referred to the study due to his concern for his son, Tom (23), who had received an HF-ASD diagnosis a year before. David reported Tom's overall level of functioning was

relatively high. He had a bachelor's degree, some occupational experience, engaged in outdoor activities, and used public transportation. However, at the time before the intervention, Tom did not work and, in spite of his disability allowance, relied on his father for all his financial needs. Tom spent much of his time compulsively praying everywhere in the house, and demanding silence during his prayers, to the deep frustration of his father and sister. David described Tom as being extremely passive ('I feel that if I won't prepare and serve him his meals, he won't eat'). David argued that as a result he did not stay away from home for more than a few hours at a time.

Prior to Tom's HF-ASD diagnosis, there were reportedly frequent clashes between him and his father. However, once the diagnosis was given, David said that he started attributing Tom's passiveness and dependence to his diagnosis ('I realised he is not lazy, he does not exploit me. He is just incapable of doing a lot of things').

David said that he was sceptical that parent counselling might help, feeling that Tom was the one in need of therapy. Tom, however, declined professional help. With the therapist's help, David wrote an announcement, declaring that he would resist Tom's neglect of household chores, his total financial dependence on his father, and his taking over the house for his rituals. The announcement was delivered in a formal manner: David described his decisions and gave Tom a written copy. The following day, David presented Tom with a new chore rotation schedule (including meal preparation, laundry, taking care of the family's pet and grocery shopping). David added that he would no longer finance Tom's mobile phone and would require some financial participation on his part for healthcare and computer services. David reported that Tom began participating in the rotation ('he no longer sits there passively, expecting my services; he has started contributing to the household'), he seemed to accept the new financial arrangements, and to limit his praying to his bedroom. When Tom failed to fulfil his tasks, David controlled his previous tendency to argue and scream, while also refraining from completing Tom's tasks in his place. Instead, David would deliver Tom a short message of resistance with a mentalisation fostering component. For example, when Tom failed to do the family laundry, David said to him: 'You are not doing your part. I guess you might feel over-burdened, yet it makes me feel very frustrated. If you need me to explain again how the rotation works, or how to work the washing machine – I will be happy to do that. Yet, if this happens again, I will understand you don't want to take part in the rotation, therefore

each of us will be responsible for his own clothes.' Tom reportedly shouted and tried to argue, but having received no escalating response from David, he gradually calmed down and in a few days started taking part in the chore.

At the concluding interview, David expressed a new belief in Tom's abilities: 'After he received the diagnosis, I only felt sorry for him. But now I feel differently. I know that he is more able, and he is also realising that.' David added he was planning to stay away overnight, and that he believed that Tom would be able to take care of himself.

#### Case 3

Dan and Rebecca sought counselling due to what they viewed as the extreme dependence of their son, Ben (22) and, reportedly, their worries for his future. Ben had received an HF-ASD diagnosis as an adolescent. He attended a special education programme, leaving home early in the morning, and coming back in the afternoon. His parents supervised him continuously when he was home, saying that they felt he could not manage on his own. Rebecca was in charge of morning and evening routines, whereas Dan was in charge of the afternoons, driving Ben to outdoor activities, reminding him to do his homework, and meeting his 'endless help requests'. Both parents emphasised their need to continuously supervise Ben (Rebecca: 'I always have to pay attention to what he's doing'). Although it did seem to the therapist that Ben's level of independence was quite low, it also seemed to her that his parents were over-involved, possibly limiting his potential functioning.

At the preliminary interview, the parents also said they were disconnected and very hostile towards each other. They said that they continued living together only out of fear that Ben would be traumatised if one of them moved out. Both felt very lonely, saying they had no family or friends who could support them. Further inquiry revealed they had relatives who lived nearby, yet they were reluctant to involve them, as they did not trust them to keep Ben safe.

The intervention in this case appeared to suffer both from the rift between Dan and Rebecca and from Rebecca's high anxiety. The parents' apparent hostility seemed to make it impossible for them to join forces. Moreover, Rebecca said she was torn between her wish that Ben would be more independent and her extreme fears for his well-being ('when I call home and he doesn't answer the phone I get a panic attack. What if he slipped and injured himself?').

