GK Research

Social & Market Research

Research report, January 2013:

Practical and process issues in the provision of lifestyle weight management services for children and young people

Report for:

The Centre for Public Health Excellence (CPHE) at the National Institute for Health and Clinical Excellence (NICE)

Report by:

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Background

The Centre for Public Health Excellence (CPHE) at the National Institute for Health and Clinical Excellence (NICE) is developing draft programme guidance on '*Managing overweight and obesity among children and young people: lifestyle weight management services'*. The key audiences for this guidance are: commissioners of weight management services; health professionals referring children and young people to such services; and the providers of weight management services.

The draft guidance is being developed by a multi-disciplinary Programme Development Group (PDG), and will make recommendations for practice based on the best available evidence of effectiveness and cost effectiveness. However the PDG is aware that there are various practical and process issues which are unlikely to be captured by reviews of evidence. For this reason NICE sought out information, using a three pronged approach:

- NICE wrote to all the service providers they were aware of, with a list of relevant questions
- NICE wrote to all registered stakeholders, asking them to forward the questions on to any relevant contacts
- An invitation to participate in the information gathering exercise was posted on the NICE website

The questions addressed 10 broad themes, namely:

1. Description of service outline
2. Information about attendees
3. Barriers and facilitators around working with commissioners of tier 2 services
4. Referral management
5. Non-attendance and drop out
6. Staff
7. Peer support
8. Ongoing support (post completion of main programme)
9. Use of incentives
10. Working with disadvantaged groups

The full request for information, including the detailed questions, can be found in appendix 5. The request was sent to stakeholders in the week commencing October 22, 2012, with the deadline for responses set at November 19, 2012.

A total of 21 responses were received, though six of these were judged to be "out of scope", with the remaining 15 being "in scope". Amongst these 15, two contained information about both "in scope" and "out of scope" services and only the former information was included in our analysis.

The main reasons for services being considered "out of scope" were that the information described a tier 3 service rather than a tier 2 service, or that the services described were either universal for all children, or had entry criteria based on parents being overweight/obese. Also excluded were programmes aimed primarily at *prevention* of obesity, and programmes focusing only on diet.

The data from these free text responses was recorded in a spreadsheet, and providers were then asked to review their own data, providing clarification and amendment where necessary. Draft spreadsheets were sent to each contributor by December 3, 2012, and returned with revisions, by December 10, 2012.

This report has been written on the basis of data in this revised spreadsheet.

Please note that this report is based on what might be best described as a small convenience sample. Consequently the reader should exercise caution in relation to the generalisability of the findings to the wider population of providers. For this reason specific percentages are generally not provided, and instead indicated very approximate proportions. Where specific numbers of responses mentioning particular opinions, policies and experiences, are provided these are intended to give very broad indications of the pattern of response, and not to encourage the calculation of specific percentage responses.

Question 1: Service outline

Please give a brief outline of your service e.g. frequency of sessions, settings, age groups covered, size of groups, type of programme and duration, referral criteria, measurement of height and weight. What components of the service do you consider to be essential and why?

Programme content

The majority of services reported that their programme featured a multi-component approach, covering issues such as parenting skills, behaviour change techniques, diet/nutrition advice and physical activity. Some programmes incorporated physical activity in the main session (sometimes children only, sometimes parents with children), and others had supplementary sessions focused specifically on physical activity. A number of providers explicitly stated that psycho-social factors, such as the raising of self-esteem, were key components of the programme.

Only two providers said that they did not have any physical activity element in their programme, though participants were given advice and encouragement to do physical activity.

Groups and one-to-one approaches

The majority of providers delivered their programmes through group work. Only one provider did no group work, using only one-to-one sessions, featuring motivational appointments. A number of those operating mainly through group work specified that they also offered one-to-one programmes, and these seemed to be targeted at families with more complex needs, such as the presence of learning difficulties[1] or behavioural problems.

Group size varied, and one provider suggested that the optimal size is calculated by balancing financial considerations with the need to have a cohesive group of participants. The presence of "high demand" individuals in the group is another consideration, with one provider stating that group size is reduced when including individuals with additional needs (e.g. behavioural issues or learning difficulties).

The most common responses on group size were in the range of 8-12 families (or child + parent/carer) per group, though a small number would include as many as 15-20, and a small number would run groups with as few as two or four families.

One provider was a clear outlier, reporting an average group membership of 50 individuals, although it would be unlikely that all were present at each individual session. This was a commercial sector provider, catering mainly for adults, with young people allowed to attend with an accompanying adult.

There was no clear relationship between the age of the child and the size of the group.

[1] Providers used both the terms "learning difficulties" and "learning disabilities". These terms have specific meanings, but it is possible that not everybody understands the difference, and in practice they are often used interchangeably by non-specialist practitioners. In this report the term "learning difficulty" is used as this was more commonly used by the contributing providers.

Target age group
All bar one of the programmes were aimed at specific age groups, though there was considerable variation in the specific age bands used. There were a cluster of programmes aimed at 5-11 years, though some providers broke this category down into 4-7 years, and 8-11 years. Another fairly common age band was 7-13 years. Only three providers had specific provision for pre-school age, one of which was a specialist under fives service.

Programmes aimed at teenagers/older children were very common, though there was considerable variation in the age definition, e.g. 12-15 years, through to 12-19+ years.

Note that age was often not specified on programmes provided for young people with learning difficulties.

Only one provider operated a service primarily aimed at adults, with children aged 11+ years welcomed as long as they attended with an adult.

Duration and frequency
The duration of the main programme varied, with eight weeks being the minimum, and the majority being in the range 8-12 weeks. Two programmes lasted significantly longer, with durations of 16 weeks and 24 weeks. Note that the 24 weeks programme consisted of one-to-one motivational appointments.

One provider offered an open-ended service, all year round, with no fixed starting or finishing dates.

Most services operated on a weekly basis, some with two sessions per week (one of which might be optional, and often focused on physical activity). Only one of the contributors operated a less frequent service, featuring monthly motivational appointments.

