

Parent Carer Standards

Date: 13th May 2022

Greater Manchester Health and Social Care Partnership (GMHSP) has been working alongside parent carers and others since September 2020 to understand and improve the lives and experiences of parent carers (defined below).

These standards are the culmination of two years of conversations, questionnaires, surveys and listening to what matters to parent carers across all Greater Manchester Localities.

We cannot underestimate the difficult experiences of parent carers across the system and the exacerbation of those negative experiences over the last few years, due, in part, to Covid-19 and emerging and established structural and systemic inequalities. The development of these standards has been both, an opportunity to listen to parent carer experiences, but also an attempt to create some consistency in the offer and inform parent carers what they can expect across the ten districts.

WHO ARE PARENT CARERS?

A carer is someone of any age who supports, unwaged a relative, partner or friend who, due to physical or mental illness, disability, frailty, or addiction could not manage without that support. A parent carer is someone who provides care to a child or young person (aged 0 – 25) with a special educational need or disability (SEND), or the child or young person may be ill, have mental health issues or substance misuse problems.

INTRODUCTION FOR PUBLIC (PARENT CARERS)

Across Greater Manchester, Local Authorities, Health Partners, and Carer Organisations are signed up to the GM Carer's Charter; a shared commitment to meet the needs of Carers, manage their caring commitments and live a life outside of caring. But we know that being a Parent Carer comes with its own unique challenges and experiences. GMHSCP, in collaboration with Parent Carers across Greater Manchester has developed a series of standards.

These standards serve two purposes:

- They guide organisations in how best to address, understand and support Parent Carers.
- They empower Parent Carers by informing them of how Organisations will meet their needs as carers.

WHAT ARE THE STANDARDS (FOR PARENT CARERS)

As a Parent Carer I am assured that:

1. Professionals will listen and collaborate with me, committing to regular check-in if that helps me.

2. Systems and information and advice aimed at me will be clear and jargon free.
3. I do not have to repeat my story; professionals share information with each other that has been agreed with the family, within legal guidelines.
4. I am known and addressed as an individual in my own right.
5. Respite care is appropriate to my family's needs
6. My wellbeing and career aspirations are treated as a priority.
7. I am treated with compassion, dignity, and respect
8. Primary care and health settings assist me with my carer journey and prioritise my appointments wherever possible.
9. I will be supported to help achieve my life and or career goals and aspirations.

INTRODUCTION FOR PRACTITIONERS

In April 2021 the GM Carers Delivery Group, lead by Bernie Enright (DASS for Manchester) asked the Parent Carer Workstream to develop a series of Standards; a set of principles and quality markers that would support the GM Carer's Charter. These standards focus on the unique challenges that Parent Carers face and will steer Local Authorities and services in shaping their offer and measure success.

The Parent Carer Standards were co-produced and developed alongside Parent Carers from across all 10 Greater Manchester localities and the Greater Manchester Parent Carer Workstream in Spring 2022. They speak to the frustrations of the Parent Carer experience – but are underpinned by the desire to work with localities and services to refine service offers. Each Standard is prefaced by a statement which reflects the experiences and voices we heard - and is suffixed with some examples of how the recommendation could be put into practice.

THE STANDARDS (FOR PRACTITIONERS)

- Professionals listen and collaborate with parent carers and commit to regular check-ins.
- Systems and information and advice to be clear and jargon free.
- To not ask parent carers to continually repeat their story. Professionals share information with other organisations in consultation with the parent/carer and/or family.
- To be known and addressed as individuals in their own right.
- That respite care is appropriate to their family's needs
- That parent/carer wellbeing is treated as a priority.
- Parent Carers are to be treated with compassion, dignity and respect
- Primary care and health settings to assist them with their carer journey and prioritise their appointments.
- Acknowledge that Parent Carers may have career aspirations. They require proactive support from social care and health care professionals to help them achieve these aspirations which are central to their wellbeing.

1.0 THE PARENT CARER JOURNEY

'I only seem to get help when we reach crisis – at which point it's too late'

'It's like having a 3-year-old in the body of a 14 year old'.

1.1 We heard that being a Parent Carer feels like a Snowball rolling down a hill; along its journey the role becomes bigger and more complex. Parent Carer needs change as the size and complexity of the task changes.

Parent Carers felt it was exceptionally difficult to arrange an opportunity to speak to a professional about this changing need.

We also heard that hormones are not to be underestimated. Supporting a child going through puberty is tough – but with added complex health needs the physical, mental and administrative challenge intensifies.