Despite the difficulties, the parents and the therapist decided that the main goal should be to improve Ben's day-to-day independence. Dan and Rebecca were asked to identify specific chores and activities which they believed Ben might be able to master. However, they reported difficulties agreeing on the chores to be included, and said that a formal joint announcement to Ben was not delivered. Next, an attempt was made to focus on developing a support network, as this might help overcome the mutual paralysis. The parents agreed to assemble a number of supporters to a meeting with the therapist, inviting Rebecca's mother, Dan's brother, and Rebecca's best friend. The meeting was encouraging, and the supporters agreed to undertake some initiatives, for instance, inviting Ben to their houses. However, the atmosphere of mistrust that characterised the family seemed to make this option less and less relevant, since the parents were hesitant to reach out to the supporters who were, in their words 'not accessible'.

Despite these difficulties, Dan and Rebecca reported that they succeeded in getting Ben to carry out some 'independence trials' in a number of routine activities, such as grocery shopping and getting to an afternoon activity on his own. Rebecca reported the careful planning of those trials allowed her to withstand her anxiety without running to Ben's assistance ('he went several times to the grocery shop by himself and he survived. I know it sounds crazy, but that's exactly how I feel'). Ben did not seem anxious or bothered. In fact, it seemed he was willing to take on more responsibilities, telling his mother: 'Don't worry, I'll be careful.' At one point, Rebecca asked Ben what further responsibilities he was willing to take on. He made her a list that included feeding their cat, making his bed, preparing a salad for dinner, and hanging out the laundry.

After seven sessions, Rebecca decided to take Ben on a trip abroad, where he reportedly had a psychotic episode. Dan and Rebecca decided to stop the treatment. They said that Ben's condition demanded their full attention, leaving them little energy to try and maintain, let alone increase, Ben's independent functioning.

In the concluding interview, Rebecca surprisingly expressed an increased belief in Ben's potential: 'I know I have to deal with my anxiety. If I don't, Ben will be closed up at home for the rest of his life, while he clearly can be more independent.' She also mentioned that the sessions with the therapist facilitated a new sort of communication between her and Dan: 'After the session, we would talk for about 15 minutes. I can't remember the last time we did that.'

#### Case 4

Sam and Rachel sought counselling due to what they felt as the intense dependency of their son, Daniel, on his father, and both parents' worries for his future. Daniel (24) had received an HF-ASD diagnosis in childhood and was placed in special education for children with communication difficulties. However, the parents said that he continuously had problems fitting in and ultimately dropped out of high school. Since then, he had reportedly not taken part in any organised activity. He used to stay at home, slept during the day and played computer games at night. At the preliminary interview, the parents described Daniel's extreme dependency on his father, who said that he took full care of him during most of the day ('actually, I can't leave the house'). Sam reportedly supervised Daniel continuously, fixed his meals, helped him pick out clothes and supervised his personal hygiene – actively helping him take showers ('he doesn't bathe well enough on his own'). Sam said that he felt this level of assistance was needed since in the past Daniel had got an infection reportedly due to self-neglect, and since he once became violent when left alone in the street. Sam said that he was frustrated by Daniel's passiveness and tried to talk him into being more responsible, but to no avail.

Sam and Rachel realised that they were unwittingly contributing to Daniel's dependence ('we don't help him become independent. We overprotect him. I think we play a part in his condition'). Besides reducing their inappropriate assistance, the parents also aimed to find a suitable housing solution for Daniel. Although still living together, the parents planned to file for divorce once Daniel became settled. However, they kept postponing this move, leaving their and Daniel's situation at standstill.

In treatment, the parents delivered Daniel an announcement, informing him they would no longer make his meals without his active participation and that his father would no longer supervise his showers or other aspects of his personal hygiene, stating they trusted him to do these on his own. Although Daniel did not seem attentive when his parents presented him with the announcement, the parents reported that he started to take responsibility for the activities mentioned in it. In the treatment sessions, it was agreed that Rachel should become more involved, as she was said to be less overprotective and could help Daniel without doing things in his stead. The parents reported that this shift became gradually more pronounced, improving the quality of their assistance to Daniel.

