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Bridging the gap: SHINE – a Tier 3 service for severely obese children and young people

Kath Sharman, James Nobles

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Article points

1. Tier 3 weight management services for children and young people are very uncommon owing to uncertainty over who has responsibility for funding them and a lack of research into their efficacy.
2. SHINE (Self-Help, Independence, Nutrition and Exercise) is an established Tier 3 service for children with severe and complex obesity in the UK.
3. SHINE follows a stepped care approach to its psychosocial interventions, with participants able to escalate treatment in line with the severity of their condition and in case of earlier treatment failure.

Key words

- Child and adolescent obesity
- Obesity Care Pathway
- Tier 3 weight management service

Authors

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In March 2014, the consultation document *Joined up Clinical Pathways for Obesity* was published, exploring options for the future commissioning responsibilities of Tier 3 and 4 weight management services. What became apparent was the lack of reference to childhood weight management services (more so at Tier 3), which mirrors the scarcity of evidence-based research in this area. This article asks a number of key questions: who should provide Tier 3 services for children and young people (CYP), what does such a service look like and who should fund these services for CYP? Greater commitment is needed from the Department of Health to provide clarity for Tier 3 service providers. SHINE (Self-Help, Independence, Nutrition and Exercise), an established Tier 3 service for CYP with severe obesity, is an example of what a Tier 3 programme can look like. Finally, it is proposed that funding is better distributed across the Obesity Care Pathway to ensure that CYP with severe obesity can access appropriate treatment.

Within the UK, a four-tiered approach is adopted to tackle the childhood overweight and obesity epidemic: the Obesity Care Pathway (Department of Health, 2013). As the severity of obesity increases, a higher tier of intervention is required and advocated, both in children and young people (CYP) and in adults (Figure 1). The majority of weight management services for CYP in the UK are delivered at the Tier 2 level. Such programmes have the aim of stabilising and reducing participants' weight through lifestyle modification, dietary improvement, reduction in sedentary behaviour and increases in physical activity (NICE, 2013). Service provision at the Tier 3 level, however, involves the management of more complex cases (e.g. higher degrees of obesity and obesity with associated comorbidities or psychosocial difficulties), which may require a variety of interventions to be delivered by specialist

multidisciplinary teams (MDTs) composed of dietitians, psychologists, nurses and paediatricians, for example. SHINE (Self-Help, Independence, Nutrition and Exercise) is a not-for-profit, community-based service which has provided Tier 3 weight management services for CYP across Sheffield since 2003. This article gives an example model for service delivery using a stepped care approach. A complete programme description, using the Template for Intervention Description and Replication (TIDieR) framework of Hoffmann et al (2014), is to be reported in a due paper (Nobles et al, unpublished).

An estimated 2.9% of girls and 3.9% of boys (age, 10–11 years) have severe obesity (BMI $\geq 99.6^{\text{th}}$ centile) in the UK (Ells et al, 2015). Data on the prevalence of severe obesity are not available in the UK for adolescents. CYP with severe obesity are at greater risk of comorbidities such as cardiovascular disease, type 2 diabetes, sleep apnoea and fatty liver