Individuals have full, rich lives before they become parent carers – including pursuing careers and professional development. These might be put on hold or have to stop completely when individuals become Parent Carers and become experts in their child's needs; but the desire to re-start them never goes away.

THE PARENT CARER STANDARD

To understand the changing challenges of this journey, professionals commit to facilitate and schedule regular check-ins with Parent Carers. This regularity should be agreed with the Parent Carer and happen at a time and location convenient to them, with adequate notice, wherever possible.

Professionals acknowledge that Parent Carer needs can change from day to day, week to week – this requires appropriate flexibility in the offer and service –and the reflexivity to bring in more support as needed

'I need more opportunities to be involved in, and inform, decision making. I shouldn't need to file formal, corporate complaints in order to speak to the person able to influence my child's situation'

Professionals acknowledge and understand the unique dynamics of a pubescent child with SEND; they signpost relevant support around sexuality, friendships and relationships before it is needed.

Small and Medium sized businesses are supported to be flexible to support Parent Carers wherever possible.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Parent Carers be provided an opportunity to feedback or request help from professionals related to their changing needs as a carer outside of a crisis situation. This could be an email address, a phone number.

Localities and Services develop a visual guide (akin to a flow chart) that shows the offers and opportunities available to them and their child as they grow. This should include a 'who do I ask for help?' function.

2.0 ACCESSING INFORMATION AND ADVICE

STATEMENT

'We only know what we know – I've had to become my daughter's admin office!'

Parent Carers told us that they felt forced into become experts in navigating overly-complicated systems, offers and jargon designed by professionals. Parent Carers told us they felt professionals were not being transparent – and might even at times be being dishonest. More than anything, they wanted assurance that progress was being made by services, without their having to chase professionals to progress actions.

Parent Carers across GM are keen to stress that their needs are not complex; but the systems they are trying to navigate are.

STANDARD

Professionals are committed to making offers and systems to Parent Carers clear and jargon free, including removal of all acronyms from public facing literature and comms.

Where a professional might not know where to go, or who to consult to support a Parent Carer, they make a written commitment to the Parent Carer to escalate appropriately with their line manager and provide an update in due course.

Parent Carers are acknowledged by professionals as experts in what they need to excel and flourish, both as parent carers and as individuals. Comms to Parent Carers should reflect this dynamic.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

'Put yourself in our shoes'; re-visit your offers and accompanying literature from a parent carer's point of view; better still, do it with a parent carer. Is your offer easy to understand what it does and how to get it?

Consider an audit on where your service offer information is accessible and maximize opportunities for exposure; consider the library, the sure start centre, the swimming pool, church and faith groups, community notice boards, nurseries – and more!

Create a checklist of your offers for conversations with Parent Carers. Parent Carer's told us they won't resent being reminded regularly of all your services.

3.0 JOIN UP THE SYSTEM

STATEMENT

'I wish there was some kind of online cloud, where I could store all my information, that professionals could consult and add to – rather than repeating myself over and over'.

We heard that Parent Carers are continually frustrated with having to tell their story, and their child's, over and over. It feels like the different parts of the system are not talking to each other, sending mixed messages; and this impacts their confidence in the system to effectively support them and their child.

Furthermore, being a Parent Carer feels like a postcode lottery. We spoke to parent carers from all 10 localities and their experiences aligned only in their variety.

STANDARD

Professionals are committed to sharing information, within appropriate GDPR guidelines, to support Parent Carers and mean they are not burdened with having to continually explain and justify their needs.

Localities commit to equity of support for Parent Carers in their borough and across GM, sharing best practice wherever possible.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Localities support and invest in the GM shared care record and summary care record projects to allow seamless sharing of information between primary, secondary and social care partners.

Look at your localities' referral process; are there system-made barriers that stop parent carers accessing offers they are entitled to.

Localities are committed to the GM Carer's Charter; what steps can be taken to reduce the 'postcode lottery' experience. Localities participate in the GM Carers Delivery group, working to bolster service offers and strategy across the region. Parent Carers gave us examples of fantastic cross-boundary working and collaboration between local authorities; this is a model we wish to nurture in GM.

4.0 MAKING IT PERSONAL

Statement

"Don't Call me Mum! Treat me with respect, call me by my name and acknowledge all facets of my character and individuality"

“Why am I asking myself ‘what price is my child’s wellbeing worth?’”