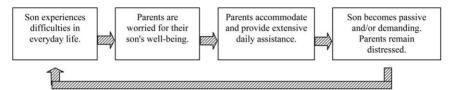


Figure 1. The Dependence trap in families of young adults with HF-ASD.

Next, a supporters' meeting with a few relatives was convened. Sam and Rachel talked openly about their situation and about Daniel's extreme self-withdrawal. The supporters seemed to react positively and started reaching out to Daniel and inviting him to visit them.

In the concluding interview, the parents mentioned that Daniel said he was happy with the fact that they were less actively involved in his daily routine. Sam and Rachel made arrangements for Daniel's transition to supported housing, taking Daniel on a successful visit to his future living place. They also started looking for separate apartments for themselves. The parents said that after years of total stagnation, they were surprised at the quick progress they made, having taken only a few initial steps.

# Qualitative analysis

*Pre-intervention*. The qualitative analysis of the transcribed pre-intervention interviews with the parents yielded four categories, matching the model of a *dependence trap* (Lebowitz *et al.*, 2012), illustrated in Figure 1 and detailed below.

- 1. The son's difficulties functioning in everyday life. This category described the parents' reports on their son's difficulties in functioning independently both in the home (e.g. meal preparation, cleaning, laundering, and personal hygiene) and outside the home (e.g. public transportation, shopping, academic or vocational activities, and finances). The category included descriptions of the son's actual functioning and of the parents' beliefs regarding his potential functioning. In the pre-intervention interview parents showed little distinction between these two descriptions, i.e. they usually doubted their son was capable of functioning more independently than he currently did.
- 2. The parents' emotional responses to the son's condition. This category described parental concerns about their son's ability to cope without their care, both in the present and in the future. The parents

- also expressed guilt about putative past failures (e.g. choosing a wrong school, failing to recognise the difficulties early enough, or making demands that the child could not meet).
- 3. Parental services linked to the son's dependent behaviour. This category addressed the kind, extent, and appropriateness of the assistance the parents provided within and outside of the home. The category also included statements about the (un)availability of additional figures (family, friends, and professionals), who might help in the provision of support for the son.
- 4. Effects of parental accommodation. This category described the effects of the parents' inappropriate assistance on the son's functioning (e.g. son becomes more passive and demanding), on the son's relationship with them (e.g. escalation of conflicts or disengagement), on the parents as individuals (e.g. enhanced distress), and as a couple (e.g. increased marital conflicts).

*Post-intervention*. The qualitative analysis of the transcribed post-intervention interviews with the parents yielded the following categories:

- 1. The parents decreased their accommodation and provided modified assistance. All parents reported a reduction in the intensive assistance they provided. They became more able to consider whether the son could perform a specific function independently and to react accordingly. Sometimes they found it was better to refer to members of the support network, who would be able to provide a less accommodating kind of assistance to their son.
- 2. The parents improved their emotional self-control. The parents reported they were better able to restrain themselves from reacting overprotectively or overemotionally. They reported this led to a reduction in accommodation and in escalation. In addition, the emphasis on messages involving mentalisation seemed to allow the parents, and possibly the son, to achieve a better level of emotional self-regulation.
- 3. The son became more active and independent. All parents reported their sons started to function more independently in the areas where they reduced their assistance. This process was said to reinforce the parents' ability to ask themselves whether the level of assistance in other areas could also be modified. In this way, the son's improved functioning and the parents' perception of the son's capabilities seemed to strengthen each other.

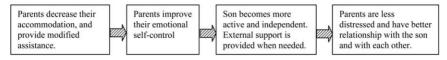


Figure 2. NVR parent training effects on the Dependence trap.

4. The parents became less distressed and the relationship (with the son and between the parents) became less burdened. The parents described an improved family atmosphere, with fewer conflicts and more cooperation. Their own lives became less burdened with oppressive duties.

These categories suggested that NVR assisted in alleviating the dependence trap in families of young adults with HF-ASD, as illustrated in Figure 2.