Settings
The majority of programmes were delivered in community venues, such as community centres and leisure centres, with children's centres also used for the younger age groups. Delivery in educational settings was rare, and associated mainly with programmes aimed at young people with learning difficulties (including training of teachers in special schools to deliver elements of the programme), or targeted work with black and minority ethnic groups. One provider reported that school-based interventions suffer from increased drop-out, because of participants being bullied by others in the school.

Measurement
All of those responding to the request for information about measurement stated that individuals were measured, with height and weight (and implicitly Body Mass Index [BMI]) most typically measured. Most specified that measurements were taken at the start and end of the programme, with around half of these adding that further measurement was attempted at later follow-up/maintenance sessions (e.g. after six months, 12 months).

In addition to the measurements mentioned above, other factors were measured by small numbers of the responding providers, sometimes using questionnaires, and these included the following:

- Waist circumference
- Psycho-social factors, e.g. self esteem, depression, self perception
- Quality of life
- Step test
- Peak flow
- Family and parenting behaviour
- Physical activity
- Diet

No details were provided about particular tools and questionnaires used in collecting this data.

Essential components of the programme

Providers were asked to specify elements of the programme which they regarded as essential. There was relatively little agreement, with the 11 answering providers (four did not answer this question) generating over 30 different "essential components". A full list can be found in appendix 1, but the components mentioned by two or more contributors are shown below, with the number of mentions shown in brackets:

- Family focus/whole family approach/empowerment of the family (5)
- Highly motivated staff/good interaction between facilitator and group (4)
- Psycho-social factors/emotional well-being (3)
- Peer support within group/group context (3)
- Goal setting/logging progress towards goals (3)
- Tailored advice/age tailored literature (3)
- Physical activity sessions (3)
- Healthy eating/food preparation sessions (3)
- Working with proven behaviour change models (2)
- Developing parenting skills (2)
- Regular attendance/regular contact with the family (2)
- Having practical illustrations to help explain key factors (e.g. how poor choices lead to weight gain (2)

<u>Question 2: Attendees</u>

It would be helpful to know whether young people attend with a parent or carer, the proportion of young people who are overweight (please specify whether 85th percentile or above, or 91st percentile or above) or obese (please specify whether 95th percentile or above or 98th percentile or above). We are also interested in the proportion of boys and girls attending the service. Do you promote your service to boys and young men as well as girls and young women? If so, are you successful and why? Is there a difference in recruitment and retention rates between males and females?

Parental attendance
For those services catering for younger ages, parental/family presence was a condition of participation, with some providers emphasising the importance of the "whole family approach". Services aimed at teenagers varied, with some having parental attendance as optional, and others operating without any parents present.

Threshold for acceptance onto programme
The majority of the programmes run by contributors required participants to be at least at the 91st BMI centile, and most reported that priority was given to those at significantly higher levels.

Only three providers had a lower threshold, one of which was a service targeting those aged 0-5, and used criteria including parental obesity. One service was available for anybody "above healthy weight" (not specified), and the third (commercial) service had no minimum criteria, although reported that, in practice, all participants were above 91st BMI centile, with two thirds at the 98th BMI centile or above.

One provider said they were intending to lower the threshold (below 91st BMI centile) in the future.

Gender of participants
Girls were in the majority for all providers reporting figures on participant gender. However, in the majority of these services, the gender balance was close to 55% female and 45% male, and only three providers had a female proportion greater than 60% (range = 68-75% female).

A clear majority of providers promote their services equally to both girls and boys. (Note that two providers do not promote services directly to children/young people, with one aimed at parents of children aged 0-5, and the commercial provider catering primarily for adults, though children are welcome to participate if accompanied by an adult).

Retention/completion of programme
Providers were asked for information about their retention levels, and in particular about any differences between male and female participants. This turned out to be a difficult question to answer, with a number of providers not answering at all, and others providing information which only partially answered the questions.

The absence of comprehensive responses suggests that this information is not easily available, and is perhaps not collected by some providers. It also raises the question of what is meant by retention/programme completion. Only one provider specified their definition of retention (attendance at 60% of the sessions in the programme), but of course other providers may have been using different definitions. Some programmes include a maintenance phase following the initial programme, and it is not clear whether attendance thresholds need to be met on both of these phases in order to be considered a "completer".

Notwithstanding these issues, the majority did provide some information, and from this data there is considerable variation in the overall level of retention/completion, from

around 53% up to 93%. Such a wide variation may be down to different definitions, quality of programme or may reflect the fact that some population groups are more difficult to work with than others.

Only three providers gave information on retention by gender. One of these reported very similar levels of retention for male and female, with both just over 90%, whilst the other two reported much lower retention among males, with 27% completing in one case, compared to 33% in the other.

Question 3: Barriers and facilitators around working with Commissioners of tier 2 services

From your experience, what are the key barriers / facilitators around working with commissioners of Tier 2, or lifestyle, weight management services for children and young people? i.e. What do you find helpful and what is not so helpful? Please include details of commissioner requirements where possible, for example: payments for achievement of quality improvement goals and if you are involved in setting or negotiating these goals.

Key barriers/unhelpful factors

More than 20 different barriers/unhelpful factors were cited by providers. There was little consensus, with only a few barriers being specified by more than one provider. A full list can be found in appendix 2, but the barriers mentioned by two or more providers are specified below, with the number of mentions shown in brackets:

- Unrealistic key performance indicators, sometimes with financial penalties attached (3)
- Poor engagement from agencies relied upon for referrals (3)
- Budget restraints/lack of investment (2)
- Late budget confirmation/overrun on commissioning timetable, squeezing the time for service planning and implementation (2)
- Commissioning services that were perceived to be lacking a basis in evidence, being unsustainable and "cheap" (2)

One provider contributed a long list of problems experienced in tendering for weight management contracts. In their opinion, those tendering for contracts were facing the following problems:

- inefficient procurement partly driven by the impact of NHS reorganisation
- the failure of World Class Commissioning[2] to benefit commissioning of weight management services
- the tendency for some PCT provider arms to see weight management services as a route to help them achieve financial self-sufficiency
- the failure of CGOU/NOO[3] guidance to better inform procurement
- the inappropriate implementation of the CGOU framework contract
- the commissioning of services that are not evidence-based

[2] World class commissioning is a statement of intent, aimed at delivering outstanding performance in the way health and care services are commissioned in the NHS.