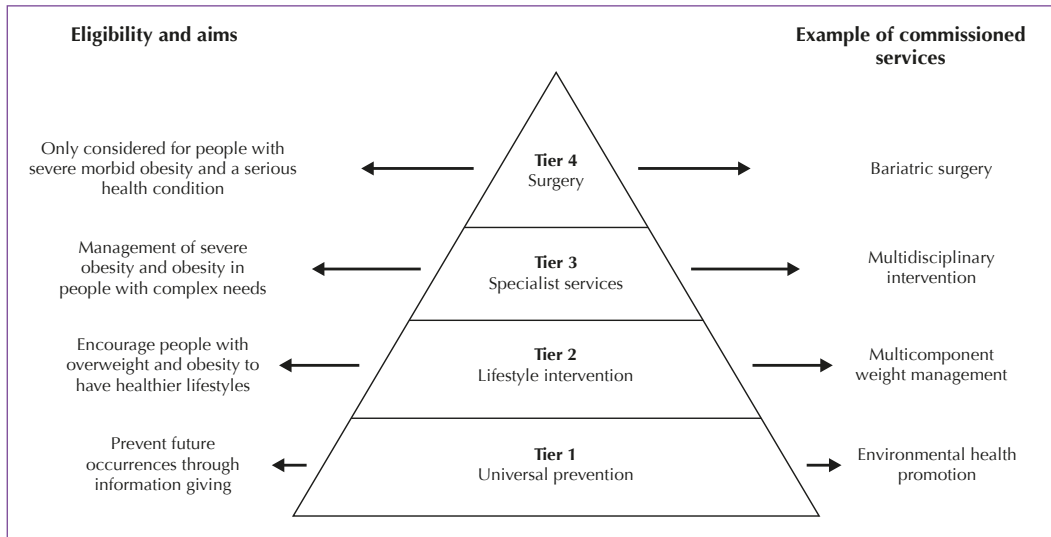


Figure 1. The UK Obesity Care Pathway (Department of Health, 2013).

disease, but they are also deemed eligible for Tier 3 intervention. Despite a growing demand for Tier 3 services for CYP, there is currently a lack of direction and guidance on a number of issues: who should provide Tier 3 services, what should Tier 3 services look like and who should be responsible for funding these services.

Who should provide Tier 3 services for CYP?

The question of who is responsible, or best positioned, to deliver Tier 3 services for CYP in the UK remains unanswered. More poignantly, there is a fundamental lack of service provision at Tier 3, which is mirrored by the paucity of research. Where should CYP with severe obesity (possibly with associated comorbidities) go if Tier 3 services are not available? Should they attend Tier 2 services, such as MEND (Mind, Exercise, Nutrition, Do it; Sacher et al, 2010), GOALS (Getting Our Active Lifestyles Started; Watson et al, 2015), or Families for Health (Robertson et al, 2008), which are not specifically designed for CYP with severe obesity, or do they miss out on weight management services altogether? And would a community-based programme or a clinically based one be best suited for CYP with severe obesity and/or complex needs?

When Tier 3 services are provided, they are often administered in a clinical setting, predominantly within hospitals and specialist obesity units (e.g. the Rotherham Institute for Obesity). These clinical

services are mainly delivered by an MDT over a non-specified amount of time and at differing doses/intensities (Royal College of Surgeons England and British Obesity and Metabolic Surgery Society, 2014). The provision of such services varies among Local Authorities, resulting in some areas with and others without Tier 3 provision. The efficacy of these services is not well documented. Similar clinical programmes (clinic-based and using a MDT) exist in the US, which could help provide information on potential programme outcomes. A Cochrane meta-analysis of 54 childhood weight management programmes (30 in the US, two in the UK and 22 based elsewhere) reported a pooled reduction of 0.14 BMI standard deviation score (SDS) units after 6 and 12 months (Oude Luttikhuis et al, 2009). Additionally, in their systematic review, Mühlhig et al (2014) reported decreases of 0.05–0.39 BMI SDS units in clinical weight management services after 1 year of treatment.

A review by Upton et al (2014) exemplified the deficiency in Tier 3 provision for CYP in the UK: whilst none of the 10 programmes reviewed explicitly stated the level of service as per the Obesity Care Pathway, only three programmes were for CYP specifically with obesity (rather than overweight in general). Furthermore, none of the programmes targeted CYP with severe obesity and all were delivered in a community setting. Changes in BMI SDS ranged from +0.06 (Fraser et al, 2012) to –0.18 (Robertson et al, 2008) at post-intervention follow-

Page points

1. Despite a growing demand for Tier 3 services for children and young people (CYP), there is a lack of direction on who should provide such services, what the services should look like and who is responsible for funding them.
2. Currently, CYP with severe or complex obesity are typically referred to Tier 2 services, which are not specifically designed to manage this patient group, or miss out on treatment altogether.
3. The provision of Tier 3 services differs between Local Authorities, resulting in inconsistent coverage across the country.