### Quantitative analysis

The analysis compared parental reports before the intervention and two months after its completion. Due to the small sample (seven parents), results should be considered as preliminary. Wilcoxon's nonparametric test for dependent samples revealed a significant decrease in parents' BDI scores (z=-1.79, p<0.05, see Figure 3) and

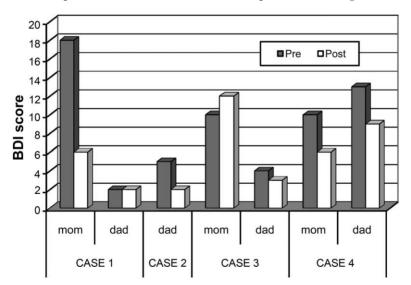


Figure 3. Parents' scores on the Beck Depression Inventory pre and post intervention.

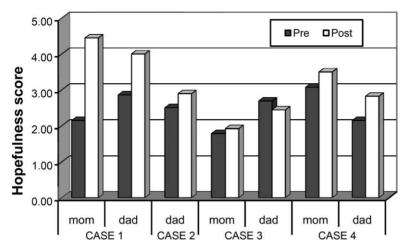


Figure 4. Parents' scores on the Hopefulness scale pre and post intervention.

a significant increase in parents' hopefulness (z=2.03, p<0.05, see Figure 4). No significant improvement was found in the son's daily living skills using the VABS-II (z=-1.46, n.s.).

#### Discussion

This study described a state of dependence and co-dependence between young adults with HF-ASD and their parents, which has been conceptualised as a *dependence trap* (Lebowitz *et al.*, 2012). The study illustrated the effects of a short-term NVR intervention (ten weeks), which, according to the parents' reports, alleviated the dependence trap in those families to different degrees.

In families with a young adult with HF-ASD, the dependence trap may stem from a combination of the neuro-developmental difficulties that are characteristic of the condition, and an overprotective and accommodating parental style (Orsmond *et al.*, 2006). Such a parental style may become more and more maladaptive as the child grows up. Although relatively high levels of parental accommodation are often required with younger children with ASD (Hirschler-Guttenberg, Golan, Ostfeld-Etzion and Feldman, 2015; Oono, Honey and McConachie, 2013), they may become more and more damaging as the child grows up. Despite the absence of comparative data regarding different levels of parental accommodation to individuals with HF-

ASD, the literature on anxiety disorders gives testimony to this process (Lebowitz *et al.*, 2013). Future studies should document this process in individuals with HF-ASD.

Our intervention aimed to alleviate the dependence trap by helping parents reduce their accommodation and enable their grown-up children to experiment in ways that may reveal a higher potential for independent functioning. NVR was the method of choice, as it focuses on promoting the parents' ability to act, even under severe constraints regarding dialogue or cooperation with their grown-up child. Through NVR, parents were able to take action and decrease their accommodation. The emphasis on the creation of a support network was especially important in areas where the parents estimated that their grown-up child still needed considerable assistance. It allowed taking some of the burden off the parents, by involving family members, friends and rehabilitation professionals in more active roles. These emphases of NVR have been shown to be relevant also for other conditions besides HF-ASD, including anxiety disorders, behaviour difficulties, and the pathological dependence of adults without ASD (Lebowitz et al., 2012, 2013; Weinblatt and Omer, 2008). The NVR principles presented here lend themselves to therapists using other styles or frames of systemic therapy. For example, Schlippe (2006, 2014) used concepts from NVR to create family sculptures, as an adjunct for family business counseling, and in marital therapy.

One of our goals was to look for ways in which the NVR protocol should be adapted so as to better serve families of young adults with HF-ASD. Two specific adaptations were made. One addressed the special difficulties of young adults with HF-ASD in understanding their own, and others', mental states through the inclusion of mentalisation fostering messages. The other involved paying more attention to the creation of a support network, due to the long-lasting rehabilitation needs of those young adults, who may need to learn to rely on support of others, in addition to (and eventually instead of) their parents'.