[3] CGOU is the Cross Government Obesity Unit, and NOO is the National Obesity Observatory

- the failure of Commissioners to understand that poorly designed services can be harmful to children and young people, leading to negative outcomes which may incur extra costs for the NHS in the future

Key facilitators/helpful factors

As with the barriers, providers specified around 18 facilitating/helpful factors. Many were mentioned by only one provider, but those mentioned by two or more are listed below, with a full list provided in appendix 3.

- Joint goal setting/jointly shaping the service/negotiating key performance indicators (including proxy measures) with Commissioner (4)
- Regular meetings/good communication/open relationship with Commissioner (2)

Observations on Commissioners requirements

Providers were asked to give any other relevant observations on Commissioner requirements. This produced comments on a diverse range of topics, some of which duplicated comments around barriers and facilitators. The following list of observations excludes such duplications, and excludes highly project-specific details, focusing on observations which may be more widely applicable.

- It takes a significant amount of time to establish an effective data collection system
- It can be difficult to demonstrate value for money, even when producing excellent outcomes
- Commissioners of children's/young people's services often ignore the specific needs of the under fives
- Some commissioners are willing to accept qualitative data amongst performance indicators
- Some commissioners are willing to accept the mix of outcome and process (e.g. attendance) data amongst performance indicators

Question 4: Referral management

Please give a brief description of how your organisation manages referrals. It would be helpful to know where referrals come from, and whether children and young people who have been referred by the NHS, local authority or other organisation receive a different service from those who self-refer or are self funded. Also if there is a difference in the referral process, or referral rates, according to participants' characteristics (e.g. age, or ethnicity).

Source of referral

Almost all providers accepted both self referral and referral from professionals, most typically health professionals in primary care, and schools/children's centre-based professionals. In a few cases there were also mentions of referrals from social workers, adult services, leisure services and other local authority staff. A number of providers also mentioned referrals via the National Child Measurement Programme (NCMP) though it was not clear whether these were self referrals following letters home, or professional referrals triggered by engagement with the NCMP.

Most providers tended to say that the majority of their clients were either mainly referred by professionals, or mainly self referrals. Only two providers said they received equal proportions from these sources.

Tailoring the service according to referral source
There was no evidence that the service delivered varies according to the referral source.

Participant characteristics and referral source
The question asked "whether children and young people who have been referred by the NHS, local authority or other organisation receive a different service from those who self-refer or are self funded", but none of the providers fully answered. Most provided no response on this, and only three provided information that constituted an answer to the question.

One said that families referred by school nurses and health professionals tended to have more complex needs, often requiring a one-to-one service. One provider (specialising in families with children aged 0-5 years) said that children aged 0-2 tended to be identified by the health visitor, and those of school age were more likely to be referred as a result of contact with the NCMP. The third provider said that relevant data was being collected, but was not currently available.

The referral process
Only a few providers described the referral process in any detail. The more comprehensive descriptions tended to emphasise the use of a standard referral form, the availability of a central administrative team to process referrals, the nature of the initial contact with the family and the importance of the first appointment for assessment.

There were examples of minimum standards in responding to referrals (e.g. within 24/48 hours), and one provider described the client management system used to monitor such contact, enabling them to track the progress of enquiries as they passed through the system.

A number of providers mentioned the importance of the initial appointment, at which the family's context, needs and preferences are assessed. The purpose of the first appointment was generally to check that the family met the service entry criteria, to decide whether group or one-to-one work was appropriate (where both were available), and to take baseline measurements. If the service was not appropriate for the family, they would be signposted to other relevant services.

Two providers emphasised the benefits of investing time in engaging with referral agencies. One said that referrers could become "recommending agents" with accompanying resources provided to them. Another described a brief intervention in the form of a three-hour training session that they offer to referring agencies, designed to increase awareness of the service and build confidence amongst the staff in both raising the subject of weight management and making referrals to the service. This brief intervention was regarded as a key aspect of their service, and is included in all of their current contracts.

Question 5: Non-attendance

5a. Please describe your organisation's policy and practice when children and young people fail to attend or drop out of the programme.

5b. What is your experience of monitoring and managing drop-out rates?

5c. Are some children, young people and their families more likely to drop out than others? If so, please explain who is more likely to drop out.

5d. If you have experience of successfully reducing drop-out rates, it would be helpful if you could explain how you did this.

Non-attendance policy

All providers said that individual families were contacted directly as a result of non-attendance, though there was some variation in whether this happened after the first non-attendance, or the second. The purpose of the contact was to find out reasons for non-attendance, with the aim of restoring commitment to the programme. One provider had developed a set script for use in these conversations.

If commitment could not be restored, or if it became clear that that the family faced major barriers in continued participation, providers said that they endeavoured to signpost the family to alternative/more appropriate provision.

Non-attendance policies generally included provision for referral agencies to be informed once it was clear that the family would not continue with the programme.

Experience of monitoring non-attendance and drop out rates

Some providers did not answer this question. Amongst those answering there was a diverse range of responses.

There was some agreement that drop out rates are higher in the early stages of the programme. There needs to be a recognition that families lead busy and complicated lives, and the programme needs to be highly engaging and relevant, in order to be sustainable.

It is important to remember that there are often genuine reasons for non-attendance and drop out, often relating to health and social problems faced by clients, such as illness, low self-esteem and anxiety.

One provider said that having both group and one-to-one services available was helpful, as clients could switch between service models, thereby reducing the risk of them dropping out completely.

A number of providers said that they sought feedback from those dropping out, in order to help inform the development of the service, though it was acknowledged that this is not always easy to obtain from the ex-participants.

Are some young people and families more likely to drop out than others?

Families with complicated/chaotic/dysfunctional lives were most commonly identified as being the most vulnerable to dropping out. Some providers made the connection that these were the kinds of families more likely to be referred by agencies (rather than self referral).