Page points

1. SHINE (Self-Help, Independence, Nutrition and Exercise) offers an example of a community-based Tier 3 service for CYP with severe and complex obesity.
2. Participants can self-refer to the service or they can be referred by professionals, with the latter option becoming increasingly common as obesity has become viewed as a form of neglect.
3. All participants are given a 1.5-hour assessment before enrolling, in order to assess the psychosocial causes of their obesity and to develop an individualised care plan.
4. SHINE offers a stepped care approach whereby treatment is intensified according to the severity of the condition and in case earlier, less intensive therapy fails.

up. These findings do not answer the question, however, of who should provide Tier 3 services. As demonstrated, weight management services are provided in the UK – many at the community level – but evidence for the efficacy of specialist provision at Tier 3 is absent. To the extent of our knowledge, the outcomes of clinical or community-based Tier 3 programmes for CYP have not been reported.

What could a Tier 3 service for CYP look like?

Due to the paucity of Tier 3 service delivery in the UK, it is challenging to understand how a Tier 3 programme may differ from a Tier 2 programme. SHINE offers an example of what a Tier 3 service might look like. It is a community-based weight management programme for CYP (age, 10–17 years) with severe obesity. Delivery is based on a psychosocial intervention model using a stepped care approach. A more in-depth discussion of the psychosocial intervention model and the stepped care approach will be provided in a later issue of this Journal (Sharman and Nobles, 2016).

Referrals

Referrals to SHINE include CYP with complex needs (BMI/waist circumference $\geq 99.6^{\text{th}}$ centile, with or without comorbidities). CYP with complex needs also include those with ancillary psychosocial issues, including self-harm, bereavement, bullying, binge eating disorder, child sexual exploitation, depression and anxiety (Girardi et al, 2013). Psychosocial issues have previously been shown to underlie or exacerbate obesity (Nieman and LeBlanc, 2012). It is acknowledged that CYP with such complex needs are commonly referred to Tier 2 services, but practitioners delivering at this level may not have the necessary qualifications, skills or experience to address these needs.

SHINE accepts self-referrals from CYP and their families, as well as referrals from professionals (school nurses, GPs, learning mentors, social services and safeguarding, and learning disability units). In the past year (2014–2015), the proportion of professional referrals has increased from 46% to 83%. This may be a result of the recent classification of obesity as a form of neglect in safeguarding policies (Allen and Fost, 2012), or an increased awareness and acceptance of the complex needs of these CYP.

Initial assessment

SHINE provides an initial assessment of 1.5 hours for all CYP entering the programme, conducted by a nurse or therapist. SHINE's approach differs from the conventional 10-minute GP consultation appointments, in which it is difficult to address this emotive subject whilst discussing practical strategies and solutions. In the past, GP consultations have left parents feeling challenged, judged and blamed (Parry et al, 2010). The long duration of SHINE's assessment is considered essential in establishing a trusting relationship to enable families to discuss weight issues and any barriers or resistance to change. Perhaps most importantly, the families (including the CYP) are informed of the severity of obesity in an empathic and understanding manner, empowering them to embark on an agreed weight management pathway to improve future health. This is achieved by offering a diverse range of interventions utilising a stepped care approach (*Figure 2*).

A stepped care approach signposts and transitions individuals to more intensive treatments if prior, less intensive treatments fail to meet their outcomes (Carels et al, 2005). They are seldom utilised in childhood weight management services. In various stepped care models, self-help behavioural approaches are recommended as a low-intensity treatment for initial weight loss efforts, prior to stepping up to greater-intensity treatment (Carels et al, 2005; 2012). Despite the success that many individuals experience after being stepped up to more intensive treatments, some continue to struggle with weight loss. According to Carels et al (2008), there is insufficient evidence to predict which participants will benefit from what intensity of intervention prior to treatment. They advocate that participants should also be provided with the opportunity to partake in a wide variety of interventions during a weight management programme. As such, at SHINE, participants can step up and down the pathway dependent on their needs. Whilst generally more costly, the initial assessment ensures that the family receives a comprehensive care plan that matches the complexity of the CYP's condition, and is thought to be partly responsible for our high retention rates: 95.1% remain enrolled at week 12.