The modified NVR protocol provided opportunities for mentalisation fostering messages. As parents were asked to delay immediate reactions to their grown-up child's dependent behaviour, in order to react in a non-escalating manner, they were able to use this delay to come up with a mentalisation fostering message. This modification was relevant for all cases, but it became a particularly dominant feature in Case 2, in which the father was coached to give a mentalisation

fostering message every single time he resisted his grown-up child's dependent or compulsive behaviours.

A special characteristic of young adults with HF-ASD is their eligibility for a disability allowance (in countries where applicable, including Israel). In our preliminary interviews, we found that in some cases, although the young adult received a disability allowance, this was not utilised for furthering his independent functioning. Instead, the parents took care of all of their grown-up child's financial needs, while the allowance accumulated in the young adult's bank account or was used for his often maladaptive leisure pursuits (e.g. purchasing computer games). In those cases, the therapist guided the parents in the process of transferring some financial obligations to the young adult's responsibility. In all of the cases, the young adults succeeded in assuming more responsibility for those given areas.

Besides the disability pension, adults diagnosed with HF-ASD may be eligible for supported housing. This was directly relevant for one of the families (Case 4), in which the parents kept postponing their grown-up child's move into supported housing. NVR enabled them to overcome their overprotective tendencies and to allow their grown-up child to benefit from the support provided by the state.

The standard NVR intervention is about ten weeks long. The present trial suggested parents of young adults with HF-ASD require a longer intervention, probably up to twenty sessions. This additional time is particularly important due to parents' vast worries for their grown-up child, which made it difficult for them to adapt to the standard pace of the treatment. Addressing the emerging dependence trap earlier (e.g. during adolescence) may require a briefer intervention.

#### Limitations and future directions

The sample in this study is restricted not only in number and in the young adults' gender, but also in its socio-cultural characteristics, as the families were all Jewish-Israeli and upper-middle class. Since parents' socio-economic status has been shown to predict adaptive functioning of adults with ASD (Howlin, 2004), the nature of the dependence trap in families with other socio-economic levels, and in other cultures, requires further examination.

The improvements reported by the parents may also be explained in other, perhaps more simple ways. For example, they might be due to the fact that the therapy helped the parents present a united front in areas where they had previously been divided. Such an interpretation is supported by Case 3, where the fact that such a unity was not achieved proved detrimental to the treatment process. Helping parents coordinate their attitudes is an explicit goal of NVR, particularly when focusing on accommodation reduction (Lebowitz *et al.*, 2013). Yet, the exploratory nature of this study cannot allow us to dismiss the possibility that reported gains are explained by the simple fact that the parents were in therapy.

In effect, the emphasis on qualitative analysis and the study's inability to dismiss alternative explanations reflect the fact that interventions to help the parents of young adults with HF-ASD are still at an early stage of development. In reporting our preliminary results, we have followed recommendations regarding different stages in the development of an evidence base for a new therapeutic intervention, according to which at the early stage of development the use of case reports and of a qualitative methodology are indicated (Bruce and Sanderson, 2005). This preparatory work should be followed by a controlled trial, with a larger sample and a systematic measurement procedure.

#### **Conclusion**

Our preliminary findings suggested NVR helps in reducing helplessness, accommodation and depression, while improving hopefulness with parents of young adults with HF-ASD. The conceptual significance of the study, however, lies in its systemic presentation and treatment of the dependence trap. We view excessive parental accommodation and the maintenance of sub-optimal functioning in the child as a pattern of interactive moves in an ongoing 'family dance' (Minuchin, 1974) that influences all family members adversely. We do not assume that the trap fulfils any necessary or vital function for the family. In our view, the family gets caught in the trap and has only to gain if it is helped to break free of its rigidified moves. NVR is specifically designed to help family members to do so, by changing parental accommodation in ways that enable both parents and their grown-up child to go beyond their previous rigid limits, thus achieving a potentially better equilibrium.

# Acknowledgements

The authors would like to thank the parents who participated in this study; the clinicians who conducted the intervention at the "Bait Echad"

center for individuals with ASD; and the Harry and Jeanette Weinberg Foundation, Inc. for their support.

#### Note

1 Since all of the young adults in our study were males, we referred to them as *sons* throughout the methods and results sections. The more generic terms *young adult* or *grown-up child* were used in the introduction and in the discussion.

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