Not surprisingly a number of providers identified those less motivated/less engaged as being more likely to drop out. For pre-teens, providers required a parent/carer to attend with the child, and this increases vulnerability to dropping out, because if one party declined to attend, the other inevitably dropped out.

One provider said that their data showed that participants with higher BMI scores were more likely to drop out. Another provider identified failure to achieve goals as a trigger to dropping out.

It was suggested that any circumstances that resulted in two or three sessions being missed would make participants more vulnerable to dropping out, and these circumstances could include travel problems, bad weather, illness or mental health problems.

One provider said that black and minority ethnic participants were more likely to drop out, and another identified those referred by "authority figures" (e.g. headteachers, social services etc) as being particularly vulnerable to dropping out.

Success in reducing drop out rates

Across all providers there was a varied list of initiatives, mostly cited as successful by just one provider. These can be summarised as follows, with the number of mentions shown in brackets:

- invest in the initial assessment, e.g. a home visit, find out what motivates them (3)
- a phone call or text message prior to the session (2)
- client feedback persuaded the proprietor to reduce the twice a week sessions down to once a week, in order to make attendance more sustainable (1)
- the "personal touch" helps keep people engaged and motivated (1)
- keep in touch with non-attenders, e.g. send material that they missed, use social media to encourage the group to keep in touch, etc (1)
- sessions must be friendly and fun (1)
- use of an exercise based games console significantly improved attendance at the next session (1)
- a Young People's committee provides feedback, to keep the sessions engaging (1)
- passionate session leaders keep people engaged (1)
- the service development plan should include initiatives to reduce drop out (1)
- help with travel (e.g. taxi costs) for those facing transport problems (1)
- allow people to switch to the one-to-one service if they are in danger of dropping out of the group based service (1)

Question 6: Staff experience, characteristics and training

6a. What sort of experience and personal characteristics do you require from staff?
6b. Is there a minimum training standard for staff who work within lifestyle weight management services? Do you offer training or support staff to obtain further training, and if so please describe your experiences of training session leaders and other staff working with children and young people?

Required experience and characteristics
A small number of providers specified that staff must be educated to degree level, or have a specialist qualification in a relevant field, although in some cases this applied only to specific positions, such as Project Managers/Leaders. However the majority of responding providers focused more on personal characteristics and relevant experience when describing their requirements.

Attributes mentioned by more than one provider are shown below, with the number of mentions shown in brackets, and the full list is shown in appendix 4.

- Motivated/enthusiastic/passionate/dynamic (6)
- Communication and listening skills (5)
- Experience in health or health promotion work (4)
- Experience in working with early years/children/families (3)
- The ability to motivate people (2)
- Ability to be a role model (2)
- Educated to degree level for some positions (2)
- Weight management specific experience (2)
- Literacy and numeracy skills (2)

Nine of the 15 providers specified CRB clearance as a requirement.

Minimum training standard
There was a degree of overlap in the way that responding providers interpreted the first question about required experience and characteristics, and the second question about minimum training standards. Therefore this section focuses specifically on training and qualifications not addressed above.

The most common minimum training/qualification required relates to subject specialisms, such as nutrition, physical activity/exercise, health training and weight management, typically at level 2 or 3 (NVQ specified by some, but not by others). Around one in three of our providers mentioned such qualifications, and a similar proportion mentioned the need for physical activity instructors to be on the Register of Exercise Professionals.

Several also mentioned their own internal induction training, which needs to be undertaken by new staff. This could include subjects such as softer skills, practice competencies, facilitating behaviour change, solution focused techniques, session content ideas and record-keeping. One provider's induction programme included training in a number of therapeutic techniques such as Cognitive Behaviour Therapy, motivational interviewing and basic counselling.

At least four providers had their own bespoke "method", and new staff received training in delivery of this method, incorporating a range of different knowledge and skills required to deliver the programme.

Further training provided for staff
All providers said that they provided further, ongoing training for staff, though they did not always specify the nature of this training. Where it was specified there was a significant degree of overlap with the "minimum training" described above.

Among the more common further training provided were sessions on physical activity/exercise, obesity and diabetes, and safeguarding children. A number of providers mentioned their staff mentoring/peer support and supervision policies, referring to the continuous development purpose of these policies.

No other subjects were mentioned by more than two providers, and the list was diverse, including subjects such as disability awareness, healthier food/diet, active play, food hygiene, smoking, Zumba, and conflict resolution. In some cases providers were contracting in bespoke training from weight management specialist organisations.

Question 7: Peer support/mentoring
Please give a brief description of any peer support or mentoring your organisation provides for staff or for users of the service. It would be helpful to know what type of training is offered to peer supporters and what characteristics you look for in peer supporters.

There appears to be some confusion arising from the terminology (e.g. some programme leaders are called "Mentors"), and the group based approach may in itself be seen as a peer support approach without any additional special measures being in place. Similarly, some of what might be considered standard staff liaison, management and supervision might be interpreted as peer support (e.g. staff meetings) and/or mentoring (e.g. advice from a manager or a specialist member of staff such as a Dietitian). The rest of this section focuses on reports with more specific evidence of peer support/mentoring.

Peer support/mentoring for participants
About one in three of the providers supplying information indicating that they operated a significant peer support element to their service. This would typically involve volunteers who may have "graduated" (i.e. previous successful participants). Only limited details of their precise role was provided, but it would appear that this may involve delivering occasional talks, or a buddying approach.

In three cases the provider specified that training was provided (e.g. "Health Champion" or "Health Trainer Champion" training), and one also said that some of the young people were going through Young Leaders Award training.

In only one case did a provider state that the programme leader needs to have successfully completed the programme as a participant.

Peer support/mentoring for staff
Around one in three of the providers gave details which indicated some form of peer support, or more typically mentoring of staff, above and beyond what one might classify as normal supervision and team communication.