Parent Carers feel frustration at being just called ‘mum’ (or ‘dad!’) – they told us they want to be acknowledged and addressed by their name, seen as a person with aspirations, ideas, abilities and a career goals - not just the Parent Carer of a child with additional needs.

Parent Carers feel decisions about offers to their families were framed by cost and not their child’s needs – and their needs as a Parent Carer. Parent Carers told us that too often they feel like what’s available to them is defined by budget and numbers on a spreadsheet

STANDARD

Professionals recognise Parent Carers as individuals beyond their immediate caring role. Professionals address parent carers by their name, consult them on their pronouns and regularly make time to discuss their ambitions beyond being a Parent Carer.

Organisations take steps to stop parent carers being names and numbers on a form are incredibly meaningful. This starts with consistent points of contact between professionals and Parent Carers, and when these points of contact change, appropriately updating the Parent Carer.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Consider offering a training course on ‘active listening’ to professionals.

Ensure professionals have appropriate time between appointments to review their case notes and prepare adequately.

Build Parent Carer’s medium and long term goals into support plans and care packages; providing opportunities for goals to be met in the future allows Parent Carers to continue to grow personally, and provides scope for them to potentially pursue professional development.

Localities commit to support local businesses with sensitive tools and advice they can in turn use to support Parent Carers

5.0 RESPITE

STATEMENT

“There’s just no rest! - I can’t think past this day to be honest”

Parent Carers told us that respite was cherished – but accessing it felt like an uphill battle. Whilst some areas of Greater Manchester offered innovative options for others the offer was hidden behind red tape and incomprehensible forms.

Parent Carers told us they were anxious that the respite care on offer would not meet the specific needs of their child and wanted assurance and clear communication. They also felt that when processes weren't properly documented and followed, the provision broke down.

STANDARD

Localities acknowledge that a variety of flexible offers is required to meet the respite needs of Parent Carers. It could take the form of a night away for the child or Parent Carer; but it also may include art therapy, work with animals and outdoor activities. Experiences that both parties will remember and cherish.

The value of respite, in both personal terms of avoiding crisis and financial terms or stopping the need for expensive interventions be relayed to staff.

Staff responsible for delivering respite care provide appropriate, scheduled assurance that their child is in safe, capable hands.

Respite offers to Parent Carers are supported by formal, documented processes to support Parent Carers to have a wider professional and social life. Informal arrangements quickly breakdown.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Fantastic Research has been conducted into how respite offers could be shaped to meet the needs of Carers and Parent Carers in Greater Manchester. Parent Carers have voiced support for voucher schemes, clearer information on local resources, explanation of transport offers, and the option to 'bank' hours for use later, rather than use them.

In some instances, access to respite at short notice as a form of contingency planning, could save a caring relationship breaking down.

Consider if respite offers could be made available over weekends/evenings

Parent Carers voiced frustration at having to wait for approved ASC (adult social care) eligibility to access respite and having to research the offers. A clear register or directory of what's available and what's required to access it in each locality would be welcome

At its best, respite is a holiday experience for the child and Parent Carer – it should be treated as such by the professionals.

6.0 PARENT CARER WELLBEING

STATEMENT

"Covid-19 is no longer an excuse - We are there for our kids; who's there for the parents?"

Parent Carers told us that at certain milestones in the Parent Carer experience they have a re-occurring realization: This is a 'life long situation, that will be consistent until either they or

their child dies'. Parent Carer described the experience as like just keeping their head above water – but ultimately the feeling caused depression and anxiety.

Parent Carers reported that their own health and wellbeing was steadily in decline. Offers to support Parent Carer health and wellbeing have been paused during the Pandemic; this should no longer stand as obstacle.

Coupled with a cost of living crisis, Parent Carers are struggling with their own mental health – but as ever, the needs of their child are placed first.

STANDARD

Parent Carer Wellbeing be monitored by professionals and treated as a priority. Parent Carers lack time and resources to address their wellbeing independently. The role of the professional is to help construct an action plan, rich with resources, that the Parent Carer can move through.

It is not enough for a 'wellbeing plan' to suggest 'taking a walk'. Steps to supporting a Parent Carer include helping them structure time to be involved in their community, pursue individual interests and develop career aspirations.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Consider mapping what wellbeing offers you have in your locality; could this be consolidated into an easy-read menu for Parent Carers to pick and choose from?

Look at what wider, holistic offers may have been closed since the pandemic – perhaps their re-launch has not been widely promoted.