Interventions offered by SHINE

SHINE offers a three-phase psychosocial intervention

programme as follows:

- Phase One – Assessment: signposting using a stepped care approach.
- Phase Two – Stabilisation: prevention of deterioration of the condition; intervention.
- Phase Three – Maintenance: sustaining change.

Phase One is the initial assessment previously described; Phase Two comprises a 12-week programme which addresses psychosocial issues; and Phase Three is a range of maintenance interventions. Additional services can also be accessed throughout the programme. This section will describe Phases Two and Three of the psychosocial intervention and contrast service delivery to Tier 2 programmes.

Of CYP who attend the initial assessment, 95% enrol in the 12-week psychosocial intervention.

This includes one induction session, five nutritional sessions, five psychosocial sessions and one final consolidation/awards ceremony session, with one session delivered per week. In contrast to Tier 2 services, the SHINE intervention pays significant attention to issues that may contribute to obesity or prevent weight loss: managing satiety, emotional eating, stress management, building self-esteem and relapse prevention planning. In contrast, Tier 2 programmes predominantly focus on modifying diet, increasing physical activity and reducing sedentary behaviours (NICE, 2013).

On completion of the 12-week psychosocial intervention, the CYP attend a one-to-one session to review their care pathway. They may choose to leave SHINE or to enrol in the maintenance programme (Phase Three). Three core maintenance interventions

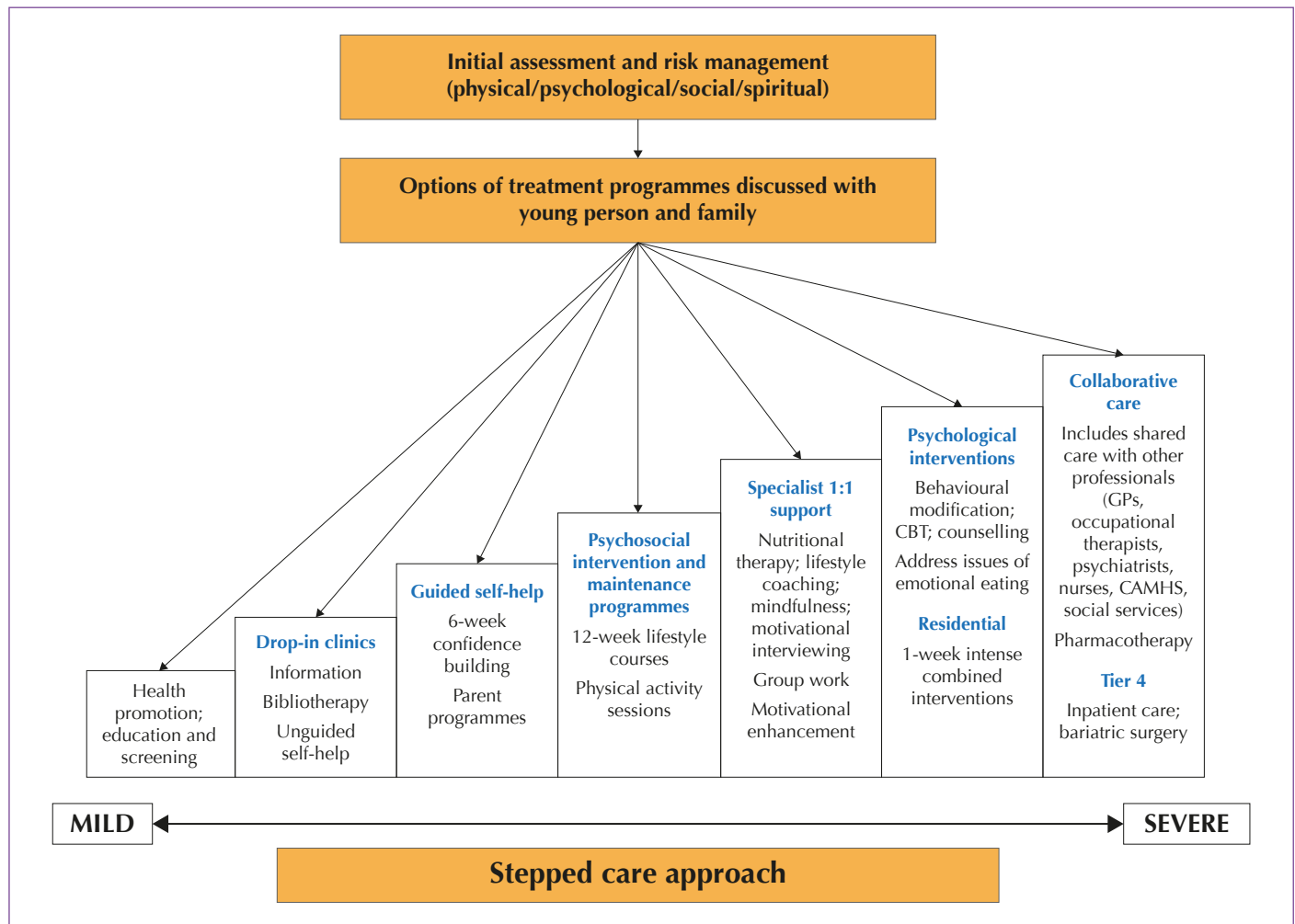


Figure 2. Interventions provided by SHINE in a stepped care approach. Intensity increases dependent on the severity of obesity. Text in blue indicates services provided by SHINE.

CAMHS=child and adolescent mental health services; CBT=cognitive behavioural therapy; SHINE=Self-Help, Independence, Nutrition and Exercise.

Page points

1. Key to SHINE is its non-didactic style, in which education and support are given but participants and their families are not directly instructed to make any changes to their behaviour or comply with the intervention.
2. In addition to its core intervention, SHINE offers ancillary services such as a confidence-building preparatory course and one-to-one therapeutic sessions.
3. The programme is also closely linked to other specialist services, including an endocrinology unit and mental health services, with information sharing between all when required.
4. The management of safeguarding issues is perhaps the most underestimated component of Tier 3 services in relation to expertise, time and cost.

are provided within this phase: sport and leisure, healthy lifestyle behaviours and social relationships. Each intervention spans 12 weeks, and individuals are encouraged to attend all three maintenance interventions. Families have a one-to-one care pathway review after completing each intervention.

SHINE is delivered in a non-didactic manner, meaning that the participants and families are empowered to make decisions for themselves. As such, SHINE acts as a platform to dispense knowledge and support to the families rather than directly instructing on what behaviours to do or not to do. Compliance with the intervention guidance is not forced; families are given the choice to make decisions without judgement. SHINE is delivered during term time (January to March, April to July and September to December), and completion of the four interventions of Phases Two and Three provides continuous support for 15 months. SHINE recognises that obesity is a chronic condition that requires prolonged support and guidance (Bray, 2003).

SHINE also offers other services under the stepped care approach. These services are ancillary to the four core interventions and include one-to-one drop-in clinics, 6-week confidence-building preparatory courses, a residential intervention and one-to-one therapy sessions (e.g. nutrition or behavioural therapy). A variety of one-to-one therapeutic sessions may be offered to CYP who have struggled in the core interventions. Six to eight counselling sessions can be provided depending on need, including person-centred therapy, behaviour modification, cognitive behavioural therapy, motivational interviewing, anger management, mindfulness, and art and creative therapy. In these sessions, individuals can explore underlying issues which may be hindering weight management. Throughout the programme, 7 hours of physical activity (fun and inclusive activities) are offered per week. Attendance at physical activity sessions is encouraged but not mandatory.

Tier 3 provision is much more extensive in duration and intensity than Tier 2 provision and, additionally, it accounts for and confronts underlying psychosocial issues. The benefits and limitations of Tier 3 provision will be explored in a later paper (Sharman and Nobles, 2016).

Multi-agency collaboration

Many young people who attend SHINE are also

linked with other specialist services, such as learning disability units, child and adolescent mental health services (CAMHS), multi-agency support teams and social services. As a result, a large proportion of children who attend SHINE are on care plans which include obesity management. This requires the sharing of information between providers through confidential report writing and attendance at multi-agency meetings and case conferences. The management of safeguarding issues is perhaps the most underestimated component of Tier 3 services in relation to expertise, time and cost. The absence of professional guidance (e.g. NICE guidelines) on how to manage referrals on care plans adds to the complexity of Tier 3 provision.

SHINE has a strong link with the Endocrinology Unit at Sheffield Children's Hospital, who provide access to Tier 4 services for CYP. Treatment at this level may include anti-obesity medication (e.g. orlistat) and bariatric surgery. SHINE's integrative and comprehensive care pathway offers a seamless transfer between levels of the Obesity Care Pathway. In the absence of SHINE's stepped care approach, CYP would frequently experience fragmented care and long waiting times for referral to ancillary services (e.g. CAMHS, Tier 4 services). These challenges are difficult for families and healthcare professionals alike.

Results of the programme

Between September 2011 and May 2013, SHINE helped 304 young people and their families. Overall, 91% of these reduced or maintained their BMI SDS after 3 months, with a mean reduction of 0.21 SDS units (95% confidence interval, 0.19–0.24). What's more, 24.6% improved their weight classification over this 3-month period (e.g. downgraded to obese rather than severely obese). A service evaluation including results at 12 months is due for publication (Nobles et al, unpublished).

Who should fund Tier 3 services?

The *Joined Up Clinical Pathways for Obesity* consultation document (NHS England and Public Health England Working Group, 2014) set out to establish who should fund the various tiers of the Obesity Care Pathway: NHS England, Clinical Commissioning Groups (CCGs) or Local Authorities. It was concluded that the provision of Tier 3 services

for adults would be placed within the funding remit of the CCGs; however, funding responsibility for Tier 3 services for CYP was not specified. The Tri-borough district of London has independently stated that Tier 3 provision for CYP is funded by the CCGs, with Tiers 1 and 2 funded by Local Authorities (Tri-borough Public Health, 2014a). Tiers 1 and 2 are provided in this district (Tri-borough Public Health, 2014b); however, there is no evidence of Tier 3 service delivery. The Tri-borough district was used here as an example only and may not reflect service provision generally. There is consensus that Tiers 1 and 2 for CYP should be funded by Local Authorities in the UK, but consensus has not yet been reached for Tier 3. Lack of funding and lack of provision may contribute to the slow development of Tier 3 services.

Conclusion

Obesity is a chronic relapsing condition which requires long-term treatment (Bray, 2003). When CYP present with severe obesity, they have often endured years of unhealthy habits that become entrenched within their lifestyle. Consequently, long-term services are required to start unravelling the complex issues that may have led to weight gain and obesity. As with anorexia nervosa and other psychological eating disorders, programme commissioners need to understand that recovery from obesity is a long and challenging process.

Despite the fact that CYP with severe obesity present with complex needs, positive change is achievable through the provision of various interventions moulded to meet the individual needs of each participant. An integrative care pathway can be costly and requires commitment from the Department of Health to provide clearer structures and frameworks, alongside ring-fenced funding across the Obesity Care Pathway. Without sufficient guidance and funding, CYP with severe obesity and complex needs will continue to fall between the gaps in service provision. ■

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