Mentoring was sometimes in place specifically for new staff, and not necessarily continued once they had become more experienced. In one arrangement the new employee shadows an experienced member of staff, and then the roles are reversed, with the experienced person shadowing the new employee as they begin to deliver sessions to participants. In another case, the Mentor works with trainees, providing monthly reviews of practice, and annual appraisals. In a third organisation course leaders identified as having particularly strong skills undertake the additional role of Team Developer, to provide extra support and guidance to other course leaders.

A small number of providers had a business model in which they were commissioned by other providers to train programme delivery staff in the commissioning organisation. An element of mentoring may be provided as part of this type of contract.

Question 8: Ongoing support

Do you provide ongoing support and follow up to children and young people and their families? If so, for how long? What is the level of uptake? What do you provide and what are the barriers and facilitators in doing so?

Almost all said that they did provide ongoing support after the completion of the programme. The three exceptions specified reasons for not doing so. In one case provision had been dropped in order to increase capacity on the main programme (i.e. post-course maintenance work has been sacrificed in order to reach more people with the main course). Another provider primarily trained local service delivery people, each of whom had different arrangements for which this provider was not responsible. In the third case provision was continuous, all year round, so the concept of post programme support was not applicable.

The nature of ongoing support

Most of the provision is in the form of periodic progress checks (e.g. 3/6/12 months after programme completion), and/or the continued opportunity to attend weekly activity sessions for the family, or in a few cases specifically for the child.

A number of providers talked about this being the “maintenance” or “consolidation” phase, during which families could get back in contact with the course leader/Mentor if needed.

Several providers mentioned the fact that an “exit plan” would be designed for family, which might involve signposting to clubs and other mainstream physical activity provision. This was sometimes accompanied by a membership card entitling the family to discounted prices on activities.

One provider also mentioned the use of reminder text messages and emails, and another gave families documentation in which they could record their progress, post-programme.

One provider offered an optional 15 month maintenance programme, incorporating the opportunity to achieve a Duke of Edinburgh award.

The provider primarily involved in training local organisations to deliver its programme had a range of different support materials available for those completing the course. This

included a progress log, a magazine, a website for self-directed learning, information about local mainstream services, and locally arranged activity sessions.

Duration of ongoing support
The most common duration was 12 months, fitting in with the tendency to have a final follow-up appointment (with measurement) 12 months after completing the programme. Only two providers reported having ongoing support for longer than 12 months.

A small number of providers offer ongoing support for only 10 or 12 weeks maintenance phase, but in both cases the maintenance phase involved an "exit plan" of some sort, for example containing taster sessions for activities that they would be encouraged to continue in the longer term.

Level of uptake
Half of the responding providers were not able to answer this question, with some specifying that data/evaluation was not available, and others simply left the answer space blank. For three of the remaining providers the question was not applicable (for reasons explained above).

Amongst those able to answer the question the range of responses was very wide, from 25% up to 75%. However it should be noted that simple percentage figures disguise the complexity of defining what is meant by "uptake". Since ongoing support is generally optional, a reliable analysis of uptake level would need to work to a common definition, and this would not be easy to define. For example, an individual may take up ongoing support, but other members of the family group may not. Some may attend their follow-up appointment after 12 months, but may not have taken part in the weekly activity sessions during that period (and vice versa). Any attempt to produce a reliable uptake figure would need to agree this definition, and enforce standard collection of data across the different providers.

Barriers to providing and taking up ongoing support
Only about half of the providers contributed answers to this question, but they came up with a varied list of issues.

The lack of resources (financial and staff capacity) was mentioned by three providers. Another three mentioned that participants tended to lose interest over time, particularly when goals have been achieved and the main programme had finished. Two providers emphasised the difficulty and expense of maintaining contact, with participants moving address and children moving school.

Other reasons included parents not engaging fully; loss of continuity due to not having access to the same venue once the programme had finished; teenagers having lots of commitments, including examinations; reliance on mainstream services providing suitable activities for people to move onto.

Facilitators to providing and taking up ongoing support
Only four providers put forward facilitating factors. These were specified as the relationship with the programme leader, who was able to encourage ongoing participation; the gathering of contact information that allowed participants to be alerted when new sessions were beginning; a good relationship with the local leisure services department, one of which was said to have a health improvement team; the provision of themed follow up sessions (e.g. Christmas, Halloween etc) was said to greatly increase uptake; provision for families on low income to have continuing activities after the programme finishes.

Question 9: Incentives and rewards

It would be helpful if you could tell us about your experience of providing incentives or rewards to participants, for example for attendance or achievement. Do they differ between NHS or local authority referrals and other participants? Do you have any reports or other written evaluations that indicate the success or otherwise of incentives?

No providers used incentives in the form of cash (or "near cash"), but rewards were very commonly used across all providers. Some gave participants resources (e.g. "goody bags"), either at the start of the programme, or on completion. These contained practical tools to encourage healthy behaviours, and to some extent were regarded as incentives/rewards.

The nature of rewards
Most said that they gave out low-level rewards when goals were achieved. These were often in the form of resources which encouraged healthy behaviour (e.g. skipping ropes, free swimming vouchers, water bottles etc). Public praise for the achievement of goals was also commonly used, sometimes accompanied by giving stickers to children in recognition of their achievements.

Several providers reported that they held fun sessions and celebrations at specified times in the programme, most typically in the form of a graduation/course completion celebration.

A number of providers also had higher value prizes for high achievers, such as the person with the best attendance record.

One provider said that rewards also have a value in their ability to demonstrate to parents how healthy rewards can be used with children.

Two providers raised potential concerns about the way that incentives/rewards are managed. One cautioned that building expectations of rewards among the children could put undue pressure on parents. Another provider emphasised the need to be aware of the potential harm that could be caused if young people were excessively incentivised, possibly causing them to achieve targets with unhealthy methods (e.g. weight loss targets).

Variation in incentives/rewards policy according to referral source
All of the responding providers said that the way they managed incentives and rewards was consistent, and not influenced by the referral source.

Evaluation of incentives/rewards
None of the providers have completed evaluations.

Question 10: Working with disadvantaged groups
What is your organisation's experience of working with disadvantaged groups within the community e.g. looked after children, children and young people with learning difficulties, or from black and minority ethnic groups or lower socio--economic groups? How do you reach these groups and provide appropriate services?

A number the providers pointed out that there is a strong link between obesity and deprivation, and this will inevitably mean that those working in this field will regularly engage with disadvantaged groups.

About one in three providers specifically mentioned engagement with young people with learning difficulties. Most commonly they were pointing out that those with mild and moderate learning difficulties[4] were accommodated in their mainstream programme delivery, with one mentioning that their staff received specific training on the subject of learning difficulty. However one provider stated that, in their experience, people with learning difficulties may struggle within a mainstream group programme.

A small number of providers also made specific reference to young people with behavioural problems, and their experience led them to believe that this was a difficult group to accommodate in mainstream provision, with one particularly citing the lack of support from parents in such cases.

The following responses were mentioned by just one or two of those answering this question: "we have a lot of experience with disadvantaged groups"; people with physical disabilities are accommodated in mainstream provision; Looked After Children are accommodated in mainstream provision; programme content is designed to be relevant to different cultures (e.g. diet information).

Reaching disadvantaged groups and tailoring services appropriately
This question elicited a range of responses that could be grouped into a number of broad themes, reflecting the variety of approaches, and the diversity within the population categorised as "disadvantaged groups".

One of the most prominent themes was around the need to have accessible/convenient sessions (venues and times), located in the relevant neighbourhoods, because access to transport can be a major barrier. One provider mentioned locating and scheduling sessions in order to fit in with mosque attendance, and providing sessions on school premises to encourage mothers to attend, with the school allowing participating children out of lessons, and providing volunteers to interpret.

[4] Providers used both the terms "learning difficulties" and "learning difficulties". These terms have specific meanings, but it is possible that not everybody understands the difference, and in practice they are often used interchangeably by non-specialist practitioners. In this report the term "learning difficulty" is used as this was more commonly used by the contributing providers.

There was also a grouping of responses around the theme of working with a range of partners who had existing contacts with disadvantaged groups. This might be social workers, health improvement teams, or local community groups etc. One provider emphasised the success they had from offering a brief intervention to partner organisations, developing confidence amongst staff in talking to clients about weight management, and raising awareness of the service and referral methods.

A number of providers said that they had a specific programme available for young people with learning difficulties, and two said that they reduced the size of the mainstream group if it contained young people with learning difficulties. One provider had trained teachers in special schools so that they could deliver elements of the programme. Another used volunteers to provide extra support in sessions for those with learning difficulties.

Other methods, mentioned by only one or two providers, included the following:

- the adaptation of programme materials to be more relevant to specific groups, e.g. dietary information and dress code for black and minority ethnic communities, materials adapted specifically those with learning difficulties, and alternative formats for visually impaired participants
- having access to language and signing support staff
- using trusted and prominent local people to act as advocates for the service, e.g. Community Champions, faith leaders etc
- provision of vouchers, e.g. Change for Life
- having advertising/flyers in appropriate locations, e.g. GP clinics in deprived neighbourhoods
- offering free or low-cost services
- recruiting and training black and minority ethnic staff, to work on programmes delivered in areas with black and minority ethnic populations
- identifying financial help for those for whom money is a barrier to participation, e.g. transport costs
- running a disability club for those who cannot be accommodated in mainstream provision
- developing bespoke programmes for individuals and families with complex needs (this suggestion came from those with 1:1 provision)

Appendix 1
Full list of "essential components" specified at question 1.

- Family focus/whole family approach/empowerment of the family (5)
- Highly motivated staff/good interaction between facilitator and group (4)
- Psycho-social factors/emotional well-being (3)
- Peer support within group/group context (3)
- Goal setting/logging progress towards goals (3)
- Tailored advice/age tailored literature (3)
- Physical activity sessions (3)
- Healthy eating/food preparation sessions (3)
- Working with proven behaviour change models (2)
- Developing parenting skills (2)
- Regular attendance/regular contact with the family (2)
- Having practical illustrations (e.g. with props) to illustrate key factors (e.g. how poor choices lead to weight gain (2)
- Parent/child interaction (1)
- A 12 week programme with an additional maintenance phase (1)
- Understanding/explaining the concept of energy balance (1)
- Focus on behaviour change, not weight loss (1)
- Reducing energy dense foods, rather than calorie counting (1)
- Integrated data collection (1)
- The young person making their own choices (1)
- Having staff with suitable qualifications/experience (1)
- Regular praise (1)
- Early intervention (1)
- Having a range of services with higher order services available to those who have not succeeded on previous interventions
- The trainer/consultant should have achieved on the programme themselves
- Easily accessible venues, at convenient times
- Having home visits, in order to fully engage with the family
- Providing services free of charge or low-cost
- Community development and adequate time for recruitment
- BMI growth charts to explain changes

Appendix 2
Full list of perceived key barriers specified at question 3

- Unrealistic key performance indicators, sometimes with financial penalties attached (3)
- Poor engagement from agencies relied upon for referrals (3)
- Budget restraints/lack of investment (2)
- Late budget confirmation/overrun on commissioning timetable, squeezing the time for service planning and implantation (2)
- Commissioning cheap/non-sustainable/non-evidence-based services which may be harmful to young people (2)
- Uncertainty about how the service will be valued after it is transferred from the PCT (1)
- The person specification for the coordinator role is too vague (1)
- BMI criteria for acceptance is too narrow, and many enquiries have to be refused because children are below the minimum threshold (1)
- Commissioners are only interested in children only/young people only services, and this provider does not provide such services (1)
- Being a small part of a large block contract makes it difficult to get focus on service improvements and investment, and it would be better to have payment by results (1)
- Difficulty of balancing demand and affordable capacity (1)
- Commissioner is focused solely on delivery through groups (1)
- The presence of normal weight siblings within groups distorts weight measurement figures (1)
- inefficient procurement partly driven by the impact of NHS reorganisation (1)
- the failure of World Class Commissioning to benefit commissioning of weight management services (1)
- the tendency for some PCT provider arms to see weight management services as a route to help them achieve financial self-sufficiency (1)
- the failure of CGOU/NOO guidance to better inform procurement (1)
- the inappropriate implementation of the CGOU framework contract (1)
- the commissioning of services that are not evidence-based (1)
- the failure of Commissioners to understand that poorly designed services can be harmful to children and young people, leading to negative outcomes which may incur extra costs for the NHS in the future (1)

Some responses to this question addressed barriers which were not specific to Commissioners, and these included the following:

- Parents can be unwilling to acknowledge the child has a weight problem (2)
- The letter received by parents from the National Child Measurement Programme sometimes perceived to be inappropriately phrased, thus creating negativity among parents (1)
- The lack of an up-to-date needs assessment

Appendix 3
Full list of perceived key facilitating factors specified at question 3.

- Joint goal setting/joint shaping/negotiating KPIs (including proxy measures) with Commissioner (4)
- Regular meetings/good communication/open relationship with Commissioner (2)
- Having a knowledgeable Commissioner, prepared to share information (1)
- Having a commissioner who understands the complexity of the service (1)
- Having a commissioner who supports the service (1)
- Coordinated/complimentary service delivery by weight management staff and school nurses/nursery nurses (1)
- Not having payment by results (1)
- Having an evidence-based programme (1)
- Focusing on achieving the essential elements of the National Obesity Observatory's Standard Evaluation Framework (1)
- Having a flexible programme that can be adapted around the needs of the families (1)
- Having a health improvement team based in leisure services (1)
- Having (non-public sector) Commissioners who understand the importance of psycho-social factors (1)
- Having the opportunity to speak to parents

Providers made a number of suggestions for helpful factors that they would like to see in future.

- Light touch commissioning, only using the full tendering process where necessary (1)
- The collection of benchmark data for attendance and completion, across tier 2 services, in order to enable Commissioners to make more realistic judgements on achievable targets (1)
- Reverse some of the structural changes to the NHS, if possible without further damaging morale (1)
- Having better budget and procurement process advice for Commissioners, e.g. how to engage with bidders, disclosure of the available budget to bidders to reduce the risk of unaffordable bids (1)
- Joint commissioning between areas, in order to make contract sizes more viable (1)

Appendix 4
Full list of key required staff attributes specified at question 6.

- Motivated/enthusiastic/passionate/dynamic (6)
- Communication and listening skills (5)
- Experience in health or health promotion work (4)
- Experience in working with early years/children/families (3)
- The ability to motivate people (2)
- Ability to be a role model (2)
- Educated to degree level or specific subject qualifications for some positions (2)
- Weight management specific experience (2)
- Literacy and numeracy skills (2)
- Nutritional knowledge (2)
- NVQ level 2 qualification in school-aged children's weight management and qualifications from specialist weight management organisations(1)
- Behaviour change knowledge (1)
- IT skills (1)
- Administrative skills (1)
- Being caring (1)
- Working on own initiative (1)
- Project management skills (1)
- Ability to build relationships, e.g. with stakeholders and partner organisations (1)
- Self-confidence (1)
- Being non-judgemental (1)
- Facilitating skills (1)
- Educated to at least A-level (1)

Appendix 5: Website notice and questions for providers

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

PUBLIC HEALTH GUIDANCE

Managing overweight and obesity among children and young people: lifestyle weight management services

QUESTIONS FOR PROVIDERS OF LIFESTYLE WEIGHT MANAGEMENT SERVICES FOR CHILDREN AND YOUNG PEOPLE

Responses to be received no later than 9am on Monday 19th November

Background

The National Institute for Health and Clinical Excellence (NICE) has been asked by the Department of Health (DH) to develop guidance on managing overweight and obesity in children and young people through lifestyle weight management services.

This guidance will provide recommendations for good practice, based on the best available evidence of effectiveness and cost effectiveness. It is aimed at commissioners, health professionals and providers of lifestyle weight management services. It will also be of interest to managers in local authorities, schools and early years' settings, as well as to young people, their parents, carers and families.

The scope of the guidance describes what it will cover. See Overweight and obese children and young people - lifestyle weight management services.

NICE has searched and reviewed the published literature for evidence of effectiveness and cost effectiveness and of the barriers and facilitators to the implementation of lifestyle weight management services for children and young people.

NICE is now seeking more detailed information about the current provision, in England, of lifestyle weight management services for children and young people.

We would be grateful for your responses to the questions in the table below.
Please respond by inserting your answers in the space below each question. The space will expand if necessary.

Using the highlighter tool in MS Word, please highlight any information that you would like us to treat as 'commercial in confidence'. See Appendix A for more details.

Please note: We are unable to accept any attachments whether published or unpublished reports, reference lists or promotional material.

Name/ Organisation
NICE has commissioned an independent consultant to collate the findings of this information gathering exercise. The consultant has no connection with any provider of weight management services and will abide by NICE confidentiality processes. If you are content for your contact details to be passed on to the consultant and for them to contact you to check that your contribution has been accurately represented, please provide your email address in the space below. If you do not wish to be contacted by the consultant or for your contact details to be passed on to them, please state this below.
Question 1
Please give a brief outline of your service e.g. frequency of sessions, settings, age groups covered, size of groups, type of programme and duration, referral criteria, measurement of height and weight. What components of the service do you consider to be essential and why?
Question 2
It would be helpful to know whether young people attend with a parent or carer, the proportion of young people who are overweight (please specify whether 85th percentile or above, or 91st percentile or above) or obese (please specify whether 95th percentile or above or 98th percentile or above). We are also interested in the proportion of boys and girls attending the service. Do you promote your service to boys and young men as well as girls and young women? If so, are you successful and why? Is there a difference in recruitment and retention rates between males and females?
Question 3
From your experience, what are the key barriers / facilitators around working with commissioners of Tier 2, or lifestyle, weight management services for children and young people? i.e. What do you find helpful and what is not so helpful? Please include details of commissioner requirements where possible, for example: payments for achievement of

quality improvement goals and if you are involved in setting or negotiating these goals.
Question 4
Please give a brief description of how your organisation manages referrals. It would be helpful to know where referrals come from, and whether children and young people who have been referred by the NHS, local authority or other organisation receive a different service from those who self-refer or are self funded. Also if there is a difference in the referral process, or referral rates, according to participants' characteristics (e.g. age, or ethnicity).
Question 5
5a. Please describe your organisation's policy and practice when children and young people fail to attend or drop out of the programme. 5b. What is your experience of monitoring and managing drop-out rates? 5c. Are some children, young people and their families more likely to drop out than others? If so, please explain who is more likely to drop out. 5d. If you have experience of successfully reducing drop-out rates, it would be helpful if you could explain how you did this.
Question 6
6a. What sort of experience and personal characteristics do you require from staff? 6b. Is there a minimum training standard for staff who work within lifestyle weight management services? Do you offer training or support staff to obtain further training, and if so please describe your experiences of training session leaders and other staff working with children and young people?
Question 7
Please give a brief description of any peer support or mentoring your organisation provides for staff or for users of the service. It would be helpful to know what type of training is offered to peer supporters and what characteristics you look for in peer supporters.

Question 8
Do you provide ongoing support and follow up to children and young people and their families? If so, for how long? What is the level of uptake? What do you provide and what are the barriers and facilitators in doing so?
Question 9
It would be helpful if you could tell us about your experience of providing incentives or rewards to participants, for example for attendance or achievement. Do they differ between NHS or local authority referrals and other participants? Do you have any reports or other written evaluations that indicate the success or otherwise of incentives?
Question 10
What is your organisation's experience of working with disadvantaged groups within the community e.g. looked after children, children and young people with learning difficulties, or from black and minority ethnic groups or lower socio--economic groups? How do you reach these groups and provide appropriate services?

We would be grateful if you could send your responses to:
Overweightandobesechildren@nice.nhs.uk by 9am on Monday 19th November 2012.

Paper copies can be sent to: Rukshana Begum, Project coordinator, Centre for Public Health Excellence, National Institute for Health and Clinical Excellence
71, High Holborn, London WC1V 6NA.

We look forward to receiving your information and thank you in advance for your help.

Annex A

The use of 'commercial in confidence' and 'academic in confidence' data in the development of public health guidance: statement of principle

1. NICE is under obligations of transparency and fairness to all stakeholders, among others, in the development of its guidance

2. The rights of the owners of the data provided to NICE must be respected.

Definitions

3. Commercial in confidence information is information provided in confidence relating to the commercial interests of the owner of the information.

4. Academic in confidence information is information provided in confidence in circumstances where disclosure could prejudice future publication of the information in a scientific publication. It would be expected that any information marked as academic in confidence is going to be published at some stage and that a timeline for publication can be given.

Submission of data

6. The amount of information submitted on an 'in confidence' basis should be kept to a minimum. The whole submission should not be marked as confidential. It is likely to be unacceptable to mark complete sections as confidential.

7. Only information that is genuinely confidential, such as actual numbers, should be marked as in confidence. NICE will only treat information in confidence if the material is in fact either 'commercial in confidence' or 'academic in confidence'.

8. When marking data as confidential, organisations should indicate if this status will apply at the time NICE anticipates publication/presentation of the data. The last opportunity for organisations to review the confidential status of information is during the consultation on the draft guidance and its supporting evidence.

9. For all unpublished data submitted as 'academic or commercial in confidence' the minimum that should be made available for release is that which normally would be included in a CONSORT (or PRISMA) compliant abstract (http://www.consort-statement.org/?o=1011) and be suitable for public disclosure. An equivalent approach is required for all data and studies which underpin and are included in economic analyses and models, and for the economic model included in the submission if that is marked 'academic or commercial in confidence'.

Presentation of data at PHAC or PDG meetings

10. Data that contributes to evidence of effectiveness and cost effectiveness can be presented to a PDG meeting or to a PHAC meeting provided the information is factual, accurate and not misleading.

11. 'Academic in confidence' information may be presented during the PDG and PHAC meetings, even if the meetings are conducted in public. However, the data owner retains the right to make a final decision in relation to the release of confidential information into the public domain

12. The data owner retains the responsibility for the release of 'commercial in confidence' data into the public domain. With the exception of presentation of data at PDG or PHAC meetings, the data owner retains the right to make a final decision in relation to the release of confidential information into the public domain.

Publication of data

13. In circumstances where NICE wishes to publish data regarded by the data owner as academic or commercial in confidence, both NICE and the data owner will negotiate in good faith to seek to find a mutually acceptable solution, recognising the need for NICE to support its recommendations with evidence and the data owner's right to publication. However the data owner retains the right to make a final decision in relation to the release of confidential information into the public domain.

Economic models

14. NICE will normally disclose in full economic models provided by manufacturers/sponsors to NICE as part of a submission of evidence, together with the data on which such models are based. Exceptionally, data within a model can be treated as confidential if they contain or make practical the reverse engineering of confidential data inputs which are credibly specified as confidential by the organisation or company.

15. Model structures will not be accepted as confidential information, and by submitting a model the manufacturers/sponsor will be taken to have agreed that the model structure may be put into the public domain.

Disclosure of confidential data

16. NICE is challenged that confidential information it has received should be released in the interests of fairness, during the guidance development process or otherwise, data owners must on request promptly reconsider whether it is in fact necessary to maintain confidentiality.

17. NICE does not intend to make repeated requests for a prima facie tenable claim of confidentiality to be abandoned or modified, and it will accept the data owner's judgement in that regard.

18. NICE cannot ‘second guess’ the motives of a data owner. If a data owner would not agree to the specific request for disclosure made, but would agree to some more limited disclosure (for example to a “confidentiality club”,) then it is asked itself to suggest the disclosure it would find acceptable, rather than wait for NICE to propose the specific formula it may have in mind and discuss and agree a potential solution with NICE.

19. If disclosure is not possible the data owner must be prepared to assert publicly that the information is considered to be confidential, and must submit evidence giving the justification for maintaining confidentiality in defence of NICE's maintenance of that confidentiality. In the absence of any such assertion and evidence, NICE shall be entitled to conclude that the information is no longer confidential.