Where could a Parent Carer be sign posted to volunteering opportunities – these are chances for them to grow their involvement in the local community, social networks and bolster their CV. Discuss with Parent Carers what steps need to happen to allow them to participate in these opportunities.

Professionals identify more opportunities to discuss contingency (or emergency) planning, beyond the carers assessment. Repeated planning for unthinkable 'what if?' scenarios with Parent Carers requires a culture change that must be service led – Parent Carers will feel reassured by knowing their child will have their needs met when they can no longer provide them.

7.0 THE UNCOMFORTABLE CONVERSATION

STATEMENT

'At various stages as my child has grown, I have realized that I will do this job until I die'

When parents have children, they do not expect to be caring for them (in some cases) for the rest of their lives. The path of a parent/carer is a long one. Whilst parent carers love their children unconditionally, the administration, processes, systems, and structures that parent carers must navigate in order to access support can sometimes feel like a brick wall. It takes

immense emotional, physical, and mental energy - all the while caring for their child. Whilst parent carers, in the main are willing and want to support and love their child there are times when it becomes too much. Practitioners should always have at the front of their minds, and in particular in situations where the parent carers child is over 18, that their caring role, both the physical and mental support for their child and navigating systems is a choice for the parent carer and one that whilst they, in the main want to do this role, professionals should be aware that it take an immense effort to hold everything together, professionals should acknowledge that the dramatic shift in role and identity is not always embraced.

STANDARD

Professionals address the Parent Carer with compassion, dignity, and respect.

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Active listening, a proactive approach to supporting their wellbeing, providing opportunities to be listened to.

8.0 IDENTIFICATION OF PARENT CARERS IN HEALTH SETTINGS

STATEMENT

“It’s been so hard to see my GP”

Parent Carers told us that their journey starts at self-identification. Carers Hubs across GM routinely report carers presenting (self-referring) to them only when they reach crisis point. GPs, District Nurses, Mid-wives and other Health Care Professionals are the colleagues best placed to identify Parents on the verge of becoming Parent Carers and to aid them through that transition – but these professionals in turn need support in understanding how to have those conversations and where to signpost.

The Covid-19 Pandemic has seen Primary Care Settings reducing their in-person appointments and a more significant stress placed on their resources, making arranging an appointment difficult. Parent Carers told us they feel frustrated at not having their role identified sooner and the difficulty in getting an appointment.

STANDARD

Local Authorities and Carer Services take a proactive approach to engaging and collaborating with Primary Care settings to offer ‘early identification training’ as trialed by organisations such as N-Compass.

Using the ‘Consider-Articulate-Recognize-Explain-Refer (CARER) process, Health Care professionals can assist in starting Parent Carers on their carer journey.

Work with PCNs to communicate why carer identification is so important and why, in some case, it is necessary to prioritize appointments with carers (e.g. to stop breakdown of carer relationship)

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Identify training tools that can be used with professionals in health care settings and identify appropriate times to deliver that training.

Make sure that information for carers is as equally available to health care professionals, including but not limited to, Referrals/requests for Assistive technology, Access to peer support groups, Referrals for Statutory Assessment, CarersUK digital resources (now available for free via PCNs), Support to complete emergency card/contingency plan and Support to take a break from the caring role.

9.0 SUPPORT TO ACHIEVE LIFE GOALS

Parent Carers told us that a life outside of their caring responsibilities was integral to their wellbeing. Support in terms of their child's health and wellbeing and supporting their Parent Carer role is as important as their feeling of working towards personal life goals. Life goals may be certain professional achievements - but they may also refer to wider aspirations. For a sustainable Parent Carer role, Parent Carers must feel culturally and socially fulfilled as well as challenged in different, meaningful ways.

STANDARD

Local Authorities and Carer Services will support parent carers to meet their life and/or career goals and aspirations

RECOMMENDATIONS ON HOW TO EMBED THE STANDARD

Each locality in Greater Manchester is rich in opportunities and experiences. Parent Carers living here are as equally entitled to access them as every other resident, regardless of their caring responsibilities. Facilitating Parent Carers to enjoy the countryside, visit the theatre, acquire a new qualification, or apply for a job/promotion is as equally important to their wellbeing as the fundamental support to their caring responsibilities. Carer providers and professionals should consider signposting Parent Carer to local relevant volunteering opportunities, 'meet-ups' with like-minded individuals and free/affordable and accessible cultural events (festivals, parades, concerts etc). If a Parent Carer has a clear desire to pursue career goals, they should be encouraged and supported to do so wherever